Texas Cancer Plan 2005

Texas Cancer Council

A statewide blueprint for cancer prevention and control in Texas

Texas Cancer Plan 2005:

A statewide blueprint for cancer prevention and control in Texas

4th Edition

Texas Cancer Council
P.O. Box 12097
Austin, Texas 78711
(512) 463-3190
Fax: (512) 475-2563
Email: tcc@tcc.state.tx.us

TEXAS CANCER COUNCIL

January 2005

The Honorable Rick Perry
The Honorable David Dewhurst
The Honorable Tom Craddick
Members of the Texas Legislature
All Texans

In accordance with its statutory charge to ensure that Texas has a current, timely cancer plan, the Texas Cancer Council submits this 2005 revision of the *Texas Cancer Plan* to the people of Texas.

The process of updating the *Texas Cancer Plan* involved a large and representative group of more than 70 physicians, nurses, public health experts, epidemiologists, behavioral scientists, representatives from the state's key cancer organizations, non-physician health professionals, communications specialists, and survivors. Representation was from a geographic cross section of the state that included the state's major metropolitan areas and their surrounding suburban and rural communities.

While the Texas Cancer Council has statutory responsibility for planning and carrying out the comprehensive cancer *Plan*, the Council cannot achieve this alone. In a state of more than 20 million people, where the cost of cancer approaches $14 billion each year, no single entity could eliminate the entire cancer burden or fulfill all the goals of the *Plan*. For this reason, the Council supports collaborative efforts that focus on cancer prevention, early detection, screening, appropriate treatment, and other related or supportive efforts that advance the goals of the *Texas Cancer Plan* for the people of Texas.

As Chairman of the Texas Cancer Council, I would like to thank the many individuals who donated their time, expertise, and skill in contributing to the update of the *Texas Cancer Plan*. It is through this collaborative effort that we now have a blueprint for fighting cancer in Texas that will promote a unified, collaborative approach to cancer prevention and control and that will be useful at both community and statewide levels.

I am confident that with the *Texas Cancer Plan* as their guide and continued support from the Texas Legislature, our continued collaborative efforts and public-private partnerships will significantly reduce cancer's burden on Texans.

Respectfully submitted,

James D. Dannenbaum
Chairman

P.O.Box 12097 Austin, TX 78711 • (512)463-3190 • Fax 475-2563
Website: www.tcc.state.tx.us • Email: tcc@tcc.state.tx.us

Acknowledgements

The process of updating the *Texas Cancer Plan* involved a large and representative group of more than 70 physicians, nurses, public health experts, epidemiologists, behavioral scientists, representatives from the state's key cancer organizations, non-physician health professionals, communications specialists, and survivors. Representation was from a geographic cross section of the state that included the state's major metropolitan areas, East and West Texas, and the Rio Grande Valley. Additionally, eight community forums were conducted in cities across the state to provide community-level input into the plan revision.

The Council would like to thank the many individuals and institutions that participated on the project's various committees. The following individuals generously donated their time, expertise, and skill in reviewing and contributing to this document:

Lewis Foxhall, MD
Project Director and Chair,
Executive Steering Committee
The University of Texas M. D. Anderson Cancer Center

Carla Strom, MLA
Project Coordinator and Chair,
Literature Subcommittee
The University of Texas M. D. Anderson Cancer Center

Executive Steering Committee

American Cancer Society - Texas Division, Inc.
Judy Jonas, PhD, RD, *Chair, Data Subcommittee*
Karen Torges
Department of State Health Services
Philip Huang, MD, MPH
Anne Williamson, MEd
Juanita Salinas, MSW
Fleishman-Hillard, Inc.
Aili Jokela
Susan G. Komen Breast Cancer Foundation, Austin
Ramona Magid, MBA
SUMA Orchard Social Marketing, Inc.
Susan Nenney, MPH
Texas A&M University System Health Science Center - Scott & White Hospital
V. O. Speights, Jr., DO
Texas Cancer Council
Audreyjane Castro, *Outgoing Board Member*
Donald C. Spencer, MD, *Board Member*
Sandra Balderrama, MPA, BSW
Jane Osmond, BS, RRT
Texas Tech University Health Sciences Center
Davor Vugrin, MD, FACP,
Chair, Toolkit Subcommittee
The University of Texas at Austin School of Nursing
Mary Lou Adams, PhD, RN, CS, FNP
Heather Becker, PhD
The University of Texas Health Science Center - San Antonio
David H. Boldt, MD
The University of Texas Health Science Center at Houston, School of Public Health
Maria E. Fernandez, PhD
The University of Texas M. D. Anderson Cancer Center
Therese Bevers, MD
Patricia Diana Brooks, MEd, MS, *Chair, Resource Subcommittee*
Joel S. Dunnington, MD
Angelina Esparza, RN, *Chair, Health Disparities Subcommittee*
Lyle D. Green, MBA, CHE, CPHIMS
JoAnn Ward, MPH, *Chair, Survivorship Subcommittee*

Work Group & Subcommittees

Additionally, the following organizations sent representatives to participate in the work group and various subcommittees:

American Cancer Society - Texas Division, Inc.
Baylor College of Dentistry/Texas A&M Health Science Center
Baylor College of Medicine
Colon Rectal Surgical Association of San Antonio
Department of State Health Services
Lance Armstrong Foundation
National Cancer Institute's Cancer Information Service
Pasadena Public Library
The Rose Breast Imaging Center
Sisters Network, Inc.
Texas A&M University System School of Rural Public Health
Texas Cancer Council
Texas Cooperative Extension Service
Texas Medical Association
Texas Nurses Foundation
Texas Partnership for End-of-Life Care
The University of Texas M. D. Anderson Cancer Center
The University of Texas Medical Branch at Galveston
The University of Texas - Pan American
The University of Texas - Southwestern
YWCA Breast Project of Abilene

Writers, Editors, & Design

David Berkowitz - Editor
The University of Texas M. D. Anderson Cancer Center
Carolyn Bernard, CPHIMS - Webmaster
The University of Texas M. D. Anderson Cancer Center
Janet Jackson - Design and Production
Arc Graphic Design
Mary Sieber - Editor
Sandi Stromberg - Writer and Editor
The University of Texas M. D. Anderson Cancer Center
Renee Twombly - Writer
Twombly / Ryan Communications

The Texas Cancer Council would also like to acknowledge the elected officials of the state of Texas for their continued support and funding of the Council and its efforts to reduce the burden of cancer on all Texans. Because of the vision of our state's governmental leaders, Texans have a comprehensive, coordinated, and innovative approach to cancer control planning.

CONTENTS

EXECUTIVE SUMMARY

The *Texas Cancer Plan* is a statewide blueprint for cancer prevention and control in Texas. It is a consensus-based, strategic document used by public and private cancer control organizations, and provides a planned, evidence-based approach to reducing the impact of cancer on Texans.

To ensure that *Texas Cancer Plan* is responsive to the needs of Texans and remains up-to-date in order to continue supporting the state's cancer control planning efforts, the Texas Cancer Council (TCC) called for a revision of the state's document. The project staff were charged with coordinating the update and, in order to reflect the needs of all Texans, worked with numerous institutions, organizations, experts, and survivors across the state who all share the goal of reducing the burden of cancer in Texas.

There is no single known cause or cure of cancer and everyone is at risk.

Cancer in Texas

Cancer is not a single disease. Cancer represents more than 100 distinct diseases that are all characterized by the uncontrolled growth and spread of abnormal cells in the body. Despite some similarities in processes of cell mutation and *proliferation*, each type of cancer possesses distinct *risk factors* and manifestations that require different prevention measures and medical interventions. There is no single known cause or cure for cancer and everyone is at risk.

Cancer *incidence* rises with age; adults in midlife or older are the most affected. In Texas, as in the nation, the increasing population of older adults means that more and more people will be affected by cancer. Still, cancer risk, even in the elderly, can be modified; behavioral and lifestyle factors are the leading causes of cancer mortality in the United States.[1] The human and economic toll from illness and untimely death resulting from cancer is enormous, thereby making present-day prevention efforts all the more imperative.

Sociodemographics of Texas

Population Growth Factors

Texas's population is projected to approach 25 million in the next six years. Between 1990 and 2003, the population grew by almost 23 percent. In 2000, Texas's non-white population was more than 45 percent, but by the year 2025, it is estimated that Texas, among all states, will have the largest African-American population, the second largest Hispanic population, and the fifth largest Asian population. Hispanics currently make up 32 percent of the Texas population and by 2026 will outnumber all other race/ethnic groups.

Socioeconomic Factors

Texas ranks consistently low in national rankings for median family income. In 2001, median family income for Texans was $25,850, a fact that placed the state in the bottom quarter of the 50 states. One in five Texans lives at or below the federal poverty level ($14,348 for a

family of three). In 2002, an estimated 3.4 million people in Texas lived in families with incomes below the federal poverty guidelines. The Texas poverty rate of 15.6 percent ranks it seventh highest in the nation, after only Arkansas (19.8 percent), Mississippi (18.4 percent), New Mexico (17.9 percent), Louisiana (17.5 percent), the District of Columbia (17.0 percent), and West Virginia (16.8 percent). The county area in Texas with the highest poverty rate of almost 50 percent is Starr-Zapata. Some of the most populous counties in Texas with the highest poverty rates in 2001-02 were:

- Hidalgo (36.2 percent)
- Cameron (34.8 percent)
- El Paso (26.7 percent)
- Nueces (23.1 percent)

Educational levels in Texas are lower than for most large states. In 2002, 22 percent of the Texas population over age 22 had not finished high school, compared to 16 percent nationwide. Regarding educational level among Hispanics, Texas ranked last; 49 percent of this group had not completed high school. Only 26 percent of Texans aged 25 or older had a bachelor's degree or higher in 2002, and Texas ranked last (16 percent) in the percentage of African-Americans who had a bachelor's degree or higher.

Health Coverage

Uninsured

Texas ranks last in the nation in percentage of uninsured; 25 percent of its residents do not have insurance. Additionally, 22 percent of children under age 18 in Texas are uninsured, a percentage that is higher than the national average. Hispanics have more than double the uninsured rate of other racial/ethnic groups in Texas, with more than 53 percent uninsured.[2]

Cancer Trends

Incidence

The number of Texans diagnosed with cancer is increasing due to the aging of the population and the more widespread use of cancer-screening tests. The *incidence rates* for lung, breast, prostate, colorectal, oral, and skin cancers rise significantly with age. Incidence rates also are influenced by the use and availability of early-detection tools. For example, the incidence of prostate cancer has increased

Demographic Profile of the Texas Population Without Health Insurance in 2001

Variable/Demographic Category	Number Without Health Insurance in 2001	Percent Share of Total Population Without Health Insurance in 2001	Percent in Demographic Category Without Health Insurance in 2001
Sex			
Male	2,606,499	52.55%	25.10%
Female	2,353,330	47.45%	22.04%
Total	4,959,829	100.00%	23.55%

Variable/Demographic Category	Number Without Health Insurance in 2001	Percent Share of Total Population Without Health Insurance in 2001	Percent in Demographic Category Without Health Insurance in 2001
Race/Ethnicity			
Anglo & Other	1,476,407	29.77%	13.06%
Black	555,055	11.19%	24.15%
Hispanic	2,928,368	59.04%	39.25%
Total	4,959,829	100.00%	23.55%

Data Source: U.S. Census Bureau: March of 2002 Current Population Survey (CPS) for Texas.
Note: Based on a comparison with program administrative records, it has been concluded that the March 2002 CPS under-estimated the number of Texans covered by Medicaid / CHIP in 2001 by 230,000. Therefore, it is very likely that the March 2002 CPS may have over-stated both the number and the percentage of uninsured Texans in 2001. Of the 230,000 Medicaid / CHIP participants not accounted for by the March 2002 CPS, some 173,000 were children under the age of 19.
Analysis Prepared By: Research and Forecasting Department; Texas Health and Human Services Commission, Austin, Texas, April of 2003

Cancer is currently the second-leading cause of death in Texas and is expected to become the national leading cause of death within the next decade.

dramatically, primarily due to early detection made possible by the increasing use of *prostate-specific antigen (PSA)* blood tests.

Mortality

An estimated 37,000 Texans will die from cancer in 2004. Cancer is currently the second-leading cause of death in Texas and is expected to become the national leading cause of death within the next decade. In the United States, cancer is responsible for every one out of four deaths.[3]

The proportion of cancer deaths relative to all deaths in Texas has been increasing steadily for the past half-century. These increases are influenced by a corresponding decrease in heart disease deaths due to advances in cardiac surgery and medications, behavioral changes related to improved nutrition, more exercise, and decreased smoking.

Although cancer remains the second leading cause of death in the United States, there was an overall declining trend in cancer mortality between 1990 and 2000. The overall decline in cancer mortality demonstrates progress in tobacco control and early detection and treatment of cancer. Despite this downward trend, an increase in lung and bronchus cancer mortality in women remains.[4]

Survival

The stage or degree to which cancer has spread within a person's body at the time of diagnosis greatly affects chances of long-term survival. *Five-year survival* rates for lung, breast, prostate, colon, oral, and cervical cancers drop significantly once the cancer has spread to other parts of the body. Prevention, early detection, and treatment interventions for these cancers can greatly improve five-year survival rates.[5]

Long-term survival increasingly has become a reality for people diagnosed with cancer. Sixty-three percent of cancer patients now live at least five years after diagnosis. Advances in early detection, diagnosis, and treatment have created a larger pool of Texans who are cancer survivors. This growing population, which includes both children and adults, has created a burgeoning demand for long-term follow-up services and psychosocial support services, as well as a need for public policies that ensure employment and insurance opportunities.[6]

Cancer Health Disparities & Priority Populations

Health Disparities

Health disparities refers to the inequity or discordance of health care and health outcomes across different groups within the population. Current data and numerous reports state that ethnic minority populations, as well as low-income populations from all races and ethnicities, tend to be in poorer health than other Americans.[7] Cancer incidence and death rates vary based on a person's race and *ethnicity*. There are many contributing factors to health disparities. Among the most frequently discussed are access to care and a patient's care experience, which may differ among racial, ethnic, *socioeconomic*, and geographic groups. Other underlying factors may include: incidence of illness, *genetic* predisposition to disease, local environmental conditions, or lifestyle choices. Reports have also been able to outline differences in cultural beliefs, linguistic barriers, degree of trust in health care providers, or variations in delay in seeking care for different reasons. Obviously, this is a complex problem that calls on *health care professionals*, policymakers, and the public at large to work together to ensure improved health outcomes for all segments of the population.

Priority Populations

The term *priority population* is used to describe both specific population groups and geographically defined groups that experience health disparities. Priority populations may change and be defined differently based on geographic location or community needs. The National Health Disparities report, which developed the first annual report on health disparities, included data and analysis for the following populations currently experiencing disparities in the United States: low-income groups, racial and ethnic minority populations, women, children, the elderly, individuals

Age is the primary risk factor for cancer: 76% of cancer is diagnosed among Texans who are aged 55 or older.

with special health care needs, the disabled, people in need of long-term care, people requiring end-of-life care, and geography of residence.

For the purpose of the *Texas Cancer Plan*, the following populations have been discussed in more detail.

Older Populations

Age is the primary risk factor for cancer, so a person's chance of developing cancer increases as he or she becomes older. Currently, 76 percent of cancer is diagnosed among Texans who are aged 55 years or older. The fact that the aging population will markedly increase in the coming decades holds great implications for the burden of cancer on Texans. Cancer deaths will continue to increase unless the trend is reversed through advances in cancer knowledge and treatment, or by significant improvements in prevention and early detection for those most at risk.

Racial & Ethnic Population Groups

Medically underserved 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.[8] This is due in large part to delayed diagnosis coupled with less than appropriate patient care.[9] In addition, individuals of all ethnic backgrounds who are poor, lack health insurance, or otherwise have inadequate access to quality cancer treatment experience higher cancer incidence, higher *mortality rates*, and poorer survival rates.[10] As these priority populations continue to grow at a rapid rate, they will as a whole become the "majority" population of our nation. Potential reasons for disparities in cancer and death rates have been outlined by the American Public Health Association to include the following: frequency of medical care, unequal care, geography, health literacy, poverty, education, environmental risks.[11]

African-American Texans have the highest rates of mortality for lung, breast, prostate, colon, and cervical cancers. Nationally, the five-year survival rate for African-Americans diagnosed from 1989 through 1993 was 44 percent, compared to 60 percent for non-Hispanic whites. This large difference in survival is attributed to later diagnosis of cancer among African-Americans, a trend that affects African-Americans nationwide. Except for cervical, liver, and gallbladder cancer, Hispanics in Texas, to date, have lower cancer mortality rates than whites or African-Americans. Mortality rates for Asian-American and Native American priority populations in Texas are not available.

Geographic Factors

The size and diversity of Texas's geography have a direct impact on the availability of cancer diagnosis, treatment, prevention, and control resources. Second only to Alaska in geographic area, Texas has more than 260,000 square miles. A 1,000-mile border with Mexico winds through an extremely rural area. El Paso and Beaumont, Texas's eastern- and western-most cities, are both closer to Florida and California, respectively, than they are to each other.

In such a large state, geographic differences also exist among the state's populations. Hispanics are heavily represented along the border region, African-Americans can be found in large numbers in East Texas, and the Houston-Galveston-Brazoria area has the third largest Vietnamese population in the country.

The State of Texas Department of Health and Human Services has developed a designation to identify areas in Texas that demonstrate a need for increased medical services. In Texas 176 out of 254 whole counties and 88 partial counties have been designated as *Medically Underserved Areas (MUA)*. Counties with the greatest identifiable needs include portions of Harris County, far East and West Texas, and the Texas /Mexico Border area.

Medically Underserved

There have been numerous reports that have outlined significant barriers to care for patients. These have been broadly classified as structural, cultural, and linguistic. Structural barriers can include but are not limited to geographic availability of services, access to timely care, etc. Cultural barriers have often only been discussed in terms of ethnic differences but can also extend to the culture of the health care system and the barrier it presents to lay populations. Linguistic barriers are a growing concern in Texas with more of the population having limited English proficiency (LEP).

As Texas continues to see an influx of immigrant populations, the need for multilingual health care workers

will increase. Statistics indicate that, as of 2000, close to 47 million people, 18 percent of the U.S. population, spoke a language other than English at home. In comparison, in 1990 only 13.8 percent of the population spoke a language other than English at home.[12] Limited English proficiency can result in the provision of substandard health care due to inaccurate or incomplete information.[13]

There are a number of state and federal laws that compel publicly funded health care programs and activities to provide language assistance.

Children

The types of cancers that children develop are significantly different from those seen in adults. In children, the most common cancer sites are blood and bone marrow, lymph nodes, the brain, and the nervous system. Between 1995 and 2001, approximately 5,500 children in Texas were diagnosed with cancer. Cancer is the main cause of death by disease for children under the age of 15.

Cancer is the main cause of death by disease for children under the age of 15.

Especially noteworthy, however, is the fact that children survive cancer at a much higher rate than do adults. Due to advances in diagnosis and treatment, children now have about a 70 percent survival rate. This phenomenon is producing a new set of questions regarding long-term developmental, education, and insurance coverage needs, and these issues require development of policies on childhood cancer survival. This edition of the *Texas Cancer Plan* discusses the needs of childhood cancer survivors and focuses on preventative measures to decrease the risk of developing cancer by implementing healthy nutrition, physical activity, and the prevention of tobacco use.

Goals

The aim of the *Texas Cancer Plan* is to address these challenges and identify goals to unite the state's efforts to reduce the burden of cancer in Texas; the *Plan* includes objectives, strategies, and action steps to assist all those in the fight against cancer to achieve these goals.

GOAL I: PREVENTION INFORMATION & SERVICES

Texans will have the most current information and the opportunities necessary to reduce their risks for developing cancer.

GOAL II: EARLY DETECTION & TREATMENT

Texans will have prompt access to information and services that enable the early detection, diagnosis, treatment, and support of cancer.

GOAL III: PROFESSIONAL EDUCATION & PRACTICE

Texas health care professionals will have up-to-date knowledge and skills about cancer prevention and control and will use them to provide quality prevention, education, screening, diagnostic, treatment, and support services.

GOAL IV: CANCER DATA ACQUISITION & UTILIZATION

Texans will have comprehensive and responsive cancer data and information systems that will be used for planning, implementing, and evaluating programs, policies, and cancer research.

GOAL V: SURVIVORSHIP

The end of cancer treatment is not the end of the cancer experience. A diagnosis of cancer is the beginning of the survivorship journey. All Texans will have an awareness and understanding of the issues and impacts of survivorship in our state.

INTRODUCTION

History of the *Texas Cancer Plan*

The Speaker of the Texas House of Representatives appointed the Legislative Task Force on Cancer in Texas in 1984. The 52-member citizen group was asked to develop short-term and long-range plans to reduce the burden of cancer in Texas, and their report described initiatives that needed to be implemented quickly, as well as long-range strategies. Responding to the recommendations in the report, the Texas Legislature established the Texas Cancer Council as a state agency in 1985 and charged it with responsibility for developing and implementing the *Texas Cancer Plan*.

The Task Force enlisted the help of 300 volunteers, representing hospitals, cancer research centers, health professions, volunteer organizations, and the general public from all geographic regions of the state. Their findings, produced from a yearlong study, formed the Goals and Strategies of the first *Texas Cancer Plan*.

Purpose

The *Texas Cancer Plan* is a statewide blueprint for cancer prevention and control in Texas. The *Texas Cancer Plan* guides Texas Cancer Council actions and initiatives. It is a consensus-based, strategic document used by public and private cancer control organizations, and provides a planned, evidence-based approach to reducing the cancer burden in Texas. The *Plan* is recognized in the nation as a model comprehensive cancer plan. Other states, including New Mexico, Georgia, Missouri, Rhode Island, North Carolina, and Arkansas have used the *Texas Cancer Plan* as a model for their state comprehensive cancer plans.

The Texas Cancer Council

The Texas Cancer Council was established in 1985 by the 69th Texas Legislature. The Council is statutorily charged with developing and working to implement the *Texas Cancer Plan*; promoting the development and coordination of effective and efficient statewide public and private policies, programs, and services related to cancer; and encouraging cooperative, comprehensive, and complementary planning among the public, private, and volunteer sectors involved in cancer prevention, detection, treatment, and research (Chapter 102, Health and Safety Code).

By using the *Plan* as a blueprint, communities will become part of a statewide effort to battle cancer in a comprehensive and unified manner.

While the Texas Cancer Council has statutory responsibility for planning and carrying out the comprehensive cancer plan, the Council cannot achieve this alone. In a state of more than 20 million people, where the cost of cancer approaches $14 billion each year, no single entity could eliminate the entire cancer burden or completely fulfill all the Goals of the *Plan*.

Putting the *Plan* into Action

The *Texas Cancer Plan* serves as a blueprint for cancer prevention and control in the state. Cancer experts in data and planning; prevention, diagnosis, and treatment; and survivorship have come together to develop a plan for fighting cancer in Texas. The *Plan* identifies the challenges, discusses the important issues, and presents a set of Goals, Objectives, Strategies, and Action Steps to help guide local communities in preparing for the cancer battle in their own community. By becoming familiar with the *Texas Cancer Plan*, they will learn what the issues are that face communities all over Texas. By using the *Plan* as a blueprint, communities will become part of a statewide effort to battle cancer in a comprehensive and unified manner.

The Texans Conquer Cancer specialty license plate benefits nonprofit organizations that provide services to Texas cnacer patients needing assistance during their cancer fight. To learn more or to purchase your own visit www.texansconquercancer.org

Many issues faced in local communities are the same statewide. Communities can use the *Plan* at the local level by first becoming familiar with it. They should identify Goals from the *Plan* that are of particular interest to them and that seem to fit with the cancer needs in their area. Communities can then establish local coalitions that can further identify and describe how local cancer issues can be addressed, using the Goals and Objectives and the various Strategies and Action Steps put forth in the *Plan*.

A *Cancer Control Toolkit* will be ready for dissemination in mid-2005 and can act as a companion piece to the *Texas Cancer Plan*. The *Toolkit,* a collaborative effort between the Texas Cancer Council and the Department of State Health Services, will provide a guide for Community Cancer Control Planning and will contain information, materials, and resources to assist communities in implementing the *Texas Cancer Plan*.

In 2004, the American Cancer Society produced *Texas Cancer Facts and Figures* as a partnership publication with the Texas Cancer Registry and the Center for Health Statistics at The Department of State Health Services, the Texas Cancer Council, and the Texas Cancer Data Center at the University of Texas M. D. Anderson Cancer Center. The document is primarily intended to assist the public in understanding the burden of cancer in Texas. It can also serve as a companion piece to the *Texas Cancer Plan* to facilitate outcomes-based, data-driven cancer control planning. *Texas Cancer Facts and Figures* provides the data and analyses that support the *Texas Cancer Plan*.

Texas Cancer Council State-Funded Initiatives

The Council is a results-oriented agency with a proven ability to make a substantial impact. Small size, expertise in cancer, and established relationships allow the Council to respond swiftly to critical community needs for cancer prevention and control and to recognize and act on opportunities to reduce the cancer burden. Through the local initiatives it creates and funds, the Council has made an impact on Texas communities.

Texas Cancer Council Mission

The Texas Cancer Council is the state agency dedicated to reducing the human and economic impact of cancer on Texans through the promotion and support of collaborative, innovative, and effective programs and policies for cancer prevention and control.

Texas Cancer Council Philosophy

The Texas Cancer Council, with the *Texas Cancer Plan* as its guide, affirms that:

- All citizens should receive culturally appropriate information about ways in which their risks of developing and dying from cancer can be reduced and should have prompt access to high quality cancer prevention, screening, diagnosis, treatment, and rehabilitation information and services.
- The human and financial impact of cancer on the people of Texas can be reduced by forging strong, collaborative partnerships at the state and local levels.
- A cooperative and unified effort by public, private, and volunteer sector agencies and individuals can increase the ability of limited resources to serve more people and minimize duplication of efforts.

The *Texas Cancer Plan* guides all Council programs and initiatives. The Council provides startup funds, leadership, guidance, and technical assistance for cancer initiatives that range from teaching school children sun safety to educating professionals and the public about the need to improve quality of life for all cancer survivors. Council-funded initiatives focus on awareness, education, and outreach.

The Texas Cancer Council devotes nearly 90 percent of its annual budget to implementing the *Plan* through direct interventions and through the funding of local community and statewide cancer initiatives. All *Plan* Goals will be addressed each year through Council-funded initiatives that involve local and statewide partners.

Changes to the 2005 Update

The 4th edition of the *Texas Cancer Plan* has several changes from the previous edition. The primary change is the addition of *Goal V: Survivorship*. As more Texans live with, through, and beyond cancer, Texas must have a plan for meeting the challenges that face survivors, health professionals, and the health care industry. Through the achievement of this goal, we will increase knowledge of survivorship issues for the general public, cancer survivors, health care professionals, and policy-makers; increase the availability of effective programs and policies addressing cancer survivorship; and increase access to quality care and services for cancer survivors in Texas.

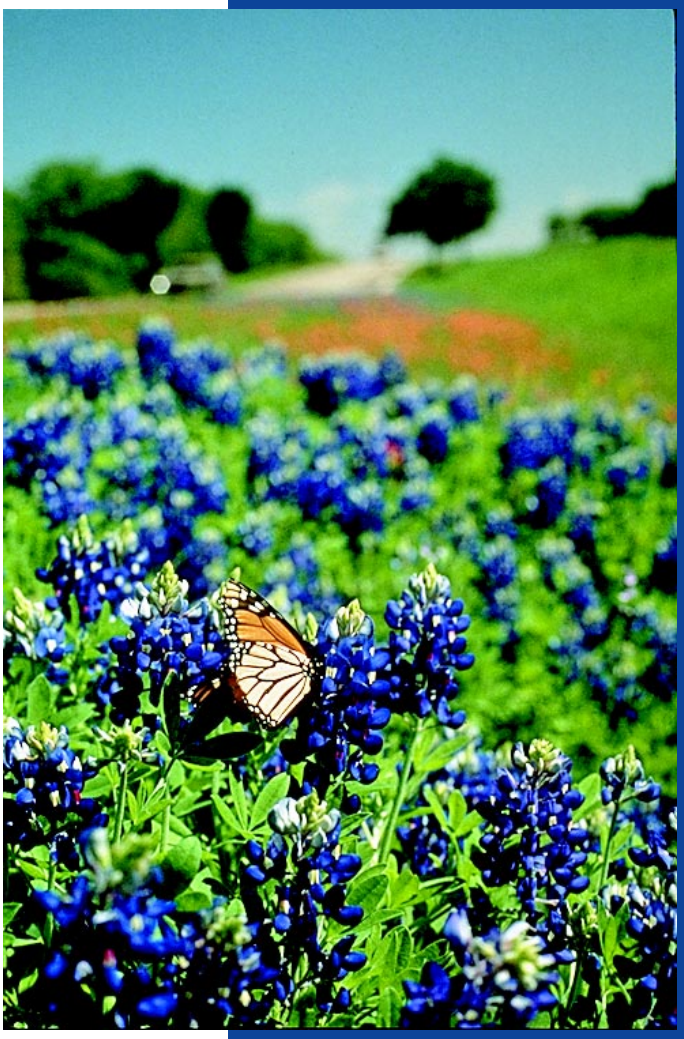
In the 4th edition, the *Plan* encourages a more focused effort to reduce and, when possible, eliminate the unequal burden of cancer on priority populations. The burden of cancer falls most heavily on those Texans who can least afford it. However, disparities in cancer prevention, early detection, treatment, and survivorship are not limited solely to those without financial resources. Other human circumstances such as race, culture, education, disability, the social and biological environment, and genetics play a role in contributing to the disparity in cancer incidence and mortality. It was thought by those involved in the *Plan* update process that the challenges of reducing disparities could best be met not by discussing them as an isolated topic but by addressing the issues within all Goals, as a part of every Objective, and as an integral part of all Strategies. Actions taken within communities to address the burden of cancer should first and foremost take into account the needs of priority populations among whom cancer strikes most harshly.

The Glossary has been updated to remove more common words and phrases and to provide a more standardized definition of words that are used in the health care field. Words with definitions found in the new section *Terminology* are identified in colored, italicized font.

An Index has been added to facilitate a more accurate search of the material.

Future

The world of cancer is continually changing as new and more effective methods of detection, diagnosis, treatment, and long-term support services are being discovered and utilized. The evaluation of the *Texas Cancer Plan* is also a continuing process. The Texas Cancer Council annually reviews the *Plan's* implementation status and biennially conducts strategic planning sessions to evaluate gaps and set new priorities for its cancer control activities. The *Plan* is updated as needed to keep up with changing knowledge and technologies.



GOAL I: PREVENTION INFORMATION & SERVICES

Texans will have the most current information and the opportunities necessary to reduce their risks for developing cancer.

Objective A - Increase Availability Of Effective Cancer Prevention Materials And Programs

What Is Cancer Prevention?

Year by year, evidence grows stronger that a majority of cancers in thousands of Texans could have been prevented by modification of the choices each person makes every day: what to put on the dinner table, whether to take a brisk walk, when to stop smoking cigarettes, how often to visit the doctor to be screened. Of the nearly 33,000 lives lost to cancer in Texas each year between 1997 and 2001, the American Cancer Society estimated that 10,500 of those residents died because of tobacco use, 30 percent of the total deaths. Scientific evidence also suggests that it may be possible to reduce cancer deaths by up to another 30-35 percent by improving nutrition and physical activity behaviors, and by keeping a normal body weight.

Given what scientific evidence suggests, that up to two-thirds of the 85,000 cancer cases estimated to occur in Texas in 2004 could have been prevented if behavioral changes had been made, cancer "prevention" plays a key role in the fight against cancer in Texas. The fact that it can reduce the human and economic toll of cancer on Texans makes cancer prevention an urgent priority. Cancer prevention includes activities aimed at eliminating or reducing the risk of developing cancer as well as minimizing the effects of the disease.

Goal I of the *Texas Cancer Plan* is dedicated to *primary prevention*. Primary prevention seeks to keep a cancer from ever occurring. It is the front line in promoting health and reducing risk in the general public. Such prevention activities include avoiding tobacco and using sunscreen to prevent skin cancer.

Goal II of the *Plan* addresses secondary and tertiary prevention. *Secondary prevention* seeks to identify and treat Texans who are at risk for developing cancer, but who have no symptoms of the disease. An example is use of a Pap smear to detect cervical *dysplasia* before it develops into cervical cancer. *Tertiary prevention* is defined as treating and supporting people diagnosed with cancer in order to minimize clinical complications and the chance that the cancer will come back, and to limit disability, and promote rehabilitation.[1]

Cancer prevention programs must be comprehensive, sustained, and culturally relevant.

Cancer prevention programs are challenging. To be effective, these efforts must be comprehensive, sustained, and culturally relevant. Experiences in the field, to date, have shown that merely providing Texans with information about the dangers of tobacco use, unhealthy diets, and excessive sun exposure does not alter personal choices on a day-to day basis. Immediate gratification from unhealthy behaviors is often an easier choice than lifelong risk reduction efforts. Despite extensive public information campaigns, many Texans continue lifestyles and personal behaviors that place them at increased risk for cancer. Prevention measures usually take years of continued reinforcement before their effect on overall *morbidity* is evident. Preventive measures taken today will not guarantee that an individual will be cancer-free during his or her lifetime; however, they will greatly reduce future risks of disease.

Studies also have shown that prevention efforts can be successful. They are preferable by far to even the most effective and advanced early detection and treatment methods because they can keep cancer from initially occurring.

Why Is Cancer Prevention Important?

Cancer is the second leading cause of death in Texas, as well as in the United States. In 2004 an estimated 37,000 Texans will die from cancer, as will more than 500,000 other Americans.[2] The most powerful tool in the fight against cancer is prevention, which can significantly reduce both morbidity and mortality from the disease as well as boost overall life expectancy and health status.[3] Prevention that starts early, with programs designed for children to help them develop healthy habits, can reduce cancer risks as well as avoid

other health problems such as obesity and alcohol abuse.[4] When these children become adults, the lifelong healthy habits and prevention behaviors they have adopted will serve as a model for their own children and for future generations.

Cancer Risks

Cancer risks include external factors that increase a person's chance of developing cancer, such as choices and lifestyle patterns set at a young age. These can be minimized through early intervention. External risks also include carcinogens — chemicals and substances such as *asbestos* and *ionizing radiation* — that may be present in the environment or at the work site, and also can be minimized or curtailed through vigilant surveillance. Internal predispositions to cancer are either passed down genetically or develop as a result of aging, and present a much more difficult prevention problem.

Delivery of Prevention Education

Educators, parents, *health care professionals*, insurance companies, the media, government agencies, and employers all have important roles to play in cancer prevention education. Consequently, prevention education can be conducted in a wide range of settings, such as homes, schools, health care agencies, communities, and workplaces. Such education should utilize appealing and effective teaching methods that increase understanding of cancer risk factors and encourage adoption of behaviors that reduce risks. Reduction of cancer risks, however, cannot be done merely through education programs alone. Texans must take personal responsibility for changing behaviors that increase their risks of cancer. Yet, government agencies and community organizations can enhance cancer risk reduction by providing culturally relevant education about cancer and prevention. They can identify and prevent workplace and environmental hazards, restrict advertising and use of unsafe products, and enact public policies that promote cancer prevention.[5] The Harvard Center for Cancer Prevention concludes that for prevention to be successful, changes must be implemented through all components of the social strategy. These experts found that for "major reductions in the burden of cancer to be achieved, we need broad-scale interventions that will shift the behavior of the whole population."

To promote sweeping change that can impact the burden of cancer, information about cancer risks and the benefits of prevention must be broadly and

effectively communicated. All Texans, regardless of ethnicity, income, or geographic location, need access to cancer prevention information and resources that they can understand, and which motivates them. The context and format of cancer prevention education materials are, therefore, crucial to delivering messages effectively to many audiences. To succeed, prevention education materials must be:

- Clear
- Accurate
- Culturally and linguistically competent
- Considerate of literacy level
- Tailored for public or professional audiences

To be most effective, cancer prevention education must do more than provide information on cancer prevention and risk reduction. Educational programs should foster positive attitudes and beliefs toward cancer prevention, impart appropriate risk-reduction skills, try to reduce *psychosocial* and physical barriers, and emphasize the benefits of long-term adherence to prevention strategies.[6]

Cancer prevention programs should foster positive attitudes and beliefs, impart appropriate risk-reduction skills, try to reduce psychosocial and physical barriers, and emphasize the benefits of long-term adherence to prevention strategies.

Prevention programs should be easily available and accessible so that as many people as possible can benefit from them. A clearinghouse of materials should be developed, and all effective, high-quality available materials that are well targeted to specific population groups should be identified and inventoried so that educators and health care professionals know they exist and how they can be accessed. To produce new prevention education material, collaboration between public and private groups and institutions is needed so that limited resources are not wasted on duplicative efforts. Clinicians trained in cancer prevention programs and messages can make valuable contributions to the design and content of these materials, especially when they specifically address priority populations. Speakers' bureaus also should be coordinated in order to provide the speakers with up-to-date cancer risk-reduction information that is best targeted to specific audiences. Efforts should be made to draw health care professionals from diverse ethnic and racial populations into these speakers' bureaus, because, as role models, they can be especially effective educators.

Health Disparities & Prevention

If the risk of developing cancer is to be minimized in Texas, then the message that is delivered is the key to success. The materials delivered on paper, the words spoken in schools and churches, community organizations and neighborhood associations, and by expert speakers must be culturally and scientifically relevant to the person receiving the information and of the appropriate literacy level. Certain groups, such as African-Americans, or those who are economically disadvantaged, have disproportionately higher death rates than others from cancer. Cancer prevention programs and information must be specifically designed to address the diversity of Texas citizens.

Educational messages and programs should, therefore, be tailored for people according to their different ages, cultural backgrounds and beliefs, educational levels, economic status, and geographic regions. Many Texans do not speak English as their primary language; almost one-third of Texans speak a language other than English at home. That means prevention information should be translated into Spanish, Korean, Chinese, and many other languages. Additionally, people with mental and physical disabilities are often overlooked in cancer prevention programs, thereby reducing the likelihood that they will take steps toward cancer risk reduction. People with lower than average literacy levels also require specific attention. In order to design effective programs for the diversity of Texas's population, a better understanding of cancer incidence, risk factors, attitudes, and utilization of cancer services by specific priority populations is essential.

Socioeconomic factors greatly influence cancer disparity. Poverty drives health disparities more than any other factor. Poverty is associated with a lack of resources, information, and knowledge; substandard living conditions; risk-promoting lifestyle; and diminished access to health care.[7]

Age is another key consideration in designing cancer prevention programs. Cancer prevention education for children should be suited to a child's age because children learn developmentally, over time, and in different ways during each stage of their development.[8] Children who develop healthy habits at an early age are more likely to continue those behaviors into adulthood and throughout life.[9] Older Texans, who have the highest cancer incidence and mortality rates, also should have access to age-appropriate information. For them it makes sense, for example, for printed materials and posters to include photographs or drawings of mature individuals with whom they can relate, in a layout that is easy to read.

The inability to read or to read well presents another challenge to prevention education. People who conceal lack of these skills from health care professionals miss an opportunity to discuss with their physician or nurse the risk-reduction recommendations contained in printed literature.

Even for Texans who are literate, attention must be given to vocabulary and the reading level when developing printed materials for cancer prevention programs. A study conducted by Texas A&M University in 1996 found the mean reading level of nationally available cancer prevention materials for African-Americans to be at the ninth grade level.[10] The National

Library of Medicine MedlinePlus guidelines "How to Write Easy to Read Health Materials" generally recommends keeping the reading level to a fourth to sixth grade level, while keeping the target audience in mind. Without a contextual explanation, many people do not understand the technical jargon used by health care professionals, such as "mammogram," "Pap smear," and "risk reduction." Medical terms and procedures must be explained.

Health literacy, the ability to understand written or oral instructions given by health care professionals, also must be considered. People without functional health literacy may experience medication errors, have adverse drug reactions, and exhibit poor compliance with medical recommendations,[11] all of which can affect their cancer experience from prevention to follow-up.

The challenges that low-literacy patients face are compounded when English is not their native language. Educational needs of people who face language barriers are often overlooked or are not fully understood by health care professionals. For example, Spanish translations and word preferences vary greatly between geographic areas and people of different national origins. Many words in Spanish have different interpretations, depending on a person's cultural background or country of origin. In order to avoid using words inappropriately or offending people, care must be given to word choices.[12] Community leaders must alert health care professionals and educational programs about problematic word choices and advocate for *culturally competent* and *linguistically appropriate* messages. Only when prevention interventions take into account the educational and societal needs and the cultural beliefs of specific population groups can they lead to increased knowledge and changed health behaviors.

Once prevention messages are tailored to meet individual cultural, age, literacy, and language needs, care must be taken to ensure that the messages are communicated effectively. Special attention must be given to the teaching methodology used to deliver prevention messages so that specific audiences receive the maximum benefit from interventions. For example, older women may be more receptive to hearing about breast self-examination from a female educator who is of a similar age and socioeconomic level. Teenagers may be more receptive to tobacco use prevention messages from their peers. All prevention materials and programs must be rigorously evaluated to ensure they convey accurate information in a manner that is well received by the specific intended audience.

Attention also must be given to selecting the right medium in which to deliver the message, be it church groups, literacy programs, civic and community organizations, or neighborhood associations. For specific priority populations, such delivery "channels" must be chosen with care.

For example, prevention information broadcast on a radio station that serves primarily a Hispanic audience and is given by a physician who is known in that community is much more likely to influence a listener than a brochure that is published for a general audience. Other examples of culturally relevant programs include producing a television public service announcement aimed at African-American men with the message delivered by a person who is considered a role model by African-American males. For an Asian audience, Asian foods can be featured in cancer prevention publications, posters, and videos as an example.

The Community Based Model for Enhancing African-American Women's Breast Cancer Screening Outreach and Case Management Services (AABCO) in Texas is an example of a culturally sensitive, community-based model to enhance African-American women's participation in early detection and follow-up services for breast cancer. The program uses three core components: (1) the utilization of outreach coordinators; (2) the development of site community and professional advisory committees; and (3) the development of community coalitions to promote education and awareness within specific communities. The program is successful because cultural awareness, sensitivity, and competence have been infused into the project from its inception. Success of the program relies on establishing positive alliances with respected members of the community, planning activities around important cultural holidays, and reaching the target population in places like churches, beauty shops, and community centers. Identifying barriers also was crucial to program success. The AABCO project staff found that the most effective way to get a woman to go for screening was to have one or more friends go with her. The project also found that it was important for African-American people to see themselves represented within the organization that is seeking to provide services for them. The AABCO program

produced *A Guide to Enhance African American Women's Participation in Breast Cancer Screening Outreach and Case Management Services in Texas*, which provides easy-to-follow, step-by-step instructions for starting a program in any community.

The Cultivando la Salud (Cultivating Health) Program for breast and cervical cancer screening is an example of a culturally and linguistically effective educational program. Cultivando la Salud (CLS) was developed by the National Center for Farmworker Health with funding from the Centers for Disease Control and Prevention (CDC) and in collaboration with researchers from the Center for Health Promotion and Prevention Research at the School of Public Health, University of Texas Health Science Center at Houston. The program developed a series of materials (including a video and flipchart) directed at the target population of Hispanic farmworker women and also developed training materials for lay health workers, including a program manual, training curriculum, and teaching guide. The effectiveness of the program was evaluated using an intervention trial and was found to be effective in increasing the use of mammography, clinical breast exams, and Pap test screening.

Workplace Issues & Cancer Prevention

Employers and health insurance companies have an economic incentive to prevent cancer.

Since the treatment and rehabilitation of cancer patients is expensive, employers and health insurance companies have an economic incentive to prevent cancer. These companies can serve a valuable role in cancer prevention education by supporting health education and by making materials and programs available to their employees or subscribers, but few have taken such an active role. That may change, however, when insurers understand the cost benefit and potential long-term savings that result from prevention efforts and utilization of educational resources that are available.

Some of the avenues for cancer prevention in the workplace include industrial health promotion programs, hygiene practices and policies, tobacco use restrictions, protective clothing and device requirements, and legal and administrative approaches to reducing carcinogen exposure, including ensuring that indoor air is clean. The workplace has the added advantage of being an excellent setting for some medical screening programs, such as mobile mammography services and skin cancer screening. Many employers, however, especially small-business owners, may need technical assistance in developing and/or strengthening work site policies and programs that foster cancer prevention. There are many relatively simple things that can be done: inserting health promotion tips with paychecks; displaying educational posters throughout the work area; or inviting local health agencies to make presentations. Even newsletters with health tips and telephone numbers for local educational programs can reinforce other community health efforts and positively affect cancer trends.

Since prevention efforts generally improve overall health, employers and communities that provide prevention education programs receive other benefits besides cancer prevention. Company morale and health can be improved, and reduction of sick days will improve employee productivity and work quality. Prevention education promotes good public relations, and when employers "partner" with community groups to deliver a unified prevention message, limited resources can be shared, and healthy behaviors can be reinforced.

The Systems Approach

Everybody knows it is wrong to drink and drive; the message is reinforced in schools, on television, and in the movies, by law enforcement and community businesses, and by "MADD" mothers who fueled a national movement. This prevention message is a good example of the "*systems approach*" that is necessary to alter behavior and to keep this new standard reinforced day to day. Cancer prevention can work in the same way, especially since so many people worry about developing the disease. A recent Gallup poll revealed that American workers believe that cancer is the single most important health problem they could face in the future; therefore, information that teaches them how to reduce their chance of developing cancer can succeed.

The American Cancer Society stresses the value of using a systems approach to reach these individuals. Systems are networks of independent parts connected by a common goal, such as school systems or hospitals

American workers believe that cancer is the single most important health problem they could face in the future.

or businesses. An initiative that encourages hospitals, clinics, and other health care agencies to provide culturally competent cancer prevention and risk reduction materials and programs is an example of a systems approach.

Systems can work with other systems to effectively spread the prevention message. A particularly relevant example is a Texas health promotion program called Top Priority, which has trained more than 400 businesses in the state to establish self-sustaining, long-term, in-house employee teams that support company-focused work site health promotion activities with minimal investment of staff, equipment, and funds. Community Resource Exchange Networks were established to provide a forum for businesses to share information and programming resources. Systems can interact with other systems to promote cancer prevention: Tenneco, Inc., The University of Texas at Austin, the American Cancer Society, Texas Division, and the Texas Cancer Council were partners in the Top Priority program, which became a statewide initiative. The coordination and sharing of information and programming resources through this public-private sector partnership made it possible for many businesses throughout the state to learn about cancer prevention and risk reduction.

Objective A - Increase Availability Of Effective Cancer Prevention Materials And Programs

Strategy 1: Design culturally competent campaigns on cancer risk awareness and risk reduction for Texas's diverse communities.

Action Steps:

a. Assess gaps in the availability, accuracy, and cultural appropriateness of campaigns and materials for all populations in Texas.

b. Consider literacy level in development of materials.

c. Identify media outlets for specific priority populations and use the outlets to promote prevention education messages in culturally relevant ways.

d. Inform specific priority population groups of the availability of cancer information materials and programs that are specifically tailored to meet their needs.

e. Use existing guidelines for developing effective print and audiovisual cancer prevention information for specific populations and develop guidelines where none exist.

f. Evaluate the effectiveness of methods used to reach specific audiences.

g. Encourage hospitals, clinics, and other health care agencies to increase their ability to provide culturally competent cancer prevention and risk reduction materials and programs.

Strategy 2: Promote the availability and accessibility of cancer prevention resources that are based on the best scientific evidence and best practices.

Action Steps:

a. Develop a clearinghouse of cancer prevention resources.

b. Promote open access to culturally and linguistically effective programs and materials.

c. Promote community-based ownership in planning and sponsoring programs.

d. Implement awareness campaigns to promote the dissemination of materials/resources through appropriate collaborations, particularly community partners.

e. Support the development and use of resource materials for promotion by Texas media.

Strategy 3: Implement cancer prevention awareness campaigns through appropriate collaborations.

Action Steps:

a. Promote collaboration with community systems such as workplaces, faith-based groups, and schools to deliver cancer prevention awareness campaigns.

b. Coordinate speakers' bureaus and facilitate dissemination of up-to-date information to speakers.

c. Develop cancer prevention television programs for children that broadcasters can use to fulfill educational programming requirements.

d. Involve community leaders and other cancer control stakeholders in the planning of and the dissemination of appropriate educational approaches for specific populations.

Objective B - Increase Awareness Of And Access To Cancer Prevention Services

Barriers to Prevention Services

The value of screening for certain cancers is clear. Cancers that can be detected earlier by screening account for about half of all new cases of cancers, including those of the breast, colon, rectum, cervix, prostate, oral cavity, and skin.[13] Early detection of these cancers leads to more successful treatment. If all cancers were diagnosed when they are confined locally (and have not metastasized or spread), the relative five-year survival rate would increase from 84 percent to 95 percent.[14] Cancer screening has led to verifiable reductions in cancer deaths in the state; Texans who aren't screened for cancer have poorer outcomes once the cancer is detected and treated.

Barriers to screening have long existed, and in Texas that has led, in part, to serious cancer disparities.[15] Evidence has consistently shown that minorities and the poor are less likely to receive screenings.[16] Cancers among these groups are more frequently diagnosed after the cancer has spread and is, therefore, harder to treat. Studies have found, for example, that minority women aged 40 or over are less likely to receive mammograms than are Caucasian women, and that only 38 percent of Hispanic women in that age range have regular screening mammograms.[17] Newer data reveals, however, that screening differences between older members of these groups depends less on the race than on differences in education (which includes literacy), income, and insurance status.[18] Population groups that experience disparities also may be defined by geography (urban or rural residence) and issues related to distance from screening facilities, clinics, and even primary care physicians.[19] In fact, more than three million Texans who live in the state's 190 rural counties are considered medically underserved.[20]

In this complex interaction of economic, social, geographic, and cultural factors that influence individual health, poverty in Texas is a critical factor.[21] High poverty levels are associated with a lower proportion of cancers diagnosed at an early *stage*, when they are most treatable, suggesting that routine screening is at a sub-par level. It is estimated that, statewide, about one-third of Texans had an annual income of less than $25,000 in 2003. In 2002, the overall poverty rate was about 16 percent; 3.4 million Texans lived below the poverty line.[22] The composition of this group was 60 percent Hispanic, 22 percent non-Hispanic white, 13 percent African-American, and 5 percent other racial/ethnic groups.[23]

Texas leads the nation in the percentage of working people who have no health insurance.

Lack of health insurance also limits access to early detection screening. A recent Robert Wood Johnson Foundation study found that Texas leads the nation in the percentage of working people who have no health insurance, and studies document that people who lack health care insurance have reduced access to preventive care and are less likely to get timely cancer screening examinations.[24] The insurance gap in Texas is especially acute among Hispanics (53 percent are without health insurance) and those who have less than a high school diploma (63 percent are without insurance).[25]

Barriers to optimal cancer screenings also arise from social and cultural factors, aside from issues of poverty or insurance status. One example adequately illustrates these myriad influences: the American Cancer Society reported in 2004 that although 82 percent of non-Hispanic white women over the age of 18 reported receiving a Pap test for cervical cancer in the last three years, rates were lower among Asian-Americans (68 percent), women with no health insurance (64 percent), and women who had been in the United States for less than 10 years (59 percent).[26]

In some cases, participation in chemoprevention *clinical trials* may help Texans overcome issues of insurance and health care access. Cancer researchers in Texas are leading some of the top national studies on cancer prevention, and state participation is generally high in most of these trials. For example, the Southwest Oncology Group in Texas is leading a national study that looks at whether the dietary supplements

selenium and vitamin E can prevent development of prostate cancer in the 35,000 men who have been enrolled. Particular attention has been placed on enrolling African-American men into the study because they have the highest incidence of prostate cancer in the world.

The Media's Role in Prevention Education

To take advantage of the entire host of cancer prevention programs in place or being developed, Texans need to know about them. One of the best ways to spread such awareness is through use of the media.

Almost every Texan is influenced by the information obtained through the media — newspapers, television, radio, magazines, online news — but news reporting about health advances can be incomplete and, therefore, misleading. Confusion exists on all levels, from the simple debate as to the health benefits of margarine versus butter, to the discussion among screening experts about whether mammography and PSA screening picks up non-lethal breast or prostate tumors. Superficial media reports on the screening issue, for example, could baffle the general public, convincing some people to skip these screenings, a recommendation no clinician would make. By improving coordination and interpretation of cancer-related news alerts, such uncertainty can be minimized.

Moreover, the media offer the ideal opportunity to reach large numbers of people at once with powerful prevention education messages that are culturally relevant, informative, and tailored to the audience. Tight coordination between the media and cancer prevention experts can help spread accurate news about new cancer prevention research and programs, and spokespersons and volunteers representing health care organizations can be trained to provide compelling cancer prevention messages. At the least, organizations can draw up a list of experts for the media's use in cancer-related news stories; at best, a coordinated regional or statewide listing of cancer experts could lead to unified prevention education that positively influences the adoption of healthy habits and public policies.

For example, a message that "five-to-nine-a-day" servings of fruits and vegetables will help prevent some forms of cancer can be spread ubiquitously through the media (which will help fulfill federal requirements to provide educational programming for children), reinforced with posters in school lunchrooms, and

The media offer the ideal opportunity to reach large numbers of people with powerful prevention messages.

through grocery sack reminders. Television, radio, and newspaper series that examine the cancer-nutrition connection, and which also offer recipes or show chefs cooking healthy meals, can be launched along with Internet sites that coordinate all these messages and offer free CD-ROMs to the public.

Another example is that African-American men are not offered screening for prostate cancer as frequently as they should be, compared to other groups. A message that encourages discussion of screening could be coordinated between the media that are popular in African-American communities, be they radio or television, and businesses that will sponsor free screenings in cooperation with local clinics. In this campaign, African-American physicians can serve as expert media contacts, and telephone hotlines to answer questions and concerns can be established.

The A Su Salud program is a good example of how the media can be used effectively to reinforce cancer prevention messages for specific populations.

Developed by cancer researchers at The University of Texas Health Science Center at San Antonio[27] and funded by the National Cancer Institute, A Su Salud uses local community members as role models in both print and broadcast media presentations. The media events and the use of local role models reinforce the prevention messages being disseminated concurrently through an organized community education campaign.

Objective B - Increase Awareness Of And Access To Cancer Prevention Services

Strategy 1: Promote awareness of culturally and linguistically appropriate cancer prevention services, particularly among high-risk groups, such as ethnically and culturally diverse populations and the medically underserved.

Action Steps:

a. Encourage use of comprehensive media campaigns that are tailored to the appropriate populations.

b. Promote cancer awareness observances as a way to disseminate information through community systems.

c. Identify and address barriers that limit effectiveness of awareness and outreach programs, particularly for high-risk groups, such as diverse populations and the medically underserved.

Strategy 2: Improve access to cancer prevention services.

Action Steps:

a. Support insurance coverage of and reimbursement for cancer prevention services.

b. Support efforts to identify and reduce barriers to prevention services at a community level, particularly among diverse and medically underserved populations.

c. Promote the development and dissemination of public nutrition education programs to include portion control and healthy food choices.

d. Promote dissemination of existing evidence-based model programs that effectively bridge gaps and reduce barriers among diverse and medically underserved populations.

e. Promote increased dissemination and availability of tobacco cessation programs and counseling.

f. Promote awareness of risk assessment counseling, including genetic testing and counseling.

g. Promote dissemination and availability of nutrition counseling.

h. Ensure that prevention services and programs are culturally and linguistically appropriate.

Strategy 3: Increase awareness of, access to, and participation in prevention clinical trials.

Action Steps:

a. Increase the participation of high-risk groups, such as ethnically and culturally diverse populations and the medically underserved, through collaborations at the community level.

b. Ensure that high-risk groups, such as diverse populations and the medically underserved, are included in recruitment strategies at the beginning and throughout the research process.

c. Create mechanisms to increase participation in clinical trials, such as increased funding for recruitment and retention of diverse populations, creation of linguistically appropriate patient information and informed consent, use of incentives, and ensuring that medical and associated costs are covered.

d. Encourage funders and researchers to include grant support for an effective communication plan to aid in clinical trial recruitment.

e. Promote better methods of communicating information about clinical trials available in Texas.

f. Develop culturally and linguistically appropriate messages regarding clinical trials and deliver them through population-appropriate channels.

g. Support efforts to reduce financial barriers, such as encouraging health benefit plans to provide access to available clinical trials through ACOS- or NCI-approved facilities.

h. Promote collaboration among the public, the research community, and diverse communities to increase knowledge of and participation in clinical trials.

i. Increase funders' and health care professionals' awareness of barriers to participation, particularly for underrepresented populations.

j. Encourage the inclusion of all clinical trials in registries.

Objective C - Promote Healthy Lifestyles And Behaviors In Children, Particularly Those At High Risk For Developing Cancer, Such As Ethnically And Culturally Diverse Populations And The Medically Underserved

Youth & Cancer Prevention

Habits acquired in youth strongly shape behavior in the adults they will become. The majority of children and adolescents who are overweight will become overweight adults. Children who don't exercise stay physically inactive throughout life. Almost 90 percent of adult smokers acquired their habit as a child or teenager, and one-third of them will die from a tobacco-related disease, including a wide variety of cancers.[28] The formative years of youth offer many opportunities to influence the development of lifelong skills and healthy behaviors needed for cancer prevention and risk reduction. Children who adopt healthy habits at an early age are more likely to continue these behaviors throughout life.[29] Additionally, children who have good health knowledge and skills perform more effectively in school, and they achieve a better lifelong health status.[30]

Children who adopt healthy habits at an early age are more likely to continue these behaviors throughout life.

Comprehensive School Health Education

The 129,000 schools that teach more than 50 million K-12 students in the United States provide a ready and available organizational structure through which to deliver cancer prevention programs that will shape those lifelong habits.[31] Schools are logical places to both improve the health of students through physical activity and nutrition and to arm youngsters with strategies that empower them to avoid health risks in the future.[32] Students who have had comprehensive school health education are less likely to drink, smoke, take drugs, or ride with drivers who have been drinking than are students with little or no health education.[33]

Thus, a number of health, education, and social service agencies, along with the American Cancer Society, promote "comprehensive" school health education, along with National Health Education Standards. Among other goals, these standards are designed to give students the skills to practice behaviors that reduce health risks. National standards are not a federal mandate, nor do they define a national curriculum, but they are intended to serve as a framework for organizing health knowledge to produce health "literate" schoolchildren.[34] The standards also are designed to help parents, the schools, and the communities create an instructional program that will help students become, and stay, healthy.[35]

To help ensure that these standards are followed, comprehensive school health education is a planned health education curriculum for preschool through grade 12. Experts recommend that students receive at least 50 classroom hours of instruction per year in health and that the following 10 areas should be included in any comprehensive school health program: community health, consumer health, environmental health, family life, mental and emotional health, nutrition, personal health, chronic and infectious disease prevention and control, safety and accident prevention, and substance use and abuse.[36] The skills children acquire to prevent lifelong cancer risks are similar to those needed for other health issues. For example, risk factors like smoking, poor diet, and little exercise are the same for several chronic diseases.

Innovative Health Promotion Strategies

Working with a population that is more focused on short-term needs, and for which there is limited time for health promotion during the school day, presents a challenge. One way to address the issue is to engage children in their own health through youth advocacy. Results from a qualitative evaluation of a youth advocacy program demonstrate that engaging youth as catalysts for change may lead to solutions that are meaningful and enduring to the intended audience.[37]

A team approach also is effective. A strategy pioneered in 1986 by the Texas Cancer Council to promote

lifelong cancer risk reduction behavior in school-children has grown into the Texas School Health Network that links all the state's school districts. The network, a collaboration between the Texas Cancer Council, the Department of State Health Services, and the Regional Education Services Centers, provides School Health Specialists who offer integrated, coordinated approaches for health education to schools within their districts.[38] For example, School Health Specialists collaborate with regional professional organizations to:

- Sponsor training and networking opportunities for school personnel
- Offer school nurse institutes and academies
- Plan conferences for physical education professionals
- Sponsor workshops for food service staff

For cancer prevention, school districts rely on their School Health Specialist for assistance on tobacco education, policies, smoking cessation, and wellness promotion programs.[39] The Texas School Health Network has become the primary mechanism for strengthening health promotion activities for school-children and has provided a way for state agencies, volunteer health organizations, education organizations, and many others to unite in a common purpose of strengthening school health education throughout Texas.

School Health Specialists also assist schools in the development of school health advisory councils. These councils, established by state law, have a variety of roles, depending on how school systems use them. Some assume cancer risk prevention roles by initiating policies related to smoking and the sale of nutritious foods in school.[40] Furthermore, recent changes in state law allow these advisory councils to have a representative from nonprofit health organizations, like the American Cancer Society, appointed to the group, giving them a definable role in risk prevention.

State policies concerning physical activity in schools can advance healthy behaviors in children. Knowing that the number of overweight children in the state has doubled in the past 20 years and that excess body weight increases the risk of developing a number of diseases, including cancer, the Texas legislature passed a law in 2001 that requires school districts to offer 30 minutes of daily physical activity for students in grades K-6.[41] Texas law currently requires physical education classes for grades 9-12.

Tailoring Health Messages

Since young people learn developmentally, it is important that cancer prevention education be appropriate for the child's age and prior learning experiences. Each lesson in cancer prevention and risk reduction should build on the achievements and knowledge gained from previous lessons. The learning skills and behaviors for cancer prevention instruction also should be developed for each level in school,[42] tailored for different cultures, languages, and ages of students, and spread throughout all regions in Texas. To illustrate, puppets can be used to reinforce health messages for children who have not yet learned to read. For older children, peer-driven programs in which teens serve as advocates for cancer prevention and healthy lifestyles may be the most effective method of instruction.

The Project S.A.F.E.T.Y. CD-ROM and Teacher's Guide are a science-based skin cancer awareness and prevention curriculum developed by The University of Texas M. D. Anderson Cancer Center for grades 4-12. Based on an earlier multimedia module developed with Texas Cancer Council funding, the Project S.A.F.E.T.Y. CD-ROM and Teacher's Guide have been in classroom use since 2002. The highly effective curriculum delivers information via animated graphics, video clips, colorful

Since young people learn developmentally, it is important that cancer prevention education be appropriate for the child's age and prior learning experiences.

charts, and activities. The 90-page Teacher's Guide contains pre- and post-achievement tests, additional activities, a glossary, a resource list for students and teachers, and lesson correlations with the Texas Science TAKS (Texas Assessment of Knowledge and Skills), Health TEKS (Texas Essential Knowledge and Skills), and the National Science and Health Education Standards. In 2002, the module earned a Silver Award at the HSCA (Health Sciences Communications Association) International Media Festival.

In the mid-1990s, the Texas Education Agency undertook an extensive review of public education curriculum and knowledge, skills, and performance expectations for students, known as Texas Essential Knowledge and Skills (TEKS). In 1997, the State Board of Education adopted the health and physical education components of TEKS. The curricula guidelines parallel those developed by the Joint Committee on National Health Education Standards, which address serious health problems through planned, sequential, and developmentally appropriate instruction. The standards seek to improve student learning by providing a foundation for curriculum development, instruction, and assessment of student performance.[43] Further, they outline ways in which students can increase their health literacy. According to the Joint Committee on National Health Education Standards, four characteristics define a person as health literate: critical thinking and problem solving; responsible and productive citizenship; self-directed learning; and effective communication.[44]

The Role of School Personnel

Given that the school setting provides the single most effective setting for accessing Texas's youth to deliver cancer prevention messages, the role of educator naturally falls to classroom and physical education teachers. Still, comprehensive school health education is required to be taught by school personnel who are trained, certified, or credentialed to teach the subject matter.[45] As of 1997, middle and high school teachers in Texas are required to be certified to teach health, as they would in any other area of certification. Health certification is not required, however, for elementary school teachers. Other school staff play important roles, such as school counselors and nurses, who perform cancer screening and risks assessments, and even food service employees, who are the guardians of healthy student nutrition. Coaches are influential role models for young athletes and can readily sway student attitudes about exercise, nutrition, and tobacco use. In fact, all school staff, including administrators, can support cancer prevention education by serving as positive role models for children and demonstrating healthy behaviors. School health programs can be further enhanced by establishing linkages between schools and community organizations, sharing new and innovative ways to teach cancer prevention.

To increase student awareness and practice of risk reduction behaviors and healthy lifestyles, it is important that youth be recognized as health consumers and be given the information and tools needed to maximize their health status.

While education aimed at preventing cancer should occur within all facets of the school, parent and community involvement, such as sports groups and summer camps, also is required to promote cancer risk prevention. Parent and community involvement can reinforce health instruction on a day-to-day level through a multitude of creative ways. Parents who work in health care can serve on school district health advisory committees, which then integrate the health interests of parent groups, businesses, and civic clubs. To increase student awareness and practice of risk reduction behaviors and healthy lifestyles, it is important that youth be recognized as health consumers and be given the information and tools needed to maximize their health status.

Objective C - Promote Healthy Lifestyles And Behaviors In Children, Particularly Those At High Risk For Developing Cancer, Such As Ethnically And Culturally Diverse Populations And The Medically Underserved

Strategy 1: Promote cancer prevention through Texas educational systems.

Action Steps:

a. Promote the adoption of healthy behaviors by working with parent groups, educational systems, and other organizations aimed at children.

b. Promote the increased use of effective cancer curricula in Texas education systems.

c. Target promotions particularly to those children at high risk for developing cancer, such as ethnically and culturally diverse populations and the medically underserved.

d. Work with state-mandated School Health Advisory Councils (SHACs) to promote cancer prevention information through schools as part of a comprehensive school health curriculum.

Strategy 2: Facilitate the development and implementation of culturally competent and linguistically appropriate innovative health promotion strategies to encourage children to adopt healthy lifestyles.

Action Steps:

a. Continue collaborative efforts among state agencies, Regional Education Service Centers, health and education organizations, and universities in designing, implementing, and promoting effective health promotion strategies.

b. Encourage use of "best practice" strategies to local school boards and other educational systems.

c. Involve community, civic, and business groups in developing, implementing, and supporting innovative cancer prevention programs, curricula, and resource materials for school-aged children.

Objective D - Promote Policies And Programs Aimed At Reducing Tobacco Use And Exposure To Secondhand Smoke

Tobacco's Link to Cancer

Tobacco use is widespread, and it is deadly. In 2002, more than one in five adults in America, 22.5 percent of the U.S. population, or 45.8 million adults, smoked cigarettes.[46] The majority of these individuals, almost 82 percent, smoke every day.[47] Yet smoking is the most preventable cause of death in the world today.[48] Worldwide, there were about 4.9 million smoking-related premature deaths in 2001, and these were divided evenly between industrialized and developing

Approximately half of all Americans who continue to smoke will die from their habit.

nations.[49] The toll is exceedingly high in the United States, as well. Tobacco use is responsible for nearly one in five deaths, or an estimated 440,000 deaths per year during 1995-1999.[50] Approximately half of all Americans who continue to smoke will die from their habit.[51] Smoking accounts for at least 30 percent of all cancer deaths and 87 percent of lung cancer deaths.[52] Lung cancer is now the leading cause of cancer death in both men and women.[53] Smoking is associated with increased risk for cancers of the mouth, larynx, pharynx, esophagus, stomach, liver, pancreas, kidney, bladder, uterine and cervical cancers, as well as myeloid leukemia.[54]

Cigarette smoking in the United States causes other serious diseases among an estimated 8.6 million people.[55] These include heart disease, stroke, emphysema, and bronchitis, as well as adverse outcomes in pregnancy.[56] These diseases impose substantial costs; for *each* of the approximately 22 billion packs of cigarettes sold in the United States in 1999, $3.45 was spent on medical care linked to smoking and $3.45 was lost in productivity.[57] The harmful effects of smoking are not just confined to the smoker. It is estimated that *secondhand smoke* has been responsible for about 3,000 lung cancer deaths and more than 35,000 deaths from heart disease among nonsmokers in the nation.[58] Researchers have firmly established that there is no safe level of secondhand smoke, which contains more than 4,000 substances, including at least 40 known carcinogens.[59]

Texas is equally impacted by tobacco's profile of disease and death. Lung cancer, the leading cause of cancer-related death in Texans of both sexes, is projected to cause 10,505 deaths in 2004. Lung cancer is the second most common cancer diagnosed in the state.[60] More men (27 percent) than women (18 percent) smoke in Texas, with the result that lung cancer incidence and mortality rates among men are almost twice those of women in the state.[61] In Texas, the burden of lung cancer is disproportionately borne by African-American males,[62] and those who are undereducated also are at risk: in Texas, adults aged 25 and older with less than a high school diploma have smoking rates higher than the state average.[63] Nationally, smoking *prevalence* is higher among adults living below the poverty line.[64]

Youth & Tobacco Use

Addiction to cigarettes and other tobacco products begins in youth. The American Cancer Society reports that 90 percent of adult smokers became addicted to tobacco before the age of 18.[65] The average age at which people begin smoking is 13 years, and the reality is that those who start a tobacco habit young become hooked, despite their desire to stop. Most youth smokers believe they will not be smoking in five years, and more than half report trying to quit within the past year.[66] But without intervention, young smokers will most likely become adult smokers.[67] In fact, studies show that among high school seniors, 73 percent of daily smokers remained daily smokers five to six years later.[68]

Tobacco use also is associated with a range of behavioral problems during adolescence, according to the U.S. Surgeon General.[69] It is considered to be a "gateway" drug, the first drug used by youth who experiment with alcohol, marijuana, or narcotics. Youth who smoke cigarettes also are more likely to get into fights, carry weapons, attempt suicide, and engage in high-risk sexual behaviors. For these reasons, the National Cancer Institute says that decreasing cigarette smoking among adolescents is a major public health objective for the nation.[70] It is critical to the prevention of future tobacco-related cancers[71] as well as other high-risk behaviors, says the American Cancer Society.

Past success in convincing the young not to smoke has been mixed, although recent data show the lowest levels of teenage smoking since national trends in tobacco use began to be studied in 1991.[72] Cigarette smoking among U.S. high school students has fluctuated in past years. It increased significantly from 28 percent in 1991 to 36 percent in 1997, but declined to 29 percent in 2001.[73] In Texas, smoking incidence in students recently dropped, but still remains high. When asked in 2001, fewer middle and high school students reported that they had ever tried smoking, compared to rates found by a survey taken in 1999, according to the federal Centers for Disease Control and Prevention (CDC) and the Department of State Health Services. Data were analyzed from the Youth Risk Behavior Surveillance System surveys to again examine the prevalence of tobacco use among Texas youth. They found that the rate of "ever" smoking a cigar, in addition to ever having tried smoking, also declined in both middle and high school students. Between 1999 and 2001, 27 percent fewer middle school students reported that they had tried smoking cigarettes at least once (48 percent versus

Anti-tobacco poster created by a child as part of an educational campaign.

35 percent). Also between those two years, 11 percent fewer high school students said they had smoked (71 percent in 1999, compared to 64 percent in 2001). Additionally, fewer middle school students also reported having tried smokeless or "spit" tobacco in 2001, but the rate remained the same in high school.

The survey also found that current use of tobacco, defined as within the 30 days preceding the survey, had declined for most, but not all, forms of the product:

- In middle and high school, current use of any tobacco product declined.
- Current use of cigarettes declined among middle school students and those in high school.
- Use of cigars, smokeless tobacco, and tobacco with a pipe either remained the same or did not significantly decline in both middle and high school students.

Although the school survey showed that more boys used tobacco than girls, current use had declined among both sexes in middle and high school. Tobacco use among racial and ethnic groups differed, however. According to the survey:

- Hispanic middle school students continued to be more likely than white and African-American students to be current users of tobacco.
- White and Hispanic high school students were again more likely than African-American students to be current users of tobacco.

The survey also found that both in 1999 and in 2001, the number of students using tobacco generally increased with each grade level, although the comparable rate between these two time periods had decreased. For example, in 2001, 17 percent of students in grade 7 said they currently used tobacco, down from the 26 percent that reported grade 7 use in 1999.

Cigarette use among high school students nationally has continued to decline, according to the most recent study. In 2003, approximately one in 5 high school students were current smokers, and one in 10 defined themselves as frequent smokers.[74]

Youth Tobacco Control

Recent declines in tobacco use among America's youth are due to effective mass media and school-based tobacco prevention efforts and to the increasing cost of cigarettes, a jump of 90 percent since 1997, according to the CDC.[75] Reducing smoking rates further will require continuing efforts on the part of states, communities, schools, and parents. The U.S. Healthy People 2010 objectives, for example, suggest the following targets: reduce the current use of any tobacco product to 21 percent; reduce youth cigarette smoking to 16 percent; increase the proportion of daily smokers who attempt to quit to 84 percent.[76]

Reaching such a goal requires the following steps, according to the CDC: targeted and effective media campaigns, reducing depictions of tobacco use in the entertainment media, promoting smoke-free homes, decreasing adult smokers so children have good role models, discouraging adults from providing cigarettes to youth, and instituting comprehensive community and school-based programs and policies that encourage smoking cessation.[77]

Progress has been made in many of these areas, and some states serve as models for others to follow. However, many programs that aim for the critical goal of smoking cessation are unsuccessful.[78] Much attention has been paid to such programs, which also have been fueled financially by tobacco taxes and the settlements that states have made from tobacco industry lawsuits, but there is little scientific evidence that these programs work.[79] Experts say that unlike the extensive research that has been undertaken to evaluate tobacco cessation treatments in adults, there is a dearth of scientific studies that judge effective treatment for youth tobacco users.[80] Several major reviews of available evidence suggest that *cognitive* behavioral treatments, which have been found effective for adult cessation, have shown promise in convincing the young to quit.[81] Such programs involve much more than just having the right "content." [82]

Reducing Youth Access

During the mid-1990s, sweeping federal and state laws were enacted to prevent youth access to tobacco products. Many studies indicated that youth had little trouble obtaining tobacco products despite laws prohibiting the sale of tobacco to minors.[83] Nationally, minors who try to buy tobacco are generally successful in purchasing it over the counter 50 to 75 percent of the time.[84] Despite state laws prohibiting the sale of tobacco products to minors, Texas children can successfully access these products through vending machines, self-service displays, free samples, mail-order sales, and other kids. U.S. regulations require tobacco-sales compliance checks. Yet, there is controversy as to their effectiveness. Even when checks produce single-digit violation rates, adolescent tobacco use often fails to decline.[85] Although statewide vendor compliance surveys conducted by the Department of State Health Services show a decrease in sales to minors, retail purchase remains the usual way that addicted adolescents get their cigarettes, as well as the cigarettes they give experimenting peers.[86]

Active enforcement of age verification policies is needed. Tobacco products are widely available at a variety of retail stores, making them easily accessible to youth. The placement of tobacco products in prominent displays and behind checkout counters falsely reinforces the idea that tobacco is safe, in great demand, and a part of everyday life.[87] Restrictions to limit access to cigarette vending machines and the "We Card" programs can deter youth from easily obtaining cigarettes, but it doesn't stop them. In its 1998-1999 youth tobacco survey, the Texas Department of State Health Services found that while access to commercial sources of cigarettes was down, access to alternate sources had increased significantly, largely by stealing cigarettes or getting them from adults.[88] Public health experts in Texas say that to reduce youth access to cigarettes, stricter policies prohibiting the sale of tobacco to minors are needed, and retailer and community education should be intensified. Similarly, the CDC concluded that giving retailers information was less effective in reducing illegal sales than active enforcement, but that still no strategy achieved complete compliance.[89]

Two primary ways to prevent and reduce tobacco use among children is through effective educational programs and enforcement of laws restricting sales of tobacco products. Comprehensive school health education is an excellent vehicle for reinforcing the dangers of tobacco use in a systematic way for grades K-12. As with the other components of comprehensive school health education, tobacco use prevention education must be age and culturally relevant and meet the developmental needs of students. Proven and effective teaching methodologies should be used, such as peer instruction. Peer influence seems to be especially important in the early stages of tobacco use.[90] Schools and school districts can underscore tobacco use prevention messages to youth by enforcing policies that ban tobacco use on school grounds and at school functions.

The effectiveness of school-based programs appears to be enhanced by involving parents, youth-oriented media, and community organizations.[91] Influential adults, such as coaches, the clergy, neighbors, scout leaders, and other role models for youth, should set a good example for youth and enforce the anti-tobacco message that is taught in schools. Adults also should support programs that seek to reduce tobacco use among youth and educate retailers about the importance of enforcing tobacco laws. Sports professionals can be especially powerful educators and should take it upon themselves to set a good example for youth by not using tobacco products. Tobacco use prevention education must do more than teach children about the health hazards. Children also must be made aware of the ways in which tobacco companies influence them with promotion and advertising of tobacco products. Marketing techniques, advertisements, product names, and packaging also influence youth attitudes about tobacco products. Children are highly susceptible to repetitive advertising of retail products, including tobacco.

Active enforcement of local, state, and federal laws is an essential component of tobacco prevention and control efforts. In Texas, an increasing number of laws limit youth access to tobacco products. Four laws passed in the state legislature since 1999 strengthened youth restrictions to tobacco products. The 2003 House Bill number 3139, for example, prohibits the delivery sale to minors and imposes requirements addressing age verification, notification, shipping, and reporting, and also specific penalties for violating these rules. The 2001 House Bill 2767 elevates the penalty for violating the existing sign-posting requirement for retail tobacco sale. The Texas Education Code[921] prohibits tobacco use and possession by students at school-related or school-sanctioned activities, on or off of school property. It also gives school personnel the responsibility of enforcing these prohibitions on school property.

Studies indicate that higher costs of tobacco products discourage youth from purchasing them. When the price of cigarettes goes up, it has been found that youth smoking rates go down. The American Lung Association reports that for every 10 percent increase in price, youth smoking rates will drop by about 7 percent. Price elasticity estimates also vary by study and range from $.25 to $1.313. Differences in sensitivity to price also have been found, with youth being more sensitive than young adults. There also have been similar estimates for the effect of price on smokeless tobacco use. Since 2001, the Texas excise tax rates are $.41 per pack of cigarettes and 35 percent of the retail price of spit tobacco.

During the 1990s, the federal government focused increased attention on youth access to tobacco, most notably through the 1992 “Synar Amendment” and the Food and Drug Administration rules enacted in 1996. The Synar Amendment requires states to enact and enforce laws that prohibit the sale of tobacco products to people under the age of 18. It also requires states to conduct random, unannounced inspections to assess compliance with the law, and to develop a strategy for achieving an inspection failure rate of less than 20 percent. Further, states are required to annually report on their enforcement activities and success rates in reducing tobacco availability to minors. The Synar Amendment authorizes the U.S. Secretary of Health and Human Services to withhold federal Substance Abuse Prevention and Treatment Block Grant funds if states do not comply with the enforcement and reporting requirements.[93]

Regulations & Litigations

Comprehensive Food and Drug Administration (FDA) tobacco regulations, released in 1996, regulate the access and appeal of tobacco products to children and adolescents.[94] The FDA rules regulate tobacco sales, restrict outdoor advertising and ads in print media, and prohibit brand-name sponsorship of sporting or entertainment events, among other measures.

Further restrictions on advertising and sales were included in the spate of lawsuits filed by states in the 1990s. Texas sued the tobacco industry in 1996, and in 1998, Texas reached an agreement for $17.3 billion. In June 1997, the tobacco industry reached the "*Master Settlement Agreement*" for $206 billion with 46 other states and with U.S. territories. Much of those funds was to be earmarked for recovering the cost of treating patients for smoking-related illnesses, as well as for conducting tobacco control programs, although many states use the funds to supplement their general revenue. For example, in 2001, the average state received $28.35 per resident from the tobacco settlement, but allocated only 6 percent of these funds to tobacco control programs.[95] Only 48 percent of tobacco control settlement funds that year were spent on health care, long-term care, and medical research.[96]

Adult Tobacco Use & Control

While the Texas Cancer Plan places priority focus on the prevention of tobacco use among youth, efforts also are needed to reduce tobacco use among adults. In 2003, more than 24,000 Texans died from tobacco-related diseases, an average of 66 Texans a day.[97]

In 2002, almost 23 percent of adults in Texas were smokers, the same percentage as seen nationally.[98] Smoking prevalence is higher among men than women, and it varies by race, ethnicity, socioeconomic status, and, now, by education. The reversal in education status has been dramatic. In the early 1960s, college-educated adults had the highest smoking prevalence, but by 2001, only 10.8 percent of college graduates smoked, compared to 30.9 percent of those who did not graduate from high school.[99] Cigarette smoking prevalence rates also vary substantially across population subgroups, according to a recent report by the CDC.[100] The prevalence of smoking was higher among men (25 percent) than women (20 percent) and inversely related to age, from 28 percent for those aged 18-24 years to 9 percent for those aged 65 or older.

Because the largest disparities exist between certain racial and ethnic groups and between education levels among smokers, experts suggest that efforts be made to target tobacco control programs to these seriously affected groups. In 2002, as in previous years, Asians (13.3 percent) and Hispanics (16.7 percent) had the lowest prevalence, and American Indians/Alaska Natives had the highest (40.8 percent). The gap in smoking prevalence between those living beneath the poverty line and those living at or above it has grown, and the percentage of people who have successfully stopped smoking is higher for people at or above the poverty line.[101]

In 2003, more than 24,000 Texans died from tobacco-related diseases — an average of 66 Texans a day.

Tobacco control programs are crucial to the future health of smokers. Many who use cigarettes try to quit, but are unsuccessful. Among the 50 states and Washington, D.C., the median proportion of "everyday" smokers who tried to quit smoking in 2001 was 52 percent.[102] Many Texans also attempted to give up their habit that year; nearly 69 percent received advice to quit and more than 47 percent tried to quit.[103] The effort, as difficult as it is, saves lives: the CDC reports that smokers who quit before age 50 cut in half their risk of dying in the next 50 years.[104]

Although tobacco control programs have had an effect in the past decade, especially through increased cigarette taxes and reduced indoor smoking, smokers who wish to quit can avail themselves of various effective treatments for tobacco dependence. One of the newest strategies is to use medication, such as Bupropion, that "resets" brain chemistry involved in addictive behaviors. Another is to use products that help replace nicotine and ease withdrawal for those who have recently stopped smoking. These are nicotine gum, inhalers, lozenges, nasal sprays, and patches. These strategies double the chance of quitting for good;[105] moving to "lighter" cigarettes or spit tobacco, however, is not a recommended strategy for quitting. Since the mid-1990s, smokers have been able to purchase some of these replacement strategies without a physician's prescription, but experts say that attention needs to be given to financial barriers that low-income Texans may face in obtaining nicotine replacement therapy, prescription medication, and access to cessation programs.

Counseling and behavioral therapies also can help. An evidence-based clinical practice guideline on cessation issued by the Agency for Healthcare Research and Quality (AHRQ) states that even brief advice to quit smoking, if given by medical providers, can work.[106] More intensive interventions, through individual, group, or telephone counseling, are even more effective. Studies

have shown that counseling sessions as brief as three minutes are effective, but longer and more intensive efforts improve cessation outcomes.[107] AHRQ guidelines recommend that insurers, purchasers, and hospital and managed care administrators work together to incorporate smoking cessation services into health plans, to implement them systematically, and to reimburse providers accordingly.

New prevention control efforts are needed, however, to close the smoking gap seen between people below and above the poverty line. Reaching such a *high risk* population will require comprehensive tobacco-control programs that discourage smoking initiation and promote smoking cessation.[108] These programs, at local, state, and national levels, must ensure that their intervention efforts reach persons with inadequate resources and limited access to health care.[109] These efforts also should address the needs of the uninsured, for example, by providing treatment through telephone quit-lines and community health centers; increase coverage for tobacco-use treatment programs; and improve workplace and social environments to better support smoking cessation, especially for low-income and blue-collar workers.[110]

Best Practices

California has become a national model for tobacco prevention control. Whereas 23 percent of the U.S. population smokes, only 16.4 percent of California's population use cigarettes, the lowest rate in America next to Utah.[111] The California Tobacco Control Program, approved in 1988, emphasizes a comprehensive approach to tobacco control, prevention, and education. It also includes strategies to change social norms related to tobacco use, and experts say that those have been crucial to the state's success.[112] California's program included novel and culturally appropriate interventions, including television and billboard advertising against smoking, and innovative and research projects to prevent youth tobacco use, as well as counseling and treatment for young people and adults.[113] As a result of this all-inclusive approach, per capita consumption declined 52 percent faster in California than in other states.

California also successfully declared communities to be smoke-free, a strategy that is being adopted in towns and states across the country now that the risks of secondhand smoke are more completely understood. Secondhand smoke includes at least 60 known carcinogens and has been linked to lung cancer, nasal sinus cavity cancer, and cervix, breast, and bladder cancer, as well as other illnesses, such as heart disease.[114] Children of parents who smoke have more respiratory symptoms and acute lower respiratory tract infections, as well as evidence of reduced lung function, than do children of non-smoking parents.[115]

Based on the successes seen in tobacco control programs across the country, the CDC is promoting the implementation of a comprehensive approach to community tobacco control as best practice. In Texas, the Texas Tobacco Prevention Initiative (TTPI) has taken on that mandate, using funds from the tobacco settlement monies. Initial funding was not adequate to implement a statewide program, so a pilot study that included 18 counties in the East Texas area examined the most effective ways to prevent tobacco use and promote cessation among Texans of all ages. In the study, a combination of interventions in school, community, enforcement, cessation, and mass media were examined. Initial findings showed that a comprehensive program, funded at only $3 per person, that included school, community, enforcement, cessation, and mass media was effective in reducing tobacco use. Lower level media campaigns and single-focus community programs did not have measurable effects on tobacco use among children and adults. TTPI was expanded so that comprehensive programming funded at $3 per person was provided in the Houston/Beaumont/Port Arthur pilot areas, and implementation of the Comprehensive Program in the pilot areas has shown tremendous reductions in tobacco use. From 1998 to 2003, current use of any tobacco products showed a 32 percent reduction among middle school students (from 24.5 percent to 16.6 percent) and a 41 percent reduction among high school students (from 40.1 percent to 23.6 percent). The prevalence of adult smoking in the comprehensive pilot area decreased 18.7 percent (from 22.6 percent in 1999 down to 18.4 percent in 2002).

As seen in California, city ordinances on indoor air quality in workplaces and other public places can help

Findings showed that a comprehensive program, funded at only $3 per person, that included school, community, enforcement, cessation, and mass media was effective in reducing tobacco use.

prevent cancer by reducing exposure to environmental tobacco smoke. As of 1997, Texas had few state-level restrictions on smoke-free indoor air in places such as government and private work sites, restaurants, and other sites. Current state law permits local governments to adopt city ordinances on tobacco control to protect nonsmokers from environmental tobacco smoke.

The effort to help Texans stop smoking, and to protect those who have never smoked from indoor pollution, has reaped unexpected benefits. Bar and restaurant owners were nervous when El Paso, a town of more than 563,000 Texans, banned all smoking in public places and workspaces on January 2, 2002. The smoking ban was the strongest smoke-free indoor air ordinance in Texas at the time and included rules that it be enforced by firefighters and law enforcement agencies at up to $500 per violation.[116] The ban, however, did not reduce revenues in bars or restaurants, and in fact, in some places, sales went up.

Objective D - Promote Policies And Programs Aimed At Reducing Tobacco Use And Exposure To Secondhand Smoke

Strategy 1: Increase awareness of the risks of tobacco use by youth, particularly youth from high-risk groups.

Action Steps:

a. Educate parents, teachers, coaches, clergy, and other influential adults on the importance of being positive role models for youth by not using tobacco.

b. Conduct media campaigns to educate youth about the risks of tobacco use and cancer and to encourage youth to be tobacco-free.

c. Include effective educational curricula and peer-driven programs on tobacco use prevention as part of comprehensive school health education in grades K-12.

d. Distribute age-appropriate prevention messages through existing youth-oriented community-based channels, such as organized athletics, youth councils, and scouts.

Strategy 2: Reduce access to and use of tobacco products by youth.

Action Steps:

a. Increase participation in campaigns that enforce state tobacco laws.

b. Support efforts in the media and arts to curb tobacco use.

c. Promote tobacco-free environments where youth congregate, such as arcades, recreational facilities, restaurants, malls, and on college campuses.

d. Encourage local health and law enforcement agencies to take an active role in enforcing laws related to tobacco sales and distribution across Texas.

e. Strongly discourage the promotion and use of tobacco products at sporting or entertainment events that are for youth younger than 18.

f. Encourage and support additional research and data to better understand drivers of tobacco use and cessation in ethnically and culturally diverse populations and medically underserved youth.

Strategy 3: Reduce the use of tobacco products by adults.

Action Steps:

a. Educate health care professionals and the public about the influence that the marketing of tobacco products has on health behavior.

b. Disseminate effective and culturally and linguistically appropriate tobacco cessation programs to communities statewide.

c. Educate policy makers about the importance of tobacco prevention and control in an effort to direct more state funding toward comprehensive tobacco cessation services for all Texans.

d. Encourage state and local, public and private entities to collaborate with one another in an effort to expand "best practice" programs statewide.

e. Promote the translation of research regarding addiction in diverse populations to improve prevention and cessation programs.

Strategy 4: Increase awareness of the risks and limit exposure to secondhand smoke.

Action Steps:

a. Target educational campaigns to bar/restaurant owners and other hospitality venues about going smoke-free.

b. Support statewide smoking ordinances that ensure that all public places are smoke-free.

c. Educate parents about the effects of secondhand smoke through community childcare programs such as Head Start and daycare centers.

d. Collaborate with local fire departments to educate the public about the dangers of smoking as it relates to the cause of fires and deaths.

e. Raise awareness and promote use of tobacco Web sites and their resources, including databases.

Objective E - Promote Policies And Programs Aimed At Addressing Cancer Risk Related To Obesity

Obesity & Cancer

The relationship between cancer, what a person eats, and how active they are, is becoming clearer and more alarming. A recent report in *The New England Journal of Medicine*, based on a 16-year study of 900,000 Americans, found that the heaviest participants had death rates from all cancers combined that were 52 percent higher for men and 62 percent higher for women than the rates for men and women of normal weight. Based on these findings, the researchers estimate that excess weight and *obesity* in Americans could account for 14 percent of all deaths from cancer in men and 20 percent of those in women.[117] They conclude that 90,000 cancer deaths a year are related to excess body weight, 16 percent of the expected 563,700 deaths expected from cancer in 2004.[118]

Researchers conclude that 90,000 cancer deaths a year are related to excess body weight.

A study estimated that if current trends continue, 20 million adults in Texas — 75 percent — might be overweight or obese by the year 2040, and the direct and indirect costs to the state would be up to $39 billion a year.

This study has been a "wake-up" call to public health experts who have documented the unprecedented rate which the *majority* of Americans are putting on weight. A recent government survey found that 64 percent of U.S. adults are either overweight or obese. Nearly one-third of all adults are now classified as obese, a condition in which a person has abnormally high amounts of unhealthy body fat that is medically defined as a body mass index of 30 or greater. Recent reports indicate that obesity in the United States increased by 61 percent between 1991 and 2000.[119] Such excess weight comes at a high price: The direct costs of inactivity and obesity account for more than 9 percent of the national health care expenditures in the United States. [120]

Obesity in Texas mirrors the national trend. A study by the Department of State Health Services found that during 2002, an estimated 10 million, or 63 percent, of adults in Texas were overweight or obese, an increase of 17 percent over 10 years. Rates of obesity alone almost doubled between 1991 and 2001, from 13 percent to 25 percent. The study estimated that if current trends continue, 20 million adults in Texas, or 75 percent, might be overweight or obese by the year 2040, and the direct and indirect costs to the state would be up to $39 billion a year.[121]

Children also are suffering from the obesity *epidemic*. Nationally, three times as many children are overweight today as in 1980. In 2000, 9 million children aged 6 to 19 (or 15 percent of the childhood population) were overweight.[122] In Texas, about 35 percent of school-aged children are overweight or severely overweight, a rate that is higher than the national average.[123] According to a 2004 study, overweight prevalence in Texas schools is highest among Hispanic boys, Hispanic girls in grade 4, and African-American girls in grades 4-8, respectively.[124] Researchers say that childhood obesity in Texas is worsening, perhaps at a faster rate than was previously thought. Estimates of overweight prevalence for girls and boys in grade 4 in Texas are now almost 50 percent higher than previously reported in a 1999-2000 national survey.

Humans deposit fat on their bodies for a number of reasons, including health status, metabolism, diet, physical exercise, hormonal factors, race, and heredity.[125] Most researchers believe that increased access to food, decreased physical activity, and *genetic susceptibility* are the main contributors to increases in obesity. The problem cuts across all socioeconomic levels and ethnicities.

Increased body weight is a known risk factor for several leading cancers, and is associated with increased death rates from all cancers combined. In 2001, experts concluded that obesity and physical inactivity may account for between 25-30 percent of colon, breast (in postmenopausal women), endometrial, kidney, and esophageal cancers.[126] Some studies also have reported links between obesity and cancers of the gallbladder, ovaries, and pancreas, while others have found a link with lymphoma and cancer of the larynx.

Obesity's Link to Major Cancers

Excessively heavy women face as much as a 50 percent higher chance of developing breast cancer, the most prevalent cancer among American women, than do women who are not obese.[127] Given that many breast cancer risk factors are not subject to intervention, avoiding weight gain is one way older women may reduce their risk of developing the cancer. Obesity seems to increase the risk of breast cancer among postmenopausal women because fat tissue can produce estrogen, and an increased level of circulating estrogen in the body is a risk factor for estrogen-receptive breast tumors. Estrogen levels in postmenopausal women are 50 to 100 percent higher among heavy versus lean women.[128] Breast cancer also is more difficult to detect in heavier versus lean women, so the disease is more likely to be diagnosed at a later stage in overweight women. Although studies that look at obesity and breast cancer in different racial/ethnic populations have been limited, recent reports have suggested that obese Hispanic women are twice as likely to develop breast cancer as non-obese Hispanic women, and that obese African-American women are more likely to have an advanced stage of breast cancer at diagnosis.[129]

Obese women also have a two to four times greater risk of developing endometrial cancer, regardless of whether or not they are postmenopausal. In fact, obesity is estimated to account for 40 percent of endometrial cancer in the United States.[130] Women who are overweight, but not obese, also are at greater risk.

Colon cancer also occurs more frequently in people who are obese than in those of a healthy weight, and the association is especially strong in men with a high body mass index. A diet high in fats and low in fruits and vegetables increases a person's chance of developing colorectal cancer, the second leading cause of cancer-related deaths in the United States.[131] In 2004, an estimated 130,200 cases of colorectal cancer will be diagnosed, and 56,300 deaths are expected to occur. Obese men are twice as likely to develop colorectal cancer as men with normal weight. Kidney cancer also is a risk factor: obese men and women are as much as three times more likely to develop kidney cancer.[132]

Healthy Food & Prevention

In contrast to factors such as fat and calories, which appear to increase cancer risk, other components of the diet may decrease cancer risk. The most compelling evidence has been for fruits and vegetables, whose consumption has been strongly correlated with a reduction in cancer risk. The most extensive review to date has been by the World Cancer Research Fund, which looked at 217 observational epidemiological studies that evaluated at least one association of fruit or vegetable intake with incidence of any type of cancer.[133] The review concluded that 78 percent of the studies showed a significant decrease in cancer risk when fruit and vegetables are eaten. Of the studies that looked at vegetable consumption, 69 to 80 percent of them found an inverse association with cancer risk. For fruit in general and citrus fruit in particular, 64 and 66 percent of studies, respectively, also found an inverse association with cancer risk.[134] The evidence was most conclusive for vegetables and fruit and cancers of the mouth and pharynx, esophagus, lung, and stomach, and for vegetables alone and cancers of the colon and rectum. The association of vegetables and fruit with cancer incidence was judged to be strong, particularly for vegetables. The overall risk was nearly halved in association with the consumption of at least five servings of vegetables and fruit per day, as compared to only one or two servings.[135]

Although the chemical components in these foods responsible for this protective effect have yet to be identified, eating at least five servings of fruits and vegetables each day is recommended by many groups, including the National Cancer Institute, which launched a "5 A Day" program in 1991. Despite this 13-year national campaign, it is estimated that only one

fourth of adults are following the government's advice.[136] In fact, the frequency of fruit and vegetable consumption has changed little across the country in recent years. A food questionnaire completed four times between 1994 and 2000 by more than 430,000 adults in 49 states and the District of Columbia found that the proportion of people who ate fruit or vegetables five or more times a day did not substantially change from an average of about 3.4 servings a day.[137]

A national campaign to change dietary habits is likely to have only a small prolonged effect, according to the researchers. Part of the reason is that any campaign, even one that is seemingly well funded, is overshadowed by a food industry that markets its products aggressively, according to researchers. From 1992 to 1999, the National Cancer Institute spent approximately $40 million on all aspects of its "5 A Day" program, compared with approximately $10 billion spent in 1999 alone on industry marketing of food, fast food, and beverages.[138]

A child's diet, of course, also is influenced by the media. Even brief exposures to televised food commercials can influence a preschooler's food preference.[139] The easy availability of high-fat foods and the positive social environment associated with some nonnutritious foods also contribute to childhood obesity. A joint study of the American Dietary Association, the Society for Nutrition Education, and the American School Food Association found that more than 84 percent of school-aged children eat too much fat.[140] More than half of them eat less than one serving of fruit a day, and 29 percent eat less than one serving a day of vegetables that are not fried. Of course, how parents eat has a strong influence on the nutrition of their children. A study that observed nutritional habits in 191 white families, each with a 5-year-old daughter, demonstrated that girls eat more fruits and vegetables if her parents do, and that this higher intake of nutritious foods leads to less consumption of fat.[141]

Because excess weight in youth often persists throughout life, the prevention of obesity should begin early in life. Educators, health professionals, and families should all set a positive example for young people to help them reach this prevention objective.[142] Schools can emphasize the importance of healthy food and nutrition, as well as an active lifestyle, by providing healthy meals and sports facilities. Texas schools serve more than 400 million lunches and 200 million breakfasts a year, and together these meals should provide 60 percent of a student's dietary meals, according to the Texas Department of Agriculture. U.S. schools generate more than $750 million a year in revenues from vending machine sales alone.[143] Schools must be given the tools they need to assume their role as community leaders in providing children with a healthy environment in which to learn and grow.[144] States also must develop policies that limit the sale of competitive foods or less healthy food choices.[145]

Physical Activity & Cancer

Lack of physical exercise contributes as much to higher prevalence of overweight and obesity as unhealthy eating behaviors. But physical activity may have an independent effect on disease development. Some studies indicate that regular physical activity reduces cancer risk exclusive of changes in body weight; others have estimated that 30-60 minutes of physical activity a day may reduce the risk of developing colon, breast, endometrial, and prostate cancers by 20-40 percent.[146] For example, a major review of observational trials published in 2002 found that physical activity reduced colon cancer risk by 50 percent. This risk reduction occurred even with moderate levels of physical activity,

such as brisk walking for 3 to 4 hours per week.[147] Most studies have found that the protective effect of physical activity extends to both lean and obese people.

The link between physical activity and breast cancer risk is somewhat different. A recent study from the national 15-year Women's Health Initiative clinical trial found that physical activity among postmenopausal women at a level of walking about 30 minutes per day was associated with a 20 percent reduction in breast cancer risk. However, this reduction in risk was greatest among women who were of normal weight. For these women, physical activity was associated with a 37 percent decrease in risk. The protective effect of physical activity was not found among overweight or obese women.[148]

Sedentary Adults & Children

About half of the adult population of industrialized countries is insufficiently active in their leisure time, and one fourth to one third can be classified as totally inactive.[149] In the United States, the situation is even worse; 40 percent of adults over age 18 are completely sedentary in their leisure time, a statistic that has not changed in the last decade despite numerous campaigns, such as Healthy People 2010, designed to convince adults to exercise five times a week for 30 minutes.[150]

The young also are less active than they need to be. Although the CDC and the Office of the Surgeon General both recommend daily school-based physical education as the best solution to the growing youth obesity epidemic, very few schools offer such daily exercise. According to the CDC's School Health Policies and Programs Study 2000, only 8 percent of elementary schools, 6.4 percent of middle/junior high schools, and 5.8 percent of senior high schools provide daily physical education or its equivalent for the entire school year for students in all grades in the school. Children and adolescents also may not be exercising at home. According to a Nielsen Media Research report cited in Education World, U.S. children between the ages of 8 and 18 spend more than three hours a day watching television and another three to four hours using the Internet and playing video games. The more they sit, the heavier they get.[151]

The situation can be reversed if children are reached through a multifaceted approach that involves schools, parents, sports organizations, and extramural activities to help stem the rising tide of obesity and a widespread sedentary lifestyle. Physical activity programs that do not rely on schools but are based in community organizations may be particularly promising, because children who participate have voluntarily chosen to do so, and thus have a sense of ownership.[152] An example of such a successful program is "Lively Ladies," a physical education and activity intervention targeted to low-income, preadolescent African-American girls in a community-based youth services organization. The girls participated in novel activities, such as soccer, relays, jogging, basketball, circuit training, and gymnastics, kept a fitness journal, were exposed to positive role models, and received a variety of reinforcements.[153]

Physical activity programs based in community organizations may be particularly promising, because children who participate have voluntarily chosen to do so, and thus have a sense of ownership.

Promoting nutritional and physical activity behavioral change in adults is more complex. Because low-income families spend, on average, about $25 per person per week on food, many families find it difficult to afford a diet rich in vegetables, fruit, and lean meat. They often resort to fast food because it is cheaper and filling, as are most high-fat, high-calorie foods that are low in nutritional value. Additionally, less affluent areas may not have traditional grocery stores with their stocked produce aisles, but may have to rely on convenience stores that carry chips and soda. Physical activity also may be limited by monetary resources, which discourages participation in health clubs and classes, and constrains the ability to purchase equipment for home use.[154] In surveys, women attribute their reluctance to exercise to inconvenience, inaccessible program locations, unwillingness to use public facilities, work conflicts, lack of energy, medical problems, lack of time, family, and lack of social support.[155]

Educational materials on the risks of obesity and inactivity for adults need to be both culturally competent and linguistically appropriate. At the population level, obesity cannot be prevented by simply issuing information. Change is difficult without a supportive environment. Governmental and community organizations, the food industry, media, employers, schools, health professionals, and educators all have a responsibility to work together to produce an

environment that is less conducive to weight gain and more conducive to exercise.[156] Such an approach can tackle societal barriers that exist in the "*built environment*," such as residential areas that are far from work sites and shopping areas, and neighborhoods that have no sidewalks. Culturally sensitive programs can address disparities, such as teaching women who are forbidden from exercising in public how to incorporate physical activity into their lifestyle in non-threatening ways. And sometimes simple solutions work: A program that reminded women to exercise through telephone counseling appeared to be a good way to help women begin a walking program.[157]

Objective E - Promote Policies And Programs Aimed At Addressing Cancer Risk Related To Obesity

Strategy 1: Increase awareness of the cancer-related risks of obesity.

Action Steps:

a. Educate the public about the link between diet and cancer, particularly among the ethnically and culturally diverse populations.

b. Increase awareness about reducing the consumption of nonnutritive foods high in sugar.

c. Educate women about the cancer-related risks of weight gain and breast cancer.

d. Encourage programs to utilize best practices, such as peer mentoring.

e. Address cultural perceptions of obesity among priority populations.

f. Promote collaboration among state and local, public and private entities that are working on the issues of obesity.

g. Promote programs through systems that address barriers to healthy nutrition and exercise.

h. Promote the translation of research into practice regarding obesity in ethnically and culturally diverse communities and the medically underserved.

i. Tailor messages and programs to better address individual populations, particularly those in high-risk groups.

Strategy 2: Improve access to and use of healthy food choices.

Action Steps:

a. Educate Texans about balanced nutrition and making healthy food choices.

b. Encourage restaurants to offer and promote healthy menu choices and smaller portion sizes.

c. Promote public education that encourages healthy nutritive food practices.

d. Support the state's school nutrition guidelines.

e. Educate and encourage teachers to promote healthy nutrition.

f. Work with parents' organizations to address child nutrition issues and promote healthy nutrition programs.

g. Promote policies that enable schools to provide good nutrition.

Strategy 3: Promote creative approaches for re-integrating physical activity into everyday life.

Action Steps:

a. Educate the public about the link between physical activity and cancer, particularly for ethnically and culturally diverse populations.

b. Encourage health promotion programs in the workplace.

c. Promote physical activity that is culturally sensitive to disparity populations.

d. Increase focus on how the built environment can enable increased daily exercise.

e. Use mass media to promote culturally appropriate physical activities for all ages and levels.

f. Promote public/private partnerships to increase access to physical activity programs and equipment for the public.

g. Advocate for increasing the quality of health and physical education programs in Texas schools, grades K-12.

h. Promote the translation of research into practice regarding the effectiveness of programs promoting physical activity, with emphasis on programs tailored for high-risk populations.

Objective F - Increase Public Awareness Of And Protection From Carcinogens In The Environment

Environmental Carcinogens

Most cancers develop because of interplay between the human body and the environment in which it lives. Cancers that arise solely from nonenvironmental factors, such as those that are purely genetic in origin, are rare, as are cancers that are triggered only by exposure to the environment.

Environmental causes of cancer include both lifestyle factors, such as smoking, diet, and physical inactivity, tobacco and alcohol use, and environmental factors, such as exposure to radiation, infectious microbes, and agents in the air and water. Most epidemiologists and cancer researchers agree that the relative contribution from the environment toward cancer risk is about 80-90 percent.[158] Even though it is known that certain lifestyle and environmental factors increase a person's chance of developing cancer, an individual's genetic profile also contributes to that risk. Patterns of gene alterations and environmental exposures make people either more susceptible or more resistant to cancer,[159] but relatively few of these "susceptibilities" have been uncovered so far, although this is a growing area of research. To date, researchers cannot predict why, given exposure to the same environment, one person will develop cancer while another will not.

Environmental causes of cancer include both lifestyle factors, such as smoking, diet, and physical inactivity, tobacco and alcohol use, and environmental factors, such as exposure to radiation, infectious microbes, and agents in the air and water.

Nevertheless, reducing exposure to *carcinogens* found in the environment is an important component of cancer prevention. The degree of cancer risk a person may have depends on the concentration or intensity, and the exposure dose of a particular carcinogen,[160] and so public awareness educational campaigns, as well as regulatory efforts to reduce exposures to known environmental carcinogens, such as *toxins*, are important in reducing individual cancer risk.[161]

Yet, only a handful of the many commonly used chemicals has been adequately tested for the ability to cause or promote cancer, according to the National Academy of Sciences.[162] While not much is known about the possible additive effects of simultaneous or sequential chemical exposures and cancer,[163] some risks are greatly increased when particular exposures occur together.[164]

Exposures to high-frequency radiation, ionizing radiation, X-rays, *radon*, and ultraviolet radiation from the sun have been proven to cause cancer.[165] Chemicals such as benzene, asbestos, vinyl chloride, and arsenic are proven cancer-causing agents,[166] and levels of many of these agents have been successfully reduced in the environment. Carcinogens found in food and beverages, including alcoholic beverages, are involved in the development of certain cancers, as are foods that are preserved with nitrates or smoke, contaminated with mold, or too salty. Of special concern are chemicals known as *heterocyclic amines (HCAs)* that develop when meat is cooked at high temperatures; researchers have identified 17 different HCAs that may pose human cancer risk.[167] Several environmental microbes, such as the human immunodeficiency virus (HIV) and human papilloma virus (HPV), are significant risk factors for certain cancers, and the bacterium *H pylori* is an important risk factor in stomach cancer. Some medications, such as estrogens and progesterone, tamoxifen and diethylstilbestrol (DES), a synthetic form of estrogen, also have been proven to increase risk of cancer.[168]

Radon, a radioactive gas released from the normal decay of uranium in rocks and soil, is the second leading cause of lung cancer in the United States. It is associated with 15,000-22,000 lung cancer deaths a year.[169] Most radon-related cancer deaths, however, occur in smokers.[170] In Texas, the public health risk from radon is minimized: on a statewide basis, Texan homes have a relatively low level of radon, and counties with the highest rates have the lowest populations.

Not all carcinogenic agents are created equal, of course. Tobacco use is the biggest risk, responsible for 30 percent of cancer deaths. The proportion of cancers due to occupational exposure, air and water pollution, medicines, and medical procedures is individually much smaller — each accounting for 5 percent of the risk or less.[171]

Public concern about environmental cancer risk often focuses on agents that have suspected links to cancer, but which have not been proven. High doses of pesticides, for example, have been shown to cause cancer in animals, but the very low concentrations found in some foods, such as fruits and vegetables, have not been associated with increased cancer risk.[172] Older, banned pesticides such as DDT also have not shown definable cancer risks, although research on these substances still continues. Some studies have suggested an association between cancer and non-ionizing radiation, but most research has not found such a link.[173] Sources of non-ionizing radiation, including electromagnetic radiation from power lines and, at low frequency, microwaves, radar, and magnetic fields associated with electric currents, household appliances, and cellular phones, have not been found to contribute to cancer in the majority of studies.[174]

Monitoring Environmental Carcinogens

There are several federal agencies that are charged with establishing permissible levels of exposure to chemical substances in the general environment, home and workplace, and in food, water, and pharmaceuticals. These include the Consumer Product Safety Commission (CPSC), Environmental Protection Agency (EPA), the Food and Drug Administration (FDA), the Occupational Safety and Health Administration (OSHA), and the U.S. Department of Agriculture (USDA).[175] The Agency for Toxic Substances and Disease Registry (ATSDR) additionally has broad jurisdiction over hazardous waste issues.

State governments also play a key role in establishing allowable exposure levels. In Texas, the Texas Commission on Environmental Quality is responsible for regulating water, air, solid waste, sewage, waste treatment, and radioactive waste disposal. Texas has long had a reputation as a major polluter. In 1993 and 1994, the EPA found in its annual Toxic Release Inventory that of the country's 60 states, Texas released the largest amount of carcinogens into the air, water, and land.[176] However, Texas has made progress in cleaning up its toxic releases. The state led the nation in short-term reductions from 1995 to 2001, and in long-term reductions from 1998 to 2001. In 2000 and 2001, the state's national rank for on- and off-site releases was fifth.[177]

Communities should be made aware of federal and state environmental regulatory agencies, and form networks with government agencies to strengthen local efforts to protect against carcinogens in the environment. Because numerous governmental agencies have a role in environmental protection, it is essential that information and regulations be reviewed regularly to ensure compatibility and to minimize conflicts.

Workplace Carcinogens

Although carcinogens found in industrial settings also are present in the environment, industrial workers have more intense and prolonged exposures to these chemicals than the general public.[178] Most widely known workplace carcinogens, such as asbestos, certain pesticides, and dyes, have been removed from common usage. The use of ventilation, protective clothing, breathing masks, and other safeguards helps keep exposures to carcinogens at permissible levels.[179] In the face of uncertainty, public health agencies operate under the principle that protection of public health is paramount and requires acceptable levels of exposure that are as much as 1,000 times below the level that causes a substantial increase of cancer in laboratory animals. [180]

The right of employees, and citizens, to know about carcinogens in their workplace or region has been established under both federal and state "right-to-know" laws. To protect communities, facilities in Texas that store significant quantities of hazardous chemicals must share this information with state and local emergency responders and planners.[181] The worker right-to-know program is administered by the Texas Hazard Communication Act (THCA), which

The worker right-to-know program is administered by the Texas Hazard Communication Act (THCA), which requires public employers to provide information, training, and appropriate personal protective equipment to their employees who may be exposed to hazardous chemicals in the workplace.

requires public employers to provide information, training, and appropriate personal protective equipment to their employees who may be exposed to hazardous chemicals in the workplace.[182]

Objective F - Increase Public Awareness Of And Protection From Carcinogens In The Environment

Strategy 1: Monitor data on exposure to carcinogens released into the air, land, and water and on exposure to radiation.

Action Steps:

a. Encourage collaboration among agencies, businesses, and environment and health organizations to coordinate monitoring of exposure to carcinogens.

b. Evaluate scientific information about carcinogens in work sites and the environment.

c. Ensure the compatibility of state and federal information and regulations on carcinogens in the workplace, with continuing reviews of policies of all levels of government.

Strategy 2: Increase awareness of and compliance with the federal and state hazard communication laws to promote worksite safety.

Action Steps:

a. Promote annual training to review information for employees on carcinogens used or manufactured at the work site.

b. Encourage employers to provide protective clothing and recommended safety aids for their employees.

c. Ensure that latest scientific data are available to businesses and employees regarding carcinogens in the workplace.

d. Promote enforcement of regulations on the production, storage, disposal, and cleanup of carcinogens.

e. Increase employer awareness of potential carcinogens in the workplace and encourage them to adopt safe practices for their employees.

GOAL II: EARLY DETECTION & TREATMENT

Texans will have prompt access to information and services that enable the early detection, diagnosis, treatment, and support of cancer.

Objective A - Increase Appropriate Utilization Of Effective Cancer Screening Services

Screening & Early Detection

Apart from maintaining a healthy lifestyle — avoiding tobacco, eating properly, and exercising — the most important thing that individuals can do to reduce their chance of dying from cancer is to be screened. For most cancers, age is one of the primary risk factors, and screening for selective cancers at recommended ages, before symptoms appear, has been shown to reduce mortality from cancers of the breast, uterus and cervix, and colon and rectum.[1] There are other cancers, such as prostate, for which screening may be associated with lower mortality, but the evidence is less certain.[2] Still, the overall value of screening is clear. Of the 563,700 Americans who are estimated to die of cancer in 2004, the National Cancer Institute estimates that up to 35 percent of those deaths could have been avoided through screening.[3] The American Cancer Society says that for cancers on which it has specific early detection recommendations (breast, colon, rectum, cervix, prostate, testes, oral cavity, and skin), the five-year relative survival rate is about 82 percent.[4] The five-year survival rate is defined as the percentage of people alive at least five years after diagnosis of cancer. That list covers five of the six leading cancers in Texas.[5]

Even as screening reduces mortality, it also leads to greater detection of tumors and to increasing cancer rates in the country, as well as in Texas. Due to increased screening on an aging population, the number of Texans who have been diagnosed with cancer is increasing. The Texas Cancer Registry projects that there will be more than 85,000 new cases of cancer diagnosed in 2004.

Screening Guidelines

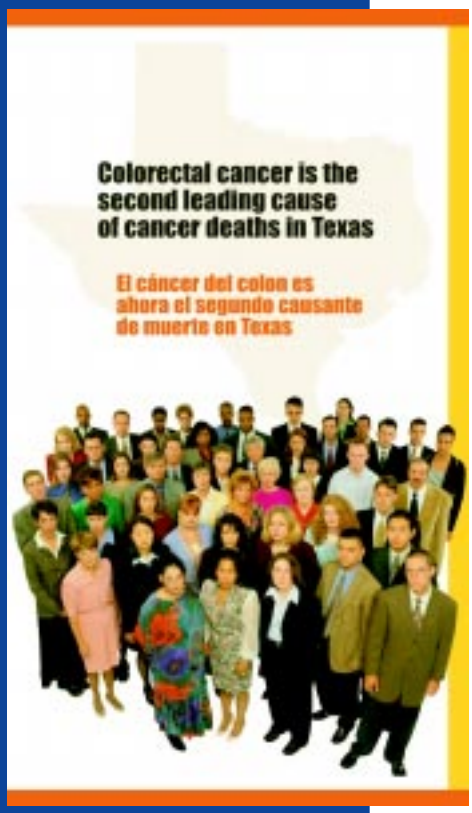
To help health care professionals know what cancers their patients might be at risk for, assessment tests are available that can quickly compute cancer risk, using factors such as gender, age, ethnicity, family history, medical history, occupation, use of tobacco, and diet. Health care professionals then can use the best available medical evidence, from medical journals, professional conferences, and national cancer groups and government agencies, to recommend specific cancer screenings for their patients. These guidelines, however, can differ substantially from each other, given the scientific debate about long-term benefits of some of these tests and whether they have been adequately tested in *randomized clinical trials*. Insurance companies, in turn, may support coverage for screening tests based on what particular screening guidelines recommend, which can limit access to these services.

For people having periodic health examinations, the American Cancer Society (ACS) suggests that a cancer-related checkup should include health counseling, and depending on a person's age, might include examinations for cancers of the thyroid, oral cavity, skin, lymph nodes, testes, breast, cervix, colon, and ovaries, as well as for some nonmalignant diseases. The ACS says the screening tests they recommend must be practical, reasonably priced, have benefits that are greater than associated risks, and be effective in detecting the cancer early enough to affect either the relative incidence or the number of deaths due to the cancer or both. ACS screening guidelines can be found at *www.cancer.org*.

Screening guidelines issued by the U.S. Department of Health's U.S. Preventive Services Task Force (USPSTF) are generally considered to be conservative because they use a much stricter interpretation of benefit. The USPSTF, created in 1984, is an independent panel of experts in primary care and prevention that systematically reviews the evidence of effectiveness. It requires that even if the screening test is accurate in detecting the cancer at an early stage, it must provide a benefit to the patient in having done so. In other words, there must be a clinical intervention that can prevent or delay progression of the cancer.[6] Furthermore, some screening tests that are commonly used by health care

professionals are not strongly endorsed by the USPSTF because they have not been evaluated in a randomized clinical trial and published in medical literature. The majority of screening guidelines first issued by the group in 1996 have been updated, many of them in 2004, or are newly created. The USPSTF cancer screening guidelines are available through their website at *http://www.ahcpr.gov*.

The National Cancer Institute (NCI) also uses an evidence-based approach. Cancer screening summaries are described based on various levels of published scientific evidence and collective clinical experience; the highest level of evidence, for example, is taken as mortality reduction in controlled, randomized clinical trials. The results of clinical studies, *case-control studies*, *cohort studies*, and other information also are considered in formulating the summaries, as well as the incidence of cancer, stage distribution, treatment, and mortality rates. The summaries are included in the Physician Data Query (PDQ), an online database developed and maintained by the National Cancer Institute (*http://www.cancer.gov*).



This is an educational colorectal poster for physicians collaboratively produced by a group of state organizations and pubished in Texas Medicine.

Differences between the groups can be illustrated by using the example of prostate cancer. While the ACS recommends offering prostate cancer screening annually for men aged 50 and over using either prostate-specific antigen (PSA) or digital rectal exam (DRE), the USPSTF concludes that evidence is insufficient to recommend for or against routine screening for prostate cancer. The NCI says that the quality of the "design" of studies conducted to date on different prostate cancer screening modalities is relatively high, but that the "validity," "consistency," and "magnitude of effect" of prostate screening are all poor.

Similarities between these screening guidelines also exist. The ACS, NCI, and USPSTF all strongly recommend that clinicians screen men and women aged 50 and older who are at average risk for developing colorectal cancer. The ACS recommends that any of five different screening methods can be used, whereas the USPSTF and NCI say evidence is insufficient to determine which particular screening strategy is better than another to use, but still urge that screening, using any method, should take place because of the overwhelming benefit it offers.

If the result of the screening test is positive or an individual shows signs or symptoms of disease, tests to detect the presence of cancer are considered diagnostic, not screening. Diagnostic tests are performed to detect the actual existence and extent of disease.

Screening Controversies

The potential harms of cancer screening must be considered against any potential benefit. Although most cancer screening tests are noninvasive or minimally invasive, some involve small risks of serious complications that may be immediate (such as *perforation* with a colonoscopy) or delayed (as in potential cancer development from radiation).[7] Another harm is the false-positive test result, a test that suggests cancer is present when none actually exists and that may lead to anxiety and unnecessary invasive diagnostic procedures.[8] Conversely, a false-negative screening test may reassure an individual that no cancer exists when it actually does, thereby delaying diagnosis and effective treatment.

Another growing harm is overdiagnosis, the diagnosis of a condition that would not have become clinically significant had it not been detected by screening. This problem is becoming more common as screening tests become more sensitive in detecting tiny tumors.[9]

For example, debates about the appropriate age for breast cancer screening and about the benefits and appropriate age for prostate cancer screening have confused women and men of all ages and their health care providers as well. Breast cancer screening by mammography, clinical breast examination, or both may decrease breast cancer mortality, but it also can result in diagnosis and treatment of indolent cancers that would never have become problematic. That is because screening mammography detects noncancerous lesions as well as in situ and invasive breast lesions that are smaller than those detected by other means, and is associated with more diagnostic testing, surgeries, radiotherapy, and anxiety. Because some of these cancers would not become clinically significant, their diagnosis and treatment constitute overdiagnosis and overtreatment.[10] Screening mammography also is more likely to miss cancers in women with dense breasts that are "radiographically" hard to see, as well as cancers that are rapidly growing. Even so, given that mammography can pick up lethal cancers in time for them to be treated, the ACS recommends that women should have a mammogram every year from age 40; and the USPSTF and NCI recommend that women aged 40 or older should be screened every one to two years.

Regarding prostate cancer, evidence does not yet exist to determine definitely whether screening for prostate cancer with PSA or DRE reduces mortality from prostate cancer.[11] Screening tests are able to detect prostate cancer at an early stage, but it is not clear whether this earlier detection and consequent earlier treatment lead to any change in the natural history and outcome of the disease, which is often slow-growing. Screening also is associated with important harms, including frequent false-positive results and unnecessary anxiety, biopsies, and potential complications of treatment of some cancers that might never have affected a patient's health.[12] Since the use of early detection tests for prostate cancer became relatively common around 1990, the prostate cancer death rate has dropped, but it has not been proven that this is a direct result of screening.[13]

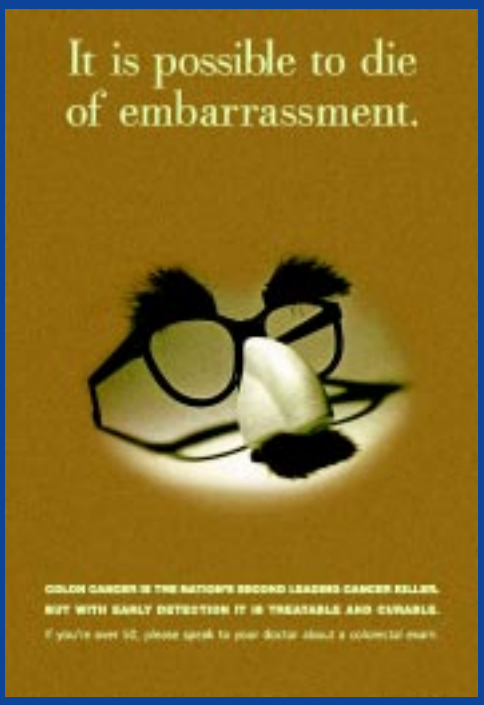
The value of screening for lung cancer also is not clear. The NCI and the USPSTF say that screening for lung cancer can detect lung cancer at an earlier stage, but evidence to date suggests that this screening does not reduce mortality. Rather, because of the invasive nature of these diagnostic tests and the possibility of a high number of false-positive tests, there is potential for significant harms from screening.[14] The ACS also says that because screening cannot find many lung cancers early enough to improve a person's chance for a cure, lung cancer screening is not a routine practice for the general public or even for people at increased risk, such as smokers.[15] Recently, however, a new X-ray technique called spiral or helical low-dose *CT scanning* has been successful in detecting early lung cancers in smokers and former smokers, and a large clinical trial called the National Lung Screening Trial (NLST) is underway to test whether spiral CT scanning of people at high risk of lung cancer will save lives.[16]

Another screening controversy that has arisen lately concerns elective screening using full-body computed tomographic (CT) devices, offered through stand-alone imaging businesses that have emerged across the country and do most of their business through direct-to-consumer marketing. These facilities have doubled in number over the last several years and are a popular option for the "worried well" who are willing to pay an average of $1,000 to ensure that their aging bodies are not secretly harboring tumors or other incipient diseases. The most definitive study of its kind has found that full-body screening may constitute more of a cancer risk than a cancer intervention. In a study published in September 2004, in the journal *Radiology*, researchers at Columbia University likened the radiation emitted during a single scan to that experienced within miles of a World War II atom bomb explosion. They estimated that the dose of radiation to the lung or stomach from a single full-body CT scan corresponds to a dose region for which there is direct evidence of increased mortality in atomic bomb survivors. The dose is also equal to 100 chest X-rays or 100 mammograms, the researchers said.[17]

The American College of Radiology has said there is no evidence that these screens offer long-term benefits, and that, more often than not, they lead to expensive follow-up testing for suspicious findings, exams that are often negative, but which can be worrisome to patients and risky to perform, such as lung biopsies.

Knowledge of Screening Recommendations & Risk Factors

Texans need to know the major risk factors for specific cancers so they can be proactive in their health care. It is imperative to increase the public's knowledge and use of cancer screening so that cancers are diagnosed in the earliest stage possible. Diagnosis of cancer at earlier stages of disease can enhance chances of



This poster is an example of early detection education materials from the Colorectal Cancer In Texas, A Guide to Community Outreach *and is available on CD-ROM. For information, please visit the Texas Department of State Health Services at* http://www.dshs.state.tx.us

successful treatment outcomes, but much progress is still needed in Texas. For example, only 6 out of every 10 cases of female breast cancer in Texas are detected at an early stage,[18] and fewer women 40 years of age and older in Texas are having a mammogram, compared to the national average. In 2002, 52 percent of Texan women who should have had a mammogram actually had one in the past year, compared to 62 percent of Americans overall.[19] The lower prevalence rate in Texas holds true for all racial and ethnic groups (white, African-American, Hispanic, etc.), compared to national averages, and is especially pronounced among women with a lower level of education (38 percent of this group in Texas had a mammogram versus 53 percent of Americans overall).[20]

Knowledge about the early warning signs of cancer can help Texans know when they should seek immediate attention by a health care professional. It is important that people be aware of their own risk factors and that they adhere to the recommended schedule for screenings and examinations for the cancers for which they are at risk. For example, a woman with a family history of breast cancer should inform her physician about her family history to determine an appropriate and tailored screening schedule.

Risk factors can be identified for groups of people as well as individuals. African-American men, for example, have a higher incidence and mortality rate from lung, colorectal, and prostate cancers. Because of the higher risks, programs about these cancers need to be designed specifically for African-American men to facilitate diagnosis and treatment at an early stage of disease.

Barriers to Screening Services

Regional and local health departments, community health centers, the American Cancer Society, and many other organizations provide information about cancer screening and diagnostic services. However, many Texans do not take advantage of local services. There is a continuing need to increase awareness by public education campaigns that stress the importance of cancer screening, and which can reassure Texans that they need not be fearful of, or embarrassed by, screening procedures.

Even if many Texans are aware of the value screening offers, access to such services poses a problem, and routine assessments are needed to determine which Texas communities have insufficient access to cancer screening and follow-up diagnostic services. For example, as of May 2004, 122 counties in Texas, nearly half of all counties in the state, did not have fixed mammography facilities.[21] Some women may have to travel up to 200 miles one way to have the most basic health service. If screening leads to either a suspicion of cancer or a firm diagnosis, then Texans need prompt access to quality services. Health care professionals throughout Texas should have the skills and motivation to routinely screen patients, recognize the early signs and symptoms of cancer, and refer their patients for the necessary diagnostic or treatment services. Diagnostic and treatment facilities also must be readily available to their patients, and that may involve creating systems that solve issues such as patient transportation issues, and a need for child care and flexible scheduling.

The cost of screening services, and whether they are covered by private health insurance, Medicaid, or Medicare, present other problems. Because insurance coverage of screening tests is not consistent across the country, or even within states, some states have passed laws that mandate all health insurance plans to cover certain screening tests and others have not. In 2001, for example, Texas passed a law that dictates coverage of colorectal screening, either by an annual fecal occult blood test, a flexible sigmoidoscopy every 5 years, or a colonoscopy every 10 years. Texas is one of only 15 states in the nation that dictate such coverage.[22]

Private insurance policies for individuals and groups vary in their coverage of screening procedures. While the two major public medical insurance programs, Medicare and Medicaid, do cover periodic screening, there are limitations in the frequency of screenings allowed and in the tests that can be given to people without symptoms. In addition, eligibility requirements for many of the services are complex and change periodically as a result of modifications in federal poverty guidelines, effects of the Welfare Reform Act of 1996, decreases in level of funding, or increased demands for services. In addition, there are many treatments which insurance companies may consider to be experimental and will not approve even though health care professionals believe they are effective.

Some states and local health programs and employers also provide mammograms and Pap tests free or at low cost. For example, the CDC coordinates the National Breast and Cervical Cancer Early Detection Program, which provides breast screening services to low-income women throughout the country. However, at current funding levels, the program has the capacity to screen only 12 percent to 15 percent of low-income, uninsured women and does not have the capacity to provide treatment. For insured women, 23 states currently require insurers to include coverage for Pap tests, and 48 states (including Texas) require insurers to provide or offer coverage for breast cancer screenings.[23]

Not all insurance programs, either public or private, will pay the costs of cancer screening tests that are recommended by the American Cancer Society and other national organizations.

The lack of local services and reimbursement options for services further hinders professionals' abilities to provide needed cancer services. Another service barrier is local community organizations' limited expertise or manpower to develop competitive grant proposals, thereby hampering their ability to secure either public or private funding for cancer services. To help them, community organizations can benefit from technical assistance and information on how to obtain funding for cancer services.

Public Awareness

Health care offices, churches, civic organizations, libraries, and governmental agencies can all facilitate distribution of information about risk factor awareness and cancer screening services. Networks need to be established statewide and in local communities to ensure that the information being distributed is up-to-date and consistent. Additionally, the Internet provides an avenue for disseminating and tailoring information to the public. For example, computerized databases on the Internet enable people to easily locate services geographically near them by searching by zip code. In Texas, the Texas Cancer Data Center, funded by the Texas Cancer Council in partnership with The University of Texas M. D. Anderson Cancer Center, maintains a Web site with databases that include Texas cancer diagnostic and treatment facilities. These databases are available to the public at *www.txcancer.org*.

Information on cancer screening services must be presented in a variety of formats and settings. Information must be tailored for specific groups, such as people who speak a language other than English, people with visual impairments, or people with low literacy. Community health fairs, community church efforts, and media events have proven extremely beneficial in Texas in providing information at the neighborhood level. Studies have shown that a simple recommendation by a doctor for cancer screening can be helpful; a person is more likely to be screened if a clinician suggests it. Multiple interventions directed at patients may provide the best approach to improving rates of cancer screening. Such a comprehensive approach can include strategies that raise awareness in patients about the need to be screened, that assist physicians in cancer screening counseling and follow-up, and that ensure that a health care system delivers high-quality and timely cancer screening as part of an individual's health care plan.[24]

Follow-up Care

Follow-up systems are essential components of cancer screening programs and must be in place prior to initiation of the screening service. Follow-up systems ensure that patients are adequately counseled about the screening outcomes and are referred for further diagnostic tests when test results are suspicious. Follow-up systems also enable those providing the screening service to determine the impact of the programs, to document the need for those services, and to forecast future patient needs. If no follow-up system is in place, there is the possibility that patients and health care professionals may remain unaware of an abnormal result. Patients may be falsely reassured because they did not hear from their health care professionals.[25] As a result, the patient's cancer may not be diagnosed until months or years later.

Breast & Cervical Cancer Control Program

The Department of State Health Services, with funds from the CDC, operates the statewide Breast and Cervical Cancer Control Program (BCCCP), one of the largest statewide cancer screening programs in the nation. In Fiscal Year 2005, the program funded breast and/or cervical cancer education, screening, and diagnostic services at over 300 clinic sites. The program serves women who are at or below 200 percent of the federal poverty level and meet the age requirements. Although about 20,000 women are served annually, the Department of State Health Services estimates that these services reach less than 3 percent of the eligible women in Texas.

In 1991, Texas was one of the first states to implement the CDC Breast and Cervical Cancer Control Program, which required Texas to develop a statewide plan to address breast and cervical cancers. Successes reported in the 2003 Action Plan on Breast and Cervical Cancers for Texas include:[26]

- In 2001, 57 percent of Texas women aged 50 and older had received a mammogram within the past year, compared with 44 percent in 1991.
- In 2001, 82 percent of Texas women had received a Pap smear within the past three years, compared with 68 percent in 1991.
- The BCCCP established guidelines and quality assurance activities for breast and cervical health for professionals in the BCCCP network.
- The number of professionals across the state increased during the past 10 years, including those in medically underserved areas (MUAs).
- The Texas Cancer Council funded 103 community projects addressing breast and/or cervical cancer i 1993-2001, all of which served medically underserved populations.
- In 2002, 128 Texas counties were designated as Health Professional Shortage Areas, compared to 153 counties in 1993.

Screening Clinical Trials

Researchers are perfecting better ways to screen for cancer before a person has symptoms, and the newest methods are tested in clinical trials for safety and effectiveness. These trials are the final stages of a careful research process that tests new approaches to screening. Mammography and Pap tests are examples of screening tests that were validated using clinical trials. Screening clinical trials can include laboratory tests, such as a check of blood or urine; genetic tests; or imaging tests, such as X-rays or computerized tomography (CT) scan, also known as computer axial tomography (CAT) scan. These trials can lead to improvements in finding cancers early, when they are more treatable. The screenings being tested also are often offered at no charge or at a low cost to trial participants.

One example of a screening clinical trial that has enrolled participants across the nation is the National Lung Screening Trial (NLST), sponsored by the National Cancer Institute. Launched in 2002, this trial compares two ways of detecting lung cancer before it causes symptoms, by using chest X-rays or by using spiral CT scans. So far, neither method has been shown to reduce a person's chance of dying from lung cancer, but this is the first trial that looks at the value of the two methods when compared with each other. By February 2004, the trial had reached its full enrollment: 50,000 current or former smokers had joined NLST at more than 30 sites across the country.[27] Information about federally sponsored screening clinical trials is available at *http://www.cancer.gov/clinicaltrials*.

Objective A - Increase Appropriate Utilization Of Effective Cancer Screening Services

Strategy 1: Promote public awareness of cancer risk factors.

Action Steps:

a. Identify and address sources of public confusion regarding risk.

b. Develop culturally competent and linguistically appropriate key messages regarding cancer risk factors.

c. Increase public awareness, through effective cultural and linguistic channels, about modifiable risk factors.

d. Educate the public regarding the relationship between family medical history and the relative risk of developing various types of cancer, particularly among high-risk populations.

e. Utilize comprehensive campaign techniques to disseminate messages.

Strategy 2: Increase public knowledge of evidence-based recommendations for screening and detection services.

Action Steps:

a. Identify and address sources of public confusion regarding screening recommendations.

b. Support community-driven efforts to increase knowledge of cancer screening and detection services.

c. Support a common methodology for the ongoing assessment of community screening education resources.

d. Develop, implement, disseminate, and evaluate cancer screening educational programs, with particular focus on reaching underserved populations and health care professionals.

e. Disseminate information to the public on current cancer screening guidelines, using comprehensive campaign techniques through effective cultural and linguistic channels.

f. Promote public awareness about the importance of prompt and appropriate follow-up diagnostic exams and the need for subsequent ongoing care when abnormalities are detected.

Strategy 3: Assess availability of cancer screening and early detection services and address identified gaps.

Action Steps:

a. Assess, by specific demographic and geographic groups, the extent to which Texans utilize services.

b. Develop and support an inventory of services by type, cost, location, and eligibility criteria.

c. Promote collaboration to expand utilization of existing community programs to address gaps.

d. Encourage the availability of cancer screening and diagnostic services through local clinics, hospitals, health facilities, and other community health organizations.

e. Encourage the recruitment of primary care professionals, including advanced nurse practitioners and physician assistants with cancer early detection and screening knowledge in underserved areas.

f. Encourage the use of nurses and allied health professionals for cancer screening.

g. Encourage private-sector involvement in providing cancer screening services in local communities and worksites.

Strategy 4: Identify and address barriers to cancer screening and detection services.

Action Steps:

a. Support the development of innovative programs addressing barriers to cancer screening services.

b. Provide communities with resources to assist them in identifying and addressing barriers and increasing screening and detection services.

c. Develop and implement a survey for community members and health care professionals to assess local barriers.

d. Develop or utilize existing community networks to increase screening and detection services.

e. Educate benefit managers about the need for health insurance policies and managed care plans to cover cancer screening and diagnostic services.

f. Promote policies that increase the availability and use of cancer screening and early detection services.

g. Encourage the development of risk assessment models that address diverse populations.

h. Identify and disseminate existing culturally relevant, evidence-based cancer screening programs.

i. Assist communities in pursuing resources for funding cancer screening services.

Strategy 5: Increase public awareness of and participation in cancer screening clinical trials.

Action Steps:

a. Increase public awareness about clinical trials through effective cultural and linguistic channels.

b. Develop strong relationships between the public, the research community, and diverse communities to increase knowledge of and participation in clinical trials.

c. Encourage funders and researchers to provide an effective communication plan to increase recruitment for trials, especially among disparity populations.

d. Develop culturally relevant and linguistically appropriate messages regarding clinical trials.

e. Develop and maintain a centralized clearinghouse for accessing information on clinical trials available in Texas.

f. Encourage the inclusion of all clinical trials in registries.

g. Support programs targeting private-sector health care professionals to promote enrollment in clinical trials.

h. Promote access to clinical trials to a broad cross section of Texas communities.

i. Encourage health benefit plans to provide access to available clinical trials through ACOS- or NCI-approved facilities.

j. Offer clinical trials in health benefit plans to eliminate cost as a barrier.

k. Increase funders' and health care professionals' awareness of barriers to participation, particularly for underrepresented populations.

l. Support efforts to reduce financial barriers to participation in clinical trials.

Objective B - Increase Access To, And Appropriate Utilization Of, Cancer Diagnostic, Treatment, And Support Services

Rural Texas

Although Texas's cancer treatment facilities and specialists are some of the premier cancer resources in the world, they are highly centralized. The major cancer treatment facilities are concentrated in urban counties. As of May 2004, nearly three-quarters of the physicians who reported specialties in oncology to the Texas Cancer Data Center were located in five urban counties. In a state of more than 260,000 square miles, this concentration leaves many Texans without access to nearby cancer services.

In July 1996, 67 rural counties in Texas had two or less practicing primary care physicians (24 of those counties had no physicians at all). More than half of Texas's 254 counties are designated primary care Health Professional Shortage areas, which are areas with less than one primary care physician per 3,500 people. There also is a shortage of advanced practice nurses and physician assistants, who make up an integral part of primary care in rural Texas. Texas must continue to encourage health care professionals to practice in rural areas of the state.

A 1995 study by the Department of State Health Services found that Texans with cancer who live in rural areas were more likely to have their cancers diagnosed at later, more invasive stages of the disease.[28] More than 75 percent of Texas's 254 counties are rural, and nearly half of those rural counties had fewer than 10,000 residents in 1996.[29] Additionally, rural Texans tend to be older, slightly poorer, and have a greater dependence on public financing for health services than the average Texan. Eighteen percent of rural Texans were uninsured in 1993.[30]

Cancer Information

Cancer patients in Texas need to be able to identify care and support services available to them. There are several statewide services that provide this information free of charge to cancer patients and their families.

Cancer Information Service

The National Cancer Institute's Cancer Information Service (CIS) is a national resource for information and education about cancer. The University of Texas M. D. Anderson Cancer Center operates the South Central Region office that serves Texas and Oklahoma. The CIS is a leader in helping people become active participants in their own health care by providing the latest and most accurate cancer information to patients and their families, the public, and health professionals by talking with people one-on-one through the 1-800-4-CANCER line, through the Internet at *www.cancer.gov*, working with organizations to meet the cancer information needs of minority and medically underserved groups, and participating in research efforts to find the best ways to help people adopt healthier behaviors.

American Cancer Society, Texas Division

American Cancer Society (ACS) has local offices in 24 Texas cities. Updated cancer prevention, early detection, clinical trials, and patient services information is available in English and Spanish by calling 1-800-ACS-2345 or via the Web at *www.cancer.org*. The Cancer Survivors Network also is available through the ACS Web site, or directly through *www.acscsn.com* to connect cancer patients, family members, caregivers, and friends to discussion groups and chats, prerecorded personal stories, and suggested books, articles, Web sites, support groups, and organizations.

Texas Cancer Data Center

The Texas Cancer Data Center (TCDC) provides information on health professionals, health facilities, demographics and statistics, and community resources via the Internet at no charge. TCDC is an information service, funded by the Texas Cancer Council and The University of Texas M. D. Anderson Cancer Center, dedicated to empowering Texans with the knowledge needed to reduce the human and economic impact of cancer. TCDC databases are accessible at *www.txcancer.org*.

Financial Barriers

Low-income and medically underserved families often have no primary care physician. Their first point-of-contact with health care professionals is at the hospital emergency room. They have no established relationship with a health care professional who can ensure that they receive appropriate diagnostic and treatment services.

Payment barriers also exist that deter people from obtaining appropriate cancer screening, diagnosis, and treatment. These include:

- Lack of health insurance, or having insurance that does not cover cancer prevention education or screening
- Insufficient financial resources for cancer prevention and screening services
- Insufficient financial resources to meet the deductible amounts for insurance policies
- Having an insurance policy that prohibits coverage for *preexisting conditions*, such as cancer[31]

In 2002, more than five million Texans were uninsured, causing Texas to have the highest rate (25 percent) nationally of uninsured residents of any state; 15 percent of the population was uninsured. More than 40 percent of all Hispanics in Texas were uninsured and 25 percent of African-Americans.[32] Additionally, 22 percent of children under 18 were uninsured in Texas in 2002, well above the national average of 12 percent.

Poverty also is an issue. In 2002, Texas had more than 4 million residents, or 20 percent of the population, living below the poverty level. Of those Texans who lived below the federal poverty level, 49 percent were uninsured, compared to the national rate of 37 percent. Almost 2 million nonelderly Texans who lived below the poverty level in 2002 were uninsured. Nearly 44 percent of unemployed Texans were uninsured in 2002, which is significantly higher than the national rate of 30 percent. More than one-fifth of all employed Texans (24 percent) did not have any health insurance in 2002.

Cost is an additional barrier that prevents Texans from obtaining necessary services when screening services are not completely covered.[33] For example, a screening mammogram typically costs between $100 and $150, and while private insurance coverage for screening mammography is mandated by law, it is usually still subject to the same dollar limits, deductibles, and coinsurance provisions as other radiologic exams. Medicare pays 80 percent of the cost of a screening

mammogram each year for beneficiaries aged 40 and older, and beneficiaries are responsible for a 20 percent co-pay.[34]

Societal Barriers

Apart from issues of insurance status and cost, access to health care is difficult for many Texans. The major barriers that deter many people from receiving essential services are those that are structural, which include a lack of health care professionals, organization of the health care system, and transportation to services; and personal barriers, such as culture, language, and ethnicity, provider attitudes, and lack of social support.[35] Among the structural barriers are the length of time patients must wait to get appointments and the lack of convenient clinic hours. Patients who use public clinics and hospital clinics for care often experience long office waiting times, limited clinic hours, and long lead times for appointments.[36] Transportation barriers faced by Texans with cancer include the distance to the treatment center, access to a vehicle, and having someone to drive the patient to care. Hispanics and African-American Texans with cancer perceive transportation to be a barrier to treatment more often than do whites.[37]

Psychosocial & Support Services

Cancer patients and their families face a wide range of psychosocial and emotional issues during diagnosis, treatment, and follow-up care. A cancer diagnosis is very distressing and usually leads to fear, anxiety, anger, and depression, and cancer treatment can result in side effects, such as loss of physical functioning, stamina, and appetite. The ability of health care professionals to interact empathically with patients and their families also affects the way in which people cope with cancer, and for that reason, doctors may need special training that covers how to discuss the diagnosis and the emotions caused by the diagnosis.

A national survey of cancer patients, which included input from Texans, found that the services deemed of highest importance were: basic information about cancer, one reliable place for cancer information, guidance and support through the health care system, financial and insurance guidance, written information on how to cope with cancer, emotional support for family members, guidance to local resources for cancer patients, and support groups of patients and family members.[38] A full range of psychosocial and supportive services is only sporadically available throughout Texas, primarily in major urban centers and even there patient resource services are limited. Texans with limited English-speaking abilities or limited financial resources who reside in rural areas of the state have th greatest difficulty accessing appropriate psychosocial and supportive services.

Informed Decision Making

Given advances in oncology, physicians and patients face an increasing number of complex choices regarding prevention, diagnosis, and treatment. Because many reasonable options exist, each of which may have a different profile of benefit, risk, and cost, physicians need to understand what a patient's preferences are. Before patients can make those decisions, they need to understand the strengths, limitations, risks, costs, and expected outcomes associated with a procedure. To help facilitate these communications, researchers are now studying the use of "shared decision making," or "informed decision making" in which patients are involved as active partners with the clinician in clarifying acceptable options and in choosing a course of care.[39]

Research has shown that greater patient involvement in decision making can have an impact on decisions about the value of screening. Several studies have shown that informed decision making resulted in small decreases in prostate cancer screening, as well as small increases in breast and colorectal screening.[40] Those

who study informed decision making stress that these interventions need to be sensitive to patients of lower socioeconomic class and literacy, as well as to cultural concerns. For example, a study that examined the way that information about prostate cancer screening was delivered to different racial and ethnic groups found cultural differences in how different groups wanted information presented to them, as well as in their attitudes toward the physician-patient relationship, screening in general, and informed decision making.[41]

Researchers are also studying the use of "decision aids" to help health care professionals and patients make shared decisions. They have found that different kinds of decision aids generally appear successful in better informing patients about their treatment options than "usual care" does.[42] Health decision aids can take many forms. The most common are combinations of written and oral information (including audiotapes), personal counseling (sometimes supplemented by a decision board), videotapes, and interactive, computer-driven multimedia programs. These aids are meant to supplement, not replace, the traditional process of patient counseling by clinicians, and incorporating them into office practice remains a formidable challenge, according to researchers.[43]

NCI-Designated Cancer Centers

The National Cancer Institute has a Cancer Centers Program that supports major academic and research institutions throughout the United States to sustain broad-based, coordinated, interdisciplinary programs in cancer research. These institutions are characterized by scientific excellence and capability to integrate a diversity of research approaches to focus on the problem of cancer and are awarded a Cancer Center Support Grant. Each institution receiving a CCSG award is recognized as an NCI-designated Cancer Center. There are three types of cancer centers, based on the degree of specialization of their research activities, from generic cancer centers to the comprehensive cancer centers that integrate strong basic, clinical, and prevention, control, and population sciences. Texas has two NCI-designated cancer centers: the San Antonio Cancer Institute and The University of Texas M. D. Anderson Cancer Center. Both have achieved Comprehensive Cancer Center status.

Clinical Trials

Research studies on human patients to test the safety and effectiveness of new treatments are the basis of increasingly beneficial cancer care. These trials offer patients access to new and potentially life-saving drugs and cures. For cancer patients, properly designed and conducted clinical trials represent an important therapeutic option, as well as a critical means of advancing medical knowledge.[44]

For example, in 2001, there were more than 402 different cancer drugs in cancer trials, according to the Pharmaceutical Research and Manufacturers of America.[45] For about 100 of these drugs, the NCI was sponsoring, or conducting trials in conjunction with drug companies. The NCI also conducts its own research through an extended network of physicians and institutions (the Clinical Trials Cooperative Groups) that work together. This network also includes about 7,000 patients enrolled through the Community Clinical Oncology Program, or CCOP, which is a network of 50 central offices in 30 states that provides the infrastructure to link community cancer specialists and primary care physicians with the Cooperative Groups. It also includes patients enrolled through minority-based CCOPs. Texas participates in both the CCOP and minority-based CCOP networks.

Even though more than 25,000 cancer patients enrolled annually in an NCI treatment trial from 1997 to 2001,[46] that represents only 2-3 percent of eligible adult patients. Lack of insurance coverage is a barrier to patients who might otherwise participate. Sixty percent of patients in one survey cited fear of insurance denial as a major reason for not participating in clinical trials, but a recent study found only a slight increase in treatment costs for adult clinical-trial patients compared to nonparticipants, $35,418 versus $33,248.[47]

When a patient enrolls in a clinical trial, the costs of tests, procedures, drugs, and any research activity directly associated with the investigation are typically covered by the group sponsoring the trial, such as a pharmaceutical company or the NCI. However, because some health plans define clinical trials as "experimental" or "investigational," health insurance coverage may or may not include some or all of the costs of "routine patient care," such as the doctor visits, hospital stays, tests, and X-rays, that patients would normally have whether or not they are enrolled in a trial. Nevertheless, a growing number of states

have passed legislation or instituted special agreements requiring health plans to pay the cost of the routine medical care a patient receives as a participant in a clinical trial. By fall 2004, 19 states had enacted laws regarding clinical trials, according to the National Conference of State Legislatures, but that list did not include Texas. Lack of such coverage is a significant barrier to many patients who might otherwise enroll in a trial.

Objective B - Increase Access To, And Appropriate Utilization Of, Cancer Diagnostic, Treatment, And Support Services

Strategy 1: Increase knowledge of cancer diagnostic, treatment, and support services.

Action Steps:

a. Increase public awareness through effective cultural and linguistic channels about current evidence-based cancer diagnostic services, treatment, and support services.

b. Support community-driven efforts to increase public knowledge about diagnostic, treatment, and support services and facilities.

c. Encourage hospitals and agencies to publicize the availability of free or low-cost services.

d. Promote programs that address evidence-based cancer diagnostic, treatment, and support services.

Strategy 2: Assess the availability and use of cancer diagnostic, treatment, and support services.

Action Steps:

a. Inventory existing resources, including their geographic distribution, to assess need for development of additional programs.

b. Assess use of available services by specific demographic and geographic groups.

c. Support programs targeting health care professionals in medically underserved areas to provide patient education materials related to treatment and support services.

d. Promote policies that will provide for diagnostic, treatment, and support services for all Texans.

Strategy 3: Identify and address access barriers to cancer diagnostic, treatment, and support services.

Action Steps:

a. Promote collaboration of organizations addressing access barriers, particularly those for the underserved.

b. Support programs that address barriers to screening, diagnostic, and treatment services, especially in uninsured and underinsured populations.

c. Develop and utilize existing networks of community organizations to increase access to services.

d. Develop mechanisms to evaluate community progress on current activities and programs that address cancer diagnostic, treatment, and support services.

e. Advocate for community groups to support increased funding for the uninsured and underserved populations within public hospitals.

f. Provide communities with resources to assist them in identifying barriers and developing action plans.

Strategy 4: Facilitate informed decision making regarding cancer diagnostic, treatment, and support services.

Action Steps:

a. Assess the use of informed decision-making practices among and between diverse populations.

b. Identify, develop, and evaluate new channels for delivery of information to promote informed decision making.

c. Develop culturally competent and linguistically appropriate materials at various educational levels to enable informed decision making.

d. Educate health care professionals regarding informed decision-making practices among diverse populations.

e. Support inclusion of caregivers and others in the informed decision-making process as appropriate.

f. Promote the use of resources by health care professionals to enhance informed decision making.

g. Support programs to assist patients in becoming advocates for their own health.

h. Encourage utilization of psychological and social support services and resources from the time of diagnosis.

Strategy 5: Increase public awareness of and participation in cancer diagnostic, treatment, and support service clinical trials.

Action Steps:

a. Increase public awareness about clinical trials through effective cultural and linguistic channels.

b. Encourage the development of community-level resources to promote public awareness and participation in clinical trials.

c. Collaborate with community leaders to promote public education to encourage participation in clinical trials.

d. Develop strong relationships between the public, the research community, and diverse communities to increase knowledge of and participation in clinical trials.

e. Advocate for funders and researchers to include support for an effective communication plan to aid in the recruitment for trials.

f. Develop culturally competent and linguistically appropriate messages regarding clinical trials.

g. Develop and maintain a centralized clearinghouse for accessing information on clinical trials available in Texas.

h. Support programs targeting private-sector health care professionals to promote enrollment in clinical trials.

i. Promote access to clinical trials to a broad cross section of Texas communities.

j. Encourage health benefit plans to provide access to available clinical trials through ACOS- or NCI-approved facilities.

k. Support effort to reduce financial barriers to participation in clinical trials.

l. Offer clinical trials in health benefit plans to eliminate cost as a barrier.

m. Increase funders' and health care professionals' awareness of barriers to participation, particularly for underrepresented populations.

n. Encourage the inclusion of all clinical trials in registries.

Objective C- Enhance Quality Of Cancer Screening, Diagnostic Treatment, And Support Services

Quality Assurance

Many cancer patients may be getting the wrong care, too little care, or too much care in the form of unnecessary procedures. The quality of cancer care is a major national concern, according to the National Cancer Institute. Evidence suggests that some patients with cancer do not receive the newer, more effective treatments, and in some cases, uncertainty exists about what constitutes optimal care.[48] The American Society of Clinical Oncologists says there is a concern that with rapid changes in the health care industry, cost-cutting measures may result in substandard care for the 1.3 million Americans in whom cancer is newly diagnosed each year.[49]

In 1999, the Institute of Medicine's National Cancer Policy Board issued a report that suggested many people with cancer are not receiving care known to be effective for their disease, a problem the board said is significant, but it noted that little data exist to determine its true extent.[50] To help define the issue, government agencies and organizations are actively defining what "quality" cancer care is, and they are checking to see if Americans are benefiting from it. For example, the President's Cancer Panel has held meetings across the country to explore why all Americans do not receive the best cancer care.[51] Comprehensive research programs are underway that,

The American Society of Clinical Oncologists says there is a concern that with rapid changes in the health care industry, cost-cutting measures may result in substandard care for the 1.3 million Americans in whom cancer is newly diagnosed each year.

Comprehensive research programs are underway that are, among other goals, aimed at defining a core set of cancer outcome measures, and investigating whether therapies found to be effective in clinical trials are being offered to patients in community clinics.

among other goals, are aimed at defining a core set of cancer outcome measures and investigating whether therapies found to be effective in clinical trials are being offered to patients in community clinics.[52]

Cancer screening also is subject to lapses in quality. Questionable results, such as from a mammogram or Pap smear, can be worse than no screening at all. High rates of false-positive reports can result in the need for follow-up diagnostic tests that are expensive, unnecessary, and cause needless anxiety. False-negative reports can result in delayed diagnosis and treatment. Therefore, quality assurance is important in all programs of cancer screening and diagnosis, especially in the interpretation and reporting of the tests.

Some screening services, such as mammography, are subject to both state and federal regulation. For example, the Mammography Quality Standards Act (MQSA) of 1992 ensures that mammograms are safe and reliable by requiring all mammography facilities to be accredited by the Food and Drug Administration (FDA). The technologists who take the mammogram, the radiologist who interprets the X-ray, and the medical physicist who tests the equipment must all meet FDA standards.[53] Texas law [54] further requires that each mammography system be certified by the Department of State Health Services and that certifications be renewed annually. The Department of State Health Services also inspects each mammography system at least once annually.

One method for ensuring quality care is to seek approval by the American College of Surgeons (ACOS), through its Commission on Cancer (CoC) Approvals Program. It encourages hospitals, treatment centers, and other facilities to improve their quality of patient care through various cancer-related programs, including those concerned with prevention, early diagnosis, pretreatment evaluation, *staging*, optimal treatment, rehabilitation, surveillance for recurrent disease, support services, and end-of-life care. Approved cancer programs at these hospitals offer a full range of medical services along with a *multidisciplinary* team approach to patient care. Approximately 80 percent of all newly diagnosed cancer patients are treated in CoC-approved cancer programs. As of 2003, Texas had 70 of these facilities,[55] ranking it sixth in number of approved programs. The database of ACOS approved programs can be accessed at *www.facs.org/cancer*.

Promoting Best Practices

Texas has many excellent health education, research, and treatment facilities, as well as countless community organizations and individuals who are committed to ensuring that all Texans have access to quality health care services. The geographic vastness of Texas, however, presents a difficult challenge for communication regarding effective program models.

As of 2004, there are 24 state planning regions and 11 health and human service regions within Texas that divide the state into groups of counties by which health resources are distributed and programs are planned. The regions also are the basis for assessing the geographic adequacy of facilities, providers, and cancer services. They also can serve as a conduit by which to share best cancer practices. For example, cancer centers, such as The University of Texas M. D. Anderson Cancer Center, have established networks and agreements with physicians and hospitals to provide cancer treatment, but no formal system of regionalized cancer services or referrals exists throughout the state. Networking with the freestanding cancer treatment centers that exist around the state could give cancer patients the ability to

remain within their communities, while receiving the best standard of care. Such coordination and cooperation can eliminate unnecessary duplication of effort or, conversely, insufficient attention to ongoing education and service delivery problems.

Objective C- Enhance Quality Of Cancer Screening, Diagnostic Treatment, And Support Services

Strategy 1: Ensure that cancer screening, diagnostic, and treatment facilities meet established standards and are accredited by appropriate accrediting organizations.

Action Steps:

a. Assess the availability of and identify gaps in, accredited diagnostic and treatment facilities for the state of Texas, particularly in medically underserved areas.

b. Collaborate with accrediting organizations to develop consistent guidelines.

c. Develop technical assistance and continuing education programs to allow facilities to meet established quality assurance standards.

Strategy 2: Increase the number of hospitals and cancer facilities with core components required by the American College of Surgeons (ACOS) for approval as a Community Hospital Cancer Program.

Action Steps:

a. Promote benefits of having ACOS programs through ACOS state chairs.

b. Encourage self-evaluation of cancer programs for limitations, best practices, and opportunities for better care.

c. Encourage cancer programs in each state planning region to adopt ACOS core components.

d. Provide technical assistance and identify resources to assist hospitals and cancer facilities seeking and maintaining approval as an ACOS Community Cancer Care Program, particularly those in medically underserved areas.

e. Encourage hospital medical staff to establish cancer committees by providing information on the organization, operation, and benefits of cancer committee review of cancer care in hospitals.

f. Promote use of mentor facilities.

Strategy 3: Promote best practices in cancer screening, diagnostic, treatment, and support services.

Action Steps:

a. Encourage the adoption and use of clinical cancer planning committees to determine the best course of treatment based on a patient's diagnosis, stage, and health status.

b. Promote programs addressing patient safety related to cancer screening, diagnostic, treatment, and support services.

c. Encourage continued emphasis on appropriate use of pain management in the delivery of health care.

d. Promote the use of appropriate diagnostic techniques to adequately diagnose and stage cancer patients.

GOAL III: PROFESSIONAL EDUCATION & PRACTICE

Texas health care professionals will have up-to-date knowledge and skills about cancer prevention and control and will use them to provide quality prevention, education, screening, diagnostic, treatment, and support services.

Objective A - Enhance Health Care Professionals' Knowledge, Skills, And Practices Regarding Cancer Prevention, Early Detection, Treatment, Support Services, And Survivorship

Simply put, health care professionals are the front line in the war against cancer. Their critical role is helping people prevent cancer development through risk reduction and detection of cancer at an earlier, more treatable stage with appropriate screening. Studies have highlighted, for example, how important a physician's recommendation for cancer screening is to a person's decision to obtain it. People who agreed to be screened for colorectal cancer said that their physician's advice was a powerful motivator, especially when they were told how important the test was and that they should not be embarrassed about receiving the exam.[1] Other studies have shown that the primary care physician is in a crucial position to facilitate mammography referral of women older than 50, and that encouraging the screening while addressing patients' concerns about the procedure can have a beneficial impact on whether women seek mammography.[2] Incorporating screening into routine office care is one way to encourage other screening procedures. For example, researchers have found that women who received routine screenings such as a Pap smear or clinical breast examination are far more likely to receive a mammogram as well.[3]

Because health care professionals — physicians, nurses, nurse practitioners, physician assistants, dentists, dental hygienists, and dietitians — are often the primary source of information that Texans have about cancer risks and screening, they must be well-trained, active players in cancer prevention and control.

Because health care professionals — physicians, nurses, nurse practitioners, physician assistants, dentists, dental hygienists, and dietitians — are often the primary source of information that Texans have about cancer risks and screening, they must be well-trained, active players in cancer prevention and control. They must be motivated and have local service capabilities to put screening guidelines into practice. Health care professionals also need easy access to cancer education, such as through the Internet, teleconferencing, and interactive educational software. These media also are especially valuable in providing continuing education for health care professionals who reside in rural communities or who have difficulty taking time away from their solo practices. The Internet and educational interactive software are practical methods of obtaining cancer information, since they can be accessed anytime. Teleconferencing allows for larger groups of individuals to obtain the information and to interact simultaneously. Texas Tech University Health Sciences Center, through its HealthNet and other services, has been a leader in providing continuing education for rural hospitals and providers through teleconferencing. Providing workshops in rural areas also has been shown to be an effective method of reaching health care professionals in those rural areas.

Improving Prevention, Screening, & Early Detection

Since 1980, the American Cancer Society has recommended a cancer-related checkup every three years for individuals aged 20 to 39, and annually for individuals aged 40 and older. In the past, it was likely assumed that routine checkups would be an opportunity to include case-finding examinations and discussions with patients that were specific to cancer. However, as recommendations for routine checkups have been replaced by recommendations that apply to specific conditions (including cancer screening) and populations, in 2003 the ACS said it has become less clear how often these general health checkups should be scheduled.[4] The organization also said it makes very little sense for a cancer-related checkup to take place as a separate visit apart from other preventive health measures and counseling relevant to cancer. Thus, the

Despite the availability of national guidelines for the early detection of cancer, health care professionals do not routinely incorporate the guidelines into their daily practices.

ACS updated its guidelines to recommend that the cancer-related checkup occur on the occasion of a general, periodic health examination, rather than as a stand-alone exam done at a specific interval based on an individual's age.[5]

Despite the availability of national guidelines for the early detection of cancer, health care professionals do not routinely incorporate the guidelines into their daily practices.[6] When medical charts are reviewed, there often are discrepancies in physician self-reports and actual prevention practices. Adherence to cancer prevention and screening guidelines is not routine, especially for individuals at high risk for cancer.

Furthermore, some physicians prefer one set of guidelines to another, or may not follow any standard at all. A study that looked at the guideline preferences of internists and family physicians in Tennessee found that most of the physicians report using ACS screening guidelines and they rate these cancer screening practices as good or very good.[7] Other physicians are unaware of screening guidelines and thus recommend such tests inappropriately.

A study of physicians located in urban inner-cities found that physicians polled were knowledgeable about national guidelines for preventive care and were less likely to counsel on smoking cessation and advise diet modifications.[8] Furthermore, a significant proportion of these physicians suggested lung and prostate cancer screening tests that were inconsistent with national recommendations. Cancer education, however, can help keep physicians informed and change attitudes.[9] Some physicians apparently approach screening based on their own biases to the benefit or detriment of their patients. One study found that recommendations for mammography differed significantly based on a physician's age and sex.[10] Another found that patients of female physicians were found to have higher rates of breast and cervical cancer screening.[11] Studies also show that people who receive a clinician's recommendation for cancer screening are more likely to be screened than those who do not receive a recommendation.[12] And the strongest determinant of receiving preventive services is having a periodic health examination by a primary care physician, researchers have determined.[13] Counseling by physicians can be a direct way to accurately inform patients about cancer prevention, and is, therefore, highly desirable.

Providing prevention counseling that addresses social factors relevant to working-class, multiethnic populations offers the best chance that people will comply with screening recommendations. A recent study of more than 1,000 people who participated in a "Healthy Directions-Health Centers" program, conducted by the Harvard Cancer Prevention Project, found that considering social "contextual" factors, or the social norms, in addition to health behaviors in counseling, resulted in success in reaching people who are traditionally unlikely to be screened.[14] Clinicians who tell patients how to behave in reducing cancer risks are much less successful than those who partner with a health advisor to create a "safety net" for patients, the researchers found. These advisors tailor their messages and materials to the patient, and also provide help in facilitating appointments, such as providing "reminder" phone calls, flexible scheduling, and assistance with transportation.

According to the American Cancer Society,[15] the best approach to improving rates of cancer screening uses a systems strategy that includes:

- Implementation of centralized or office-based systems, including computer-based reminder calls, to assist clinicians in screening, managing referrals, and follow-up examinations
- Using a variety of strategies to tell patients about the importance of cancer screening
- Providing assistance to clinicians in how they counsel their patients about screening
- Ensuring that a health care system can deliver high-quality and timely cancer screenings

Some of the common reasons cited for health care professionals' failure to routinely take preventive care steps with their patients are: education, training, and skills; discrepancies in protocols for cancer screening; personal health habits, beliefs, and perceptions; forgetfulness; and time and reimbursement constraints.[16] A national survey that looked at the colorectal cancer screening practices of more than 1,200 primary care physicians found, for example, that awareness of the need for such screening was high

Some of the common reasons cited for health care professionals' failure to routinely take preventive care steps with their patients are: education, training, and skills; discrepancies in protocols for cancer screening; personal health habits, beliefs, and perceptions; forgetfulness; and time and reimbursement constraints.

among these physicians, but "knowledge gaps" about the timing and frequency of the tests were common.[17]

Primary care physicians are being asked to do more than ever before in providing comprehensive care to their patients. Consequently, continuing education for primary care physicians is becoming increasingly important, as is finding innovative, time-efficient ways of providing education resources to them. Specialists who do not consider themselves primary care physicians also need to be aware of general cancer screening guidelines when treating older individuals with chronic conditions, because these patients often visit specialists much more frequently than primary care physicians. It is important for all Texas health care professionals to be up-to-date and supportive of cancer screening guidelines.

Artist's rendering of POEP's impact on cancer.

Telemedicine

Telemedicine enables rural health practitioners to conduct live consultations with specialists in medical centers through the use of interactive audiovisual links. The services provided by telemedicine are as diverse as interactive video consultations, teleradiology, data services for rural hospitals, health care consultations for prisons, continuing education of health care professionals, including those in rural hospitals, and the training of emergency service personnel.

In late 2001, Medicare coverage was extended to a wide range of telemedicine services and providers, allowing for medical visits, consultations, mental health services, and pharmacologic monitoring of patients living in rural areas. Payment to providers is now at a rate similar to that paid without the use of telemedicine.[18]

State-of-the-Science Debates

Lack of a consensus within the medical and scientific communities about risk factor information, screening guidelines, and treatment methods affects medical care decisions. National debates, especially between leading oncology groups and federal health agencies, lead to confusion about which interventions should be taken for specific patient populations. For example, many groups disagree with some of the more conservative recommendations made by the U.S. Preventive Services Task Force, which bases its recommendations on evidence obtained mainly from randomized clinical trials. Many physicians noted the efficacy of flexible sigmoidoscopy in their private practices or read about it in the literature submitted by their peers and instituted that screening tool for colorectal cancer into their practice. Conversely, the U.S. Preventive Services Task Force did not recommend flexible sigmoidoscopy as a screening tool in their 1989 screening recommendations. In 1996, however, after more scientific evidence was available, the Task Force amended their recommendations to include flexible sigmoidoscopy. Such controversies about screening guidelines underscore the importance of keeping health care professionals up-to-date on scientific studies, debates, and practice guidelines.

Training & Resource Needs

Increased training can enhance a physician's desire, ability, and effectiveness in implementing screening guidelines that will improve cancer prevention efforts. For example, training helps health care professionals

providing services to low-income and medically underserved families understand that these Texans often do not go to a health care provider unless they are feeling ill. Therefore, physicians should be especially attentive in assessing and educating individuals about cancer risks and facilitating access to screening services before symptoms appear.

Additionally, health care professionals need to be aware of patient education resources that are available at no cost and are appropriately tailored for their patient populations. Patient education resources are available from multiple sources, such as professional associations, volunteer health agencies, and government agencies; however, health care professionals may not know which materials are best suited for their patients or how to obtain them.

Health care professionals also should understand what constitutes good communication techniques, since poor communication can increase patients' anxiety, lead to poor compliance, and result in incomplete or inadequate treatment.[19] It is the health care professional's responsibility to give patients a conceptual framework for understanding the disease and for making treatment decisions. It also is crucial that health care professionals be sensitive to the social support needs of patients and knowledgeable about resources that can assist patients and their families.

The communication that takes place between health care professionals and patients is important in that it affects the degree to which patients are active partners in their treatment. Taking the time to discuss a patient's concerns may influence whether or not the patient accepts the physician's recommendations. Being empathetic to patients, for example, can improve the doctor-patient relationship.[20] Patients are positively influenced when their physicians communicate, with conviction, that a specific intervention is important and necessary.[21]

Health care professionals should also understand what constitutes good communication techniques, since poor communication can increase patients' anxiety, lead to poor compliance, and result in incomplete or inadequate treatment.

Additionally, health care professionals need to be aware that their messages may be received and interpreted differently, depending on a patient's cultural background and educational level. Since Texas is a multicultural state with immigrant populations that have diverse nationalities, such differences need to be included in the teaching of effective communication techniques. In some cases, for example, health messages that are illustrated work better than written communications, especially for patients with lower literacy skills. One study found that a well-designed, animated cartoon is more effective in delivering a message to some patients.[22]

Communication is a two-way street for everyone involved. All members of a health care team should feel comfortable speaking with patients, not just physicians. Oncology nurses, for example, perceive a need for advanced communication skills, particularly when taking care of dying patients.[23] Improving communication skills in patients also can help overcome misunderstandings with their physicians. An experimental program, dubbed Consultation Planning, that provided patients with a printed agenda and a verbal consultation in how to talk with their doctors resulted in improved satisfaction on both sides of the exam table.[24]

Office Management Systems

Like poor communication, poor office management can create ill-will among patients and can even contribute to negligence if patients "fall through the cracks."[25] So it is vital that every office have a system for tracking test results and referrals, and that the office then use the system. An efficient office management system can help overcome barriers to preventive and early detection services, for example, by using reminder checklist systems generated by a computer or by clinical staff, which are placed at the front of a patient's chart for review by the health care professional.

One national office management model is Put Prevention Into Practice (PPIP), launched by the U.S. Public Health Service in 1994 and transferred to the Agency for Health Research and Quality (AHRQ) in 1998. The objectives of PPIP are to make tools available and reduce barriers to facilitate the delivery of clinical preventive services. Clinician barriers include lack of skills, orientation, and training in preventive services; office barriers include clinical settings focused on illness and not the delivery and follow-up of prevention services; and patient barriers are related to inadequate

information, motivation, and lack of insurance coverage for preventive services.[26] Because the PPIP "toolkit" designed to reduce these barriers has been found to be helpful, but not sufficient to facilitate substantial change in clinical preventive practice, the Department of State Health Services altered the system. The DSHS-PPIP initiative, known as "PPIP Texas Style!," refined the PPIP model for use in the field, specifically in medically underserved communities. The collaboration created "practice products" that include training and implementation guides, which are available through *http://www.ahrq.gov*. A one-year review of the program found, among other conclusions, that PPIP Texas Style! improved rates of assessment of cancer risk and screening.[27]

Guidelines for Cancer Care

In order to deliver high-quality health care and support services, there should be a consensus among specialists about the management of the common cancers. Clinical guidelines delineate a multidisciplinary approach to cancer treatment and enable some uniformity in the evaluation, treatment, and follow-up care of cancer patients. A more detailed approach to patient management includes the development of clinical pathways that delineate specific medical interventions, such as drug doses, *chemotherapy regimens*, and imaging studies.[28]

In 1995, many of the most prestigious cancer centers, including The University of Texas M. D. Anderson Cancer Center, formed the National Comprehensive Cancer Network (NCCN). One of the Network's priorities is to develop treatment guidelines for the cancers that represent the majority of *malignancies* in the United States. These guidelines are an overview of cancer treatments, appropriately sequenced for the management of specific clinical presentations. The Network's guideline development process includes establishment of medical review criteria and a data collection system to measure guideline compliance and patient outcomes, such as survival, *quality of life*, and length of hospitalization. These guidelines allow for more realistic estimates of the costs of therapy and protect providers from the influence that cost containment might have on treatment planning. Texas's health care professionals should promote standardized guidelines to improve the consistency and the quality of cancer care for Texans. These guidelines can be found on the NCCN website at *www.nccn.org*.

Medical School Curricula

Historically, medical schools have not adequately prepared physicians in cancer control, and this serious lack of cancer preparation in Texas medical schools led to an innovative cancer education program that has become a national model. In 1990, The University of Texas Medical Branch at Galveston (UTMB) was funded by the Texas Cancer Council to identify ways in which medical schools could collaborate to ensure that medical students graduate with sufficient knowledge of, and skills in, cancer prevention and early detection.[29] Deans of eight schools met to discuss the need for curriculum improvement, and a workgroup with representatives from each school developed a collaborative project known as the Cancer Teaching and Curriculum Enhancement in Undergraduate Medicine (CATCHUM). The goal of the CATCHUM Project is to make sure that every medical student in Texas has an opportunity to become an effective agent for cancer prevention and control.

To achieve that goal, CATCHUM reviewed and improved the cancer prevention curriculum at each school by using innovative programs, such as patient case studies, as teaching tools for educating and evaluating clinical skills. It also developed a standardized instrument to assess the knowledge of undergraduate medical students about cancer prevention and screening. This scrutiny of cancer education led to curricular change and innovation, and in 1995, CATCHUM received a grant from the National Cancer Institute and is now considered a national model of how medical schools can work together to improve cancer prevention curricula.[30] Evidence from CATCHUM's self-critical examination now shows that students are performing better on the U.S. Medical Licenser Examination and on clinical evaluation exercises that test knowledge and skills of cancer screening and detection.[31] Success provided by the CATCHUM Project has spilled over to other disciplines, where teaching strategies are currently being assessed.[32]

The goal of the CATCHUM Project is to make sure that every medical student in Texas has an opportunity to become an effective agent for cancer prevention and control.

Other Academic Curricula

CATCHUM has provided a good start, but there is a need for this type of comprehensive scrutiny and improvement of the cancer prevention and detection curricula by other schools for health care professionals. If all health care professionals are to be knowledgeable and skilled in prevention and early detection of cancer, cancer prevention and control issues need to be emphasized in their respective training programs' curricula.

For example, the cancer prevention and detection skill labs that are important tools in Texas medical schools also should be made available in all nursing and dental schools. These labs provide educational models for students using state-of-the-art cancer detection techniques and diagnostic procedures, such as how to conduct a flexible sigmoidoscopy. Skills development programs such as these have the potential to increase the routine utilization of cancer screening by health care professionals.

The Nurse Oncology Education Program's (NOEP) Academic Education Committee established the Faculty Training Program (FTP) as a result of NOEP's 1988 School of Nursing Curriculum Survey. The curriculum survey revealed that only 13 of the 64 professional nursing education programs in Texas had faculty members who were academically prepared in oncology at the graduate level. The FTP is a five-day scholarship program that provides an excellent opportunity for nursing faculty to gain knowledge and experience in the latest cancer prevention, screening, and treatment modalities. The goal of this program is to increase nursing faculty's oncology knowledge through both clinical and didactic formats so that they may educate their students in oncology issues. The first FTP was held in May 1988 at the Don and Sybil Harrington Cancer Center in Amarillo. Since 1990, the faculty and staff at The University of Texas M. D. Anderson Cancer Center in Houston have conducted the FTP. From 1990 to 2004, 207 nursing faculty have attended the FTP.

Undergraduate and graduate schools have the potential to be valuable sources of continuing education programs on cancer-related topics for health care professionals. Central coordination of cancer education for all Texas universities would increase the standardization and overall quality of education and ensure that the same topics were emphasized. Academic centers, hospitals, and professional associations also should be utilized to offer continuing education classes to practicing health professionals.

Statewide Oncology Education Initiatives

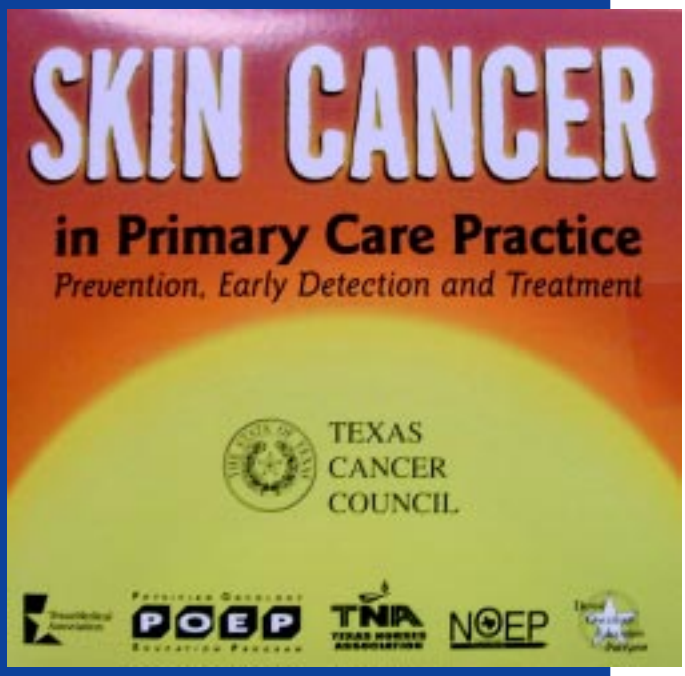
Texas has been a leader in providing health care professionals with the knowledge and skills necessary to promote cancer prevention and control. In partnership with the state medical, nursing, and dental associations, the Texas Cancer Council has established statewide collaborative programs to address the cancer education needs of physicians, nurses, and dentists. What is unique about these professional education programs is that they are guided by steering committees comprised of representatives from a wide range of academic institutions, disciplines, and professional associations. Additionally, they have developed statewide strategic plans to ensure that their efforts continue to be innovative, collaborative, and effective in addressing priority needs.

The Physician Oncology Education Program (POEP), administered by the Texas Medical Association, has steering committee members from the state's key oncology and professional organizations, institutions, and societies. The goal of POEP is to make every physician's office a cancer prevention and detection center. POEP seeks to enhance the primary care physician's role in communicating and implementing cancer prevention, screening, and early detection for major cancer sites by:

- Establishing a clearinghouse and education network on cancer issues
- Increasing the number of continuing medical education courses offered on cancer
- Developing innovative approaches to physician education
- Providing resources for cancer education
- Working with physicians to put their cancer prevention/screening knowledge into everyday practice

POEP has adopted educational objectives for prevention, screening, and early detection of the most common cancers and developed an array of videotapes, pocket guides, and other educational materials. POEP also has developed education modules, which consist of a script and a set of slides for major cancer sites, risk reduction

The goal of POEP is to make every physician's office a cancer prevention and detection center.



This CD-ROM is an example of POEP materials designed to assist physicians in putting cancer prevention into their everyday practice.

factors, and genetic testing, to facilitate continuing education on cancer through local medical societies and hospitals. In addition, POEP offers a speakers' bureau composed of physician-experts from across the state who will speak to professional and lay groups on cancer prevention, screening, and treatment. Further, POEP routinely tracks Texas physicians' attitudes and practices related to prevention and early detection to determine educational needs. To get more information about POEP, visit its Web site at *www.POEP.org*.

The Nurse Oncology Education Program (NOEP), administered by the Texas Nurses Foundation and associated with the Texas Nurses Association, operates a statewide clearinghouse and oncology education program for nurses. NOEP facilitates the collaboration of public, private, and volunteer sectors in increasing Texas nurses' knowledge and skills about cancer prevention, detection, treatment, and survivorship. The goals of NOEP are to:

- Increase the quality of oncology education in Texas schools of nursing
- Increase the quality and number of continuing education programs for nurses who care for individuals or families with cancer
- Provide continuing education programs and scholarships for cancer prevention and detection programs
- Provide support for the evaluation of cancer nursing educational activities
- Provide a statewide network for sharing cancer nursing resources and to promote interdisciplinary collaboration

Education programs cover a diverse spectrum of topics, such as chemotherapy, pain management, skin cancer screening, and tobacco prevention and control. Annually, NOEP sends nursing school faculty members to in-depth training programs at The University of M. D. Anderson Cancer Center and facilitates information exchange among oncology nurses throughout Texas. NOEP is guided by a steering committee representing key institutions, specialty organizations, and expertise in cancer prevention and control. NOEP offers scholarships to rural nurses to attend a chemotherapy administration workshop at The University of M. D. Anderson Cancer Center each year. For more information about NOEP, visit its Web site at *www.noeptexas.org*.

The Dental Oncology Education Program (DOEP), is administered through the Baylor College of Dentistry and the Texas A&M University System Health Science Center in Dallas. The DOEP steering committee consists of faculty representatives from the state's three dental schools, schools of dental hygiene, key oncology groups, and professional associations. The goals of DOEP are to increase the ability and effectiveness of dental and other health care professionals in early detection and risk factor reduction of oral cancer and to reduce the morbidity from cancer therapy and improve quality of life for all cancer survivors through supportive oral health care of the patient during and following therapy.

Major initiatives of DOEP include:

- Maintaining a resource guide for oral cancer and tobacco education materials for professionals and patients
- Providing continuing dental education programs on oral cancer prevention, early detection, and the management of oral complications of cancer therapy for health care professionals
- Maintaining a speakers' bureau of experts on oral cancer and oral health in cancer therapy
- Providing lectures and exhibits at major state dental meetings
- Publishing and distributing *The Oral Disease Update* newsletter to licensed dentists and dental hygienists in Texas

- Editing the June cancer issue of the *Texas Dental Journal* of the Texas Dental Association
- Collaborating with other state agencies and private organizations in the development of educational modules and curricula for dentists and dental hygienists
- Development and distribution of the *Oral Health In Cancer Therapy* monograph

For more information about DOEP, visit its Web site at *www.DOEP.org*.

Genetic Counseling & Testing

One rapidly changing field in cancer prevention and control in which health care professionals need training is genetic testing. Advances in cancer genetics are raising the possibility of widespread DNA testing for detecting a predisposition to cancer, possibly decades in advance of the onset of the disease itself. However, to date, these tests cannot definitively predict occurrence because cancer is caused by a complex interplay of factors, not all necessarily gene-based. An accurate gene test can tell if a mutation is present, but that finding does not guarantee that disease will develop. For example, women with the *BRCA1* breast cancer susceptibility gene have an 80 percent chance of developing breast cancer by the age of 65. The risk is high, but not absolute. Family members who test negative for the BRCA1 mutation are not exempt from breast cancer risk; over time, they can acquire breast cancer-associated genetic changes at the same rate as the general population.[33]

According to the NCI, gene testing offers several benefits. A negative result can create a tremendous sense of relief and may eliminate the need for frequent checkups and tests that are routine in families with a high risk of cancer. Even a positive result can relieve uncertainty and allow a person to make informed decisions about the future. A positive result can let a person take steps to reduce risk before disease has a chance to develop.[34] There also are major limitations to gene testing. Perhaps the most serious one, The NCI says, is that test information is not matched by state-of-the-art diagnostics and therapies. In other words, a person who tests positive for a genetic susceptibility to a cancer may not be able to find out when the disease does develop, and doctors may not be able to adequately treat the cancer when symptoms finally do appear. Even though there is no physical risk to having a genetic test — it is often just a blood sample — the confirming of the risk of a serious disease can trigger profound psychological consequences.[35]

ASCO recommends that genetic testing be offered when: (1) an individual has a strong family history of cancer or early onset of disease; (2) the test can be adequately interpreted; and (3) the results will influence the medical care of the patient or family member.

In a 2003 statement that mirrors the opinion of a number of private and public organizations, the American Society of Clinical Oncology (ASCO) recommended that genetic testing be offered when: (1) an individual has a strong family history of cancer or early onset of disease; (2) the test can be adequately interpreted; and (3) the results will influence the medical care of the patient or family member.[36] Informed consent, as well as counseling before and after the testing, are all critical components of genetic testing. In addition, patients' genetic information and test results should be protected to prevent insurance and employment discrimination. The State of Texas in 1997 passed a law prohibiting the use of genetic tests in employment, in the granting of occupational licenses, and in the determination of eligibility for health insurance.[37]

Health care professionals need access to educational materials to help patients understand the complexity of genetic testing and to assist them in making a personal decision about testing. Because many advances in molecular genetics are taking place in a short span of time, health care professionals themselves need quick and reliable access to the most current information and to have their questions answered quickly and completely.

Alternative & Complementary Medicine Therapies

Many cancer patients seek information about unconventional therapeutic approaches when undergoing cancer treatment, and a good number of them turn to *complementary* and *alternative medicine*, known among researchers as CAM. In CAM, complementary medicine is used together with conventional medicine, and alternative medicine is used in place of conventional medicine. While some scientific evidence exists regarding some CAM therapies, such as acupuncture, for most there are key questions that have yet to be answered

In CAM, complementary medicine is used together with conventional medicine, and alternative medicine is used in place of conventional medicine.

through well-designed scientific studies — questions such as whether these therapies are safe and whether they work in the diseases or medical conditions for which they are used.[38]

This kind of research is vital, given the popularity of CAM. According to the National Center for Complementary and Alternative Medicine (NCCAM), part of the NIH, 36 percent of American adults use some form of CAM. When megavitamin therapy and prayer specifically for health reasons are included in the definition of CAM, that number rises to 62 percent.[39] Use of CAM among cancer patients also seems to be widespread. One 2000 study found that 69 percent of 453 cancer patients had used at least one CAM therapy as part of their cancer treatment.[40]

To determine whether or not various forms of CAM offer any benefit to cancer patients, the NCI and the NCCAM are sponsoring a number of clinical trials. Some of these trials study the effects of complementary approaches used in addition to conventional treatments, while others compare alternative therapies with conventional treatments. As of late 2004, NCI listed trials that included examination of acupuncture, mistletoe, shark cartilage, hyperbaric oxygen, and massage therapy.[41]

Cancer patients using or considering complementary or alternative therapy must feel as free to discuss this decision with their doctor or nurse as they would any other therapeutic approach. Therefore, it is crucial that health care professionals be informed and open-minded about such therapies. Recognizing the widespread use of these therapies, health care professionals are encouraged to ask their cancer their patients about their use of CAM if they do not bring up the subject themselves.

The University of Texas M. D. Anderson Cancer Center's Complementary/Integrative Medicine Education Resources (CIMER) Web site *www.mdanderson.org/CIMER* is a resource offered to help patients and physicians decide how best to integrate such therapies into their care. A review of a variety of CAM therapies is included with a short summary in both English and Spanish, as well as evidence-based reviews of published research studies. Other resources include continuing education and links to information on potential drug interactions.

Clinical Trials

When it comes to cancer clinical trials, both health care professionals and patients are affected by a lack of information or a misunderstanding about what these trials can contribute to cancer care. Health care professionals often miss opportunities to tell their cancer patients about clinical trials that may be beneficial, and each year, less than 5 percent of adults with cancer will be treated through enrollment in a clinical trial, according to the NCI.[42] One study found that 8 out of 10 cancer patients were unaware that clinical trials could be an option for them.[43] Even when individuals with cancer do find out about the trials, the majority choose not to participate, primarily because of several central misconceptions, according to the NIH. Many patients fear getting a placebo (or inert drug) in place of actual treatment. Others fear they will become a "guinea pig" because the standard treatment is better than the experimental treatment. Health care professionals can clarify these concerns.[44] Still, federal experts recognize that big barriers to clinical trial enrollment exist for physicians, including those of time, staff, and resources, as well as lack of clinical trial experience, especially among primary care physicians.[45] To help, the NCI has established a new national system to change the way it develops, conducts, reviews, and supports clinical trials, and part of this change includes the Cancer Trials Support Unit (CTSU), designed to make it easier to enroll patients. Further information is available at *www.ctsu.org*.

Cultural Competency & Professional Education

Texas is rapidly changing to a state where minority residents are becoming the majority.[46] Yet health disparities in minority populations, such as African-

Health care professionals often miss opportunities to tell their cancer patients about clinical trials that may be beneficial, and each year, less than 5% of adults with cancer will be treated through enrollment in a clinical trial.

American, Native American, Asian-American/Pacific Islander, and Hispanic/ Latinos, have increased rather than decreased over the past decade.[47] Health care professionals need to know about the unequal burden of cancer suffering and death due to racial and ethnic disparities in health care; a number of recent federal reports have focused on the problem. As documented by a blue ribbon panel convened by the Institute of Medicine (IOM) in a report entitled "Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare," these disparities cannot be explained away by access-related factors, patients turning down care, or appropriateness of intervention.[48] Moreover, these disparities occur over a wide range of illnesses and diseases and remain even after adjusting for socioeconomic status. As a result, according to a 2004 federal report, "Making Cancer Health Disparities History," by the Trans-HHS Cancer Health Disparities Progress Review Group, minority patients receive a lower quality and intensity of health care across a wide range of procedures, treatment options, and disease areas, cancer included. Studies of the common cancers have shown a pattern of persistent undertreatment, late diagnosis, and inattention to late-stage issues such as pain control, according to the report.[49] Inequities like these are associated with worse outcomes, a situation that is unacceptable, according to experts.[50]

The IOM report found that, unlike what many have previously thought, minority patients' attitudes toward health care and preferences for treatment are not likely to be a major source of health care disparities. Instead, the report identified two other sets of factors. The first set of factors is related to the operation of health care systems and the legal and regulatory climate in which they operate. This includes cultural or linguistic barriers, fragmentation of health care systems, physician incentives to lower costs, and the location where minorities choose to receive care.[51] The second set of factors emerges from the clinical encounter, according to the IOM, and includes bias (or prejudice) against minorities; greater clinical uncertainty when interacting with minority patients; and beliefs (or stereotypes) held by the provider about the behavior or health of minorities.[52]

Given that stereotypes, bias, and clinical uncertainty may influence clinicians' diagnostic and treatment decisions, the IOM says that education may be one of the most important tools as part of an overall strategy to eliminate health care disparities. Health care professionals should be made aware of the fact that racial and ethnic disparities in health care exist, often despite the professionals ' best intentions. All current and future health care providers can benefit from cross-cultural education, according to the IOM report.[53]

The Intercultural Cancer Council in 2004 published an easy-to-reference pocket guide aimed at helping physicians and other health professionals to better screen, diagnose, and treat patients of different cultural backgrounds. The guide was developed and reviewed by experts and contains information on the cultural mores of various ethnic groups. The information is designed to help health care professionals better communicate with their patients, which can result in more accurate medical assessments and care. The guide is available through the Intercultural Cancer Council at *www.iccnetwork.org*.

Objective A - Enhance Health Care Professionals' Knowledge, Skills, And Practices Regarding Cancer Prevention, Early Detection, Treatment, Support Services, And Survivorship

Strategy 1: Encourage the inclusion of cancer prevention, early detection, and cultural competency skill development in academic programs for health care professionals.

Action Steps:

a. Assess current programs to determine if cancer prevention and control principles, techniques, and skills are appropriately included in the curriculum.

b. Identify new programs and make recommendations for curriculum enhancements.

c. Encourage and facilitate Texas universities to support central coordination and inclusion of cancer education within and among health care professional education disciplines.

d. Advocate for the development and adoption of content standards for comprehensive cancer curricula.

e. Support the development and implementation of innovative curriculum approaches to cancer education with competency-based objectives for health care professionals.

Strategy 2: Support the development and the dissemination of continuing education programs for health care professionals.

Action Steps:

a. Continue statewide collaborative programs to address the cancer prevention and control education needs of health care professionals.

b. Maintain and publicize inventories of continuing education programs on cancer prevention and early detection that are available.

c. Stimulate the development and use of innovative approaches to cancer education, such as the Internet, teleconferencing, and interactive educational software.

d. Provide continuing education and skill development on tobacco use prevention and cessation, with particular focus on preventing youth initiation.

e. Ensure that educational materials on genetic counseling and testing and other emerging issues are available.

f. Encourage and support development of continuing education modules to increase cultural competency skills.

g. Provide health care professionals with continuing education and training on survivorship to ensure their awareness and knowledge of survivorship issues.

Strategy 3: Encourage health care professionals to routinely offer cancer prevention and early detection services to patients and families during health care visits.

Action Steps:

a. Assess the factors that enhance or inhibit health care professionals' participation in cancer prevention, screening, and diagnostic training programs.

b. Promote the availability of patient education materials on cancer screening and encourage their use by all health care professionals tailored to their patient population.

c. Support programs that encourage health care professionals to obtain additional training in cancer prevention, screening, and diagnostic techniques, especially those who provide services to low-income and medically underserved populations.

d. Encourage health care professionals to utilize the knowledge and skills related to cancer genetic issues, including testing, counseling, and referrals.

e. Advocate for appropriate professional reimbursement for prevention services.

Strategy 4: Encourage health care professionals to implement organizational changes that promote best practices leading to routine offering of cancer prevention and early detection services.

Action Steps:

a. Encourage the assessment, development, and evaluation of programs to enhance cultural competency of health care professionals.

b. Educate health care professionals through multiple channels about the availability of support services, including personnel to help patients navigate the health care system.

c. Advocate for the use of standardized guidelines for screening, diagnosis, and treatment that improve the consistency and quality of cancer care for Texans.

d. Support the development of efficient office systems/ practices to promote best practices, especially for rural areas and other medically underserved populations.

Strategy 5: Enhance health care professionals' knowledge of and referrals to clinical trials.

Action Steps:

a. Identify and promote educational resources currently available on clinical trials.

b. Enhance statewide communication systems to provide information on available clinical trials.

c. Develop resources to assist health care professionals in recommending clinical trials.

d. Provide educational programs on the benefits of cancer clinical trials.

e. Identify and address clinician barriers to clinical trial referral.

f. Support the creation of continuing education resources on clinical trials, including ethical and cultural issues.

g. Encourage researchers and trial sponsors to seek funding for costs associated with clinical trial participation, especially for the underserved.

Objective B - Address Health Care Professional Workforce Issues To Adequately Serve All Texans' Cancer Health Needs

Health Care Workforce Needs

The second fastest growing state in population in the United States, Texas is challenged to meet its health care work-force needs for future generations, according to the 1994-2004 Texas State Health Plan. This plan, with its two biennial updates (2001-2002 and 2003-2004), focuses on the integration of planning, education, and regulation of the Texas health care workforce to ensure quality health care for all Texans. According to the latest update to the plan, Texas is becoming a state where the average age of health care professionals and educators is increasing; where minimally paid and trained health care workers are replacing higher paid and trained workers as a cost-savings measure; where the population is headed toward a predominantly young Hispanic *cohort* and an elderly Anglo cohort; and, where the percentage of uninsured continues to be one of the highest in the nation.[54] As such, the plan warns that the challenges of training, recruiting, and retaining health care workers in this type of environment are substantial. The challenges of training, recruiting, and retaining health care workers to care for the senior "boomers" after 2011 may be overwhelming, and it is in the aged that most cancer develops.

Correcting impending shortages of health care workers begins with the recognition that a problem exists, and the collection of good workforce information is the foundation for that awareness, according to the 2003-2004 plan update. Not only does the information need to be collected with workforce analysis in mind, but it also needs to be collected with the intent to share this information with health care analysts, planners, and legislators. The complexities and interdependent nature of today's health care system and health care workforce make it more important than ever, according to the report, to understand how the educational pipeline works and to determine what best motivates health professionals to excel in their jobs. It is important to describe how supply levels, compensation rates, employee turnover, and other factors affect recruitment, retention, and quality of the workforce.[55]

Correcting impending shortages of health care workers begins with the recognition that a problem exists.

Current data indicate a turnover rate in health care staffing at 20.7 percent for all positions, which can cost a single hospital an average of $5.5 million a year, according to a 2002 report from the Veterans Health Administration. Among the critical shortages in health care professions are a number who work in cancer diagnosis and treatment: nurses, pharmacists, medical technologists, cytotechnologists, radiographers, ultrasonographers, nuclear medicine technologists, and radiation therapists.[56] Federal legislation was passed in 2002 that began to address the crisis in nursing by offering scholarship and loan repayment programs, and Texas was one of the first states to address the nursing shortage from a legislative perspective, by passage of the Nursing Shortage Reduction Act of 2001, which focused on bolstering the nursing education pipeline.[57] The shortage of nurses is likely to remain for at least the next decade, and one of the reasons is the shortage of nursing school faculty.[58] Apart from nursing, Congress has not yet addressed critical shortages in other health care fields.

Diversification of the Workforce

As the population of the state and nation becomes more diverse, the supply of medical professionals should follow suit. Dr. Louis Sullivan, former U.S. Secretary of Health and Human Services, has created the Sullivan Commission on Diversity in the Health Workforce to investigate the number of ethnic minority health care providers as part of a way to address health disparities. The work of the Commission comes at a time when enrollment of racial and ethnic minorities in nursing, medicine, and dentistry has stagnated despite America's growing diversity. While African-Americans, Hispanics, and American Indians, as a group, constitute nearly 25 percent of the U.S. population, these three groups account for less than 9 percent of nurses, 6 percent of physicians, and only 5 percent of dentists. A study by the Institute of Medicine (IOM) recommends increasing the

Increasing the number of minority health care professionals is a key strategy to eliminating health disparities.

number of minority health professionals as a key strategy to eliminate health disparities. Examining the education and training environment in which health professionals learn and develop is critical to efforts to increase the number of health care providers who can, and will, address the health care needs of our nation. In 2003, the Institute of Medicine warned of the "unequal treatment" minorities face when encountering the health system. The data in that report are compelling and alarming. Cultural differences and a lack of access to health care, combined with high rates of poverty and unemployment, contribute to the substantial ethnic and racial disparities in health status and health outcomes. Health services research has shown that minority health professionals are more likely to serve minority and medically underserved populations. Despite this fact, there is a severe underrepresentation of minorities in our health professions. The IOM recommends increasing the number of minority health professionals as a key strategy to eliminating health disparities.[59]

Role of Other Health Care Professionals

More than half of Texas's 254 counties are designated as primary care Health Professional Shortage Areas, which are areas with fewer than one primary care physician per 3,500 in population.[60] These counties have too few primary care physicians to provide adequate cancer education, prevention, or screening services. Without access to primary care, Texans delay or refrain from routine health care and cancer screenings. Consequently, they ultimately may be diagnosed with an advanced stage of cancer.[61] As a result of unattended health problems, they turn in crisis to more expensive specialists and treatment centers and face increased chances of dying from cancer. Nurse practitioners and physician assistants play an important role in providing primary care in these Health Professional Shortage Areas. To date, minimal attention has been given to the cancer prevention and control knowledge, skills, practices, or continuing education needs of these health care professionals that would be essential in preparing them to serve a key role in addressing the state's health professional workforce issues.

The Texas Cancer Council funds Female Cancer Screening Education for Nurses in Rural or Medically Underserved Areas of Texas, a program at The University of Texas M. D. Anderson Cancer Center that provides workshops to teach nurses to do clinical breast exams. This provides an example of how nontraditional providers of clinical services can be trained to help meet the capacity needs of the health care workforce.

Palliative Care & Support Services

It has been estimated that one out of every three patients receiving treatment for *metastatic cancer* has significant disease-related pain, and this percentage increases to as much as nine out of 10 in patients with advanced disease.[62] Other experts estimate that 25 percent of all cancer patients who die do so without adequate pain relief, despite the fact that the tools for adequate pain control are available.[63] Despite technological advances in treating cancer pain, Texans continue to suffer needlessly. To reduce the prevalence of cancer pain, numerous innovative educational programs have been developed for health care professionals, and among them is a partnership between the Texas Cancer Pain Initiative and the Texas Cancer Council to publish *Guidelines for Treatment of Pain in Cancer Patients*. Also, the CATCHUM consortium of Texas medical schools is supporting collaborative activities to enhance pain education within Texas medical schools.

Legislative and regulatory initiatives have reduced some of the reluctance of Texas physicians to prescribe narcotics for cancer pain. The Intractable Pain Treatment Act of 1997 permits physicians to prescribe narcotics to patients with acute or chronic pain who have had a history of substance abuse. The Texas State Board of Medical Examiners also has adopted rules that serve as practice guidelines.

Other services are needed that assist patients and their families with the emotional, physical, and practical problems that may result from the diagnosis and treatment of cancer.[64] Among them are daily home care, transportation assistance, and financial aid. Referrals to social service agencies, counseling, and support groups provide crucial emotional support and resources for patients and their families. Patients also may need legal assistance if they face employment discrimination or require help with wills and power of attorney documents. Health care professionals need to take an active role in securing support services for patients.

Hospice care seeks to provide comfort to patients with limited life expectancy. Services can be provided in a patient's home, a hospital, or a freestanding hospice facility. Hospice services range from symptoms management for patients to respite care and bereavement counseling for family members. Health care professionals need to become informed about hospice care and when hospice referrals are appropriate. Health care professionals need training in how best to assist patients and family members to make decisions about hospice care, and how to provide *palliative care*, and must acquire competency in assisting patients in the dying process.

Objective B - Address Health Care Professional Workforce Issues To Adequately Serve All Texans' Cancer Health Needs

Strategy 1: Collaborate with State Healthcare Coordinating Council to assess current capacity of health care professions to identify gaps and address needs.

Action Steps:

a. Assess geographic distribution of cancer health care workforce.

b. Address premature loss of trained health care professionals from the workforce.

c. Support recruitment and retention of minorities into health care professions.

Strategy 2: Promote policies to address Texas cancer workforce needs.

Action Steps:

a. Assess impact of health care professional shortage on cancer care delivery.

b. Encourage allied health schools to include cancer registrar training into curriculum.

GOAL IV: CANCER DATA ACQUISITION & UTILIZATION

Texans will have comprehensive and responsive cancer data and information systems that will be used for planning, implementing, and evaluating programs, policies, and cancer research.

Objective A - Enhance Existing Cancer Data Systems To Fully Support The Needs Of Texas Health Care Professionals, Policymakers, Planners, Researchers, And The General Public

Benefits of Cancer Data Systems

If methods of collecting timely information about diagnosis and treatment of cancer did not exist, we would not know that more than 1.3[1] million new cases of cancer are projected for 2004 in the United States, and that more than 550,000 Americans will die of the disease, more than 1,500 a day.[2] Gathering such facts in Texas lets us know that in 2004, an estimated 85,000 Texans will be diagnosed with cancer, and another 37,000 will die from the disease.

Cancer data systems collect and disseminate a wide variety of information about who is being diagnosed or dying from the disease, screening rates, survivorship, and even the economic and emotional toll cancer takes on the lives of Texas citizens. These data enable physicians, public health experts, researchers, and policymakers to better understand and address the cancer burden in the state. Cancer data are critical for planning, targeting, and evaluating programs focused on preventable and/or highly screenable cancers, as well as risk-related behaviors, such as tobacco use and sun exposure. Cancer data systems also assist in the planning, implementation, and evaluation of programs that address health disparities for higher-risk, medically underserved Texans.

Cancer Surveillance

Cancer surveillance is the key to addressing and ultimately eradicating the cancer burden, according to the National Cancer Institute (NCI), National Institutes for Health (NIH), National Program for Cancer

Cancer surveillance data are the key to addressing and ultimately eradicating the cancer burden.

Registries (NPCR), Centers for Disease Control (CDC), National Center for Health Statistics - CDC (NCHS-CDC), American Cancer Society, and "C-Change Collaborating to Conquer Cancer" (formerly the National Dialogue on Cancer). Core functions of cancer surveillance include the measurement of cancer incidence, morbidity, survival, and mortality for persons with cancer. Cancer surveillance data are essential and form the basis for:

- Identifying populations at increased cancer risk for cancer control interventions
- Describing and monitoring cancer trends so that appropriate and timely interventions can be made
- Conducting and advancing research related to the etiology, prevention, and treatment of cancer
- Planning and evaluating cancer control and educational programs
- Planning health care delivery systems
- Investigating public concerns about suspected high numbers of cancer diagnosis

All these uses of cancer surveillance data are dependent on a timely, complete, and high-quality population-based state cancer registry, as well as a national cancer surveillance system that covers the whole country. The advent of the North American Association for Central Cancer Registries[3] and NPCR - CDC has made this possibility more real.[4] However, not all state population-based cancer registry data have been able to meet or maintain the high data quality standards required for certification and inclusion in this national cancer surveillance system. The Texas Cancer Registry (TCR) is one such population-based state registry.

Texas Cancer Registry

The Texas Cancer Registry (TCR), part of the Texas Department of State Health Services, is legislatively mandated to maintain a central data bank of accurate, precise, and current information to serve as an invaluable tool in

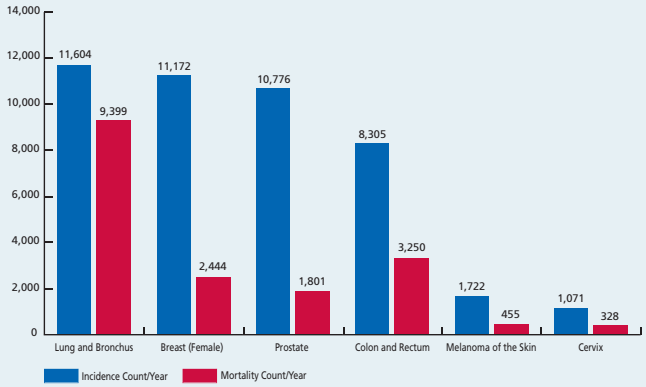
the early recognition, prevention, cure, and control of cancer. The Texas Cancer Incidence Reporting Act, which was amended in 2001, requires the reporting of cancer case information by health care facilities, clinical laboratories, and health care practitioners. The Texas Cancer Reporting Rules, adopted in 2003, specify the "Who, What, How, When and Where" for the reporting of cancer incidence data. Instructional manuals, training, technical assistance, and software are provided to assist health care professionals in cancer case reporting.

Approximately 200,000 case reports are received, coded, edited, and consolidated annually, resulting in more than 100,000 new cancer cases added to the Registry. These data are analyzed and disseminated to individuals at the national, state, and local levels for cancer research, prevention, and control.

The TCR has made improvements in the receipt and processing of cancer reports and in other registry operations. This has resulted in improvement in data timeliness, with data now being available for use within three years of diagnosis (rather than 4-5 years). These data are being used for various epidemiologic studies and cancer control activities across the state. However, TCR data still do not meet national gold standards for the completeness and timeliness of cancer data at the time of evaluation. Challenges continue in securing reports from the increased number of outpatient care sources, obtaining timely receipt of cancer reports, and eliminating ongoing record processing backlogs. Resource limitations within the Registry have contributed to Texas' not achieving national gold certification.

The TCR's inability to provide cancer data that meet national completeness and timeliness standards at the time of evaluation has significant public health ramifications at national, state, and local community levels. Texas data are not included in most national cancer incidence publications and the most current national data sets provided to researchers, public health professionals, policymakers, advocates, and local communities. Because of the uniqueness and size of the Texas population (more than 7 percent of the U.S. population) and geography, as long as TCR data are not meeting national standards, health disparities related to rural, poor, and certain minority populations (particularly Hispanics) cannot be adequately represented or addressed in public health, cancer research, prevention, or control efforts. In addition, the investigations of suspected cancer clusters, particularly those related to environmental concerns, are severely hampered by the lack of timely data.

Figure 1. Average Annual Incidence (New Cases) and Mortality (Deaths) Counts for Selected Cancers, Texas, 1997-2001



Notes: Average annual cases and deaths are rounded to the nearest whole. Melanoma cases are under-reported.
Source: Texas Cancer Registry, 1995-2001 incidence file as of 12/02/2003 and Bureau of Vital Statistics, Texas Department of State Health Services.

A true state and national model of comprehensive cancer control or cancer surveillance also is not attainable without Texas achieving and maintaining national data standards for its cancer registry. In addition, researchers at Texas health institutions are seriously disadvantaged in competing for NIH and other research grants, largely due to data deficiencies.[4]

Groups such as the Cancer Data Work Group, Texas Comprehensive Cancer Control Coalition, and Texas Health Science Centers are working together to advise and assist the TCR in meeting national data standards and achieving gold certification. However, sufficient resources are still needed that can allow the Registry not only to attain but also to maintain the highest quality cancer incidence data for the people of Texas and the nation.

As long as TCR data are not meeting national standards, health disparities related to rural, poor, and certain minority populations cannot be adequately represented or addressed in public health, cancer research, prevention, or control efforts.

Data Gaps on Racial & Ethnic Minorities

Although it is critically important, standardized data collection on racial and ethnic differences in cancer and other health care is generally unavailable, according to a March 2002 Institute of Medicine (IOM) report on health disparities. Federal, private, and state-supported data collection efforts are scattered and unsystematic, and most health care plans do not collect data on enrollees' race, ethnicity, or even primary language, which illustrates the significant obstacles that must be overcome to collect and analyze such data, according to the IOM. Furthermore, a number of ethical, logistical, and fiscal concerns present challenges to data collection and monitoring, including the need to protect patient privacy, the costs of data collection, and resistance from health care professionals, institutions, plans, and patients. In addition, there are significant concerns about how such data will be analyzed and reported, as well as who will be responsible for collecting the information. Efforts from the federal level to enforce data collection may, for example, meet resistance from state authorities, who retain primary responsibility for determining data requirements of health plans with whom states contract for Medicaid services. Federal efforts to require the collection of patients' racial and ethnic data also may raise challenges from those who find federal reporting requirements already burdensome and the federal role in dictating the terms of managed care contracts too extensive, according to the IOM report.

Federal law allows for collection of such data and a growing number of federal policies emphasize the need for such information because it is an indispensable tool for the assessment of progress toward federal goals of eliminating health disparities. For example, new federal standards for racial and ethnic data specify reporting data for a minimum of five categories of race (American Indian or Alaska Native, Asian, black or African-American, Native Hawaiian or other Pacific Islander, and white) and two categories of ethnicity (Hispanic or Latino and non-Hispanic or Latino).[5]

Some federal systems designed to collect such information have made progress, but are still riddled with complexities and complications. For example, NCI's Surveillance, Epidemiology, and End Results (SEER) program, one of the best cancer-related data systems in the country, is used to oversample racial and ethnic minorities and is making strides in reporting cancer data and statistics for racial and ethnic minorities, but it is plagued with issues related to population representation and small sample sizes.[6] Among the recommendations of the joint report on Improving the Collection and Use of Racial and Ethnic Data in HHS are that the NCI should explore the feasibility of expanding the SEER program and/or forming alliances with the state-based cancer registries to produce national cancer incidence rates for the minimum racial and ethnic categories and to allow the system to produce rates for ethnic subgroups.

Other Texas Health Information Services

Texas is a national leader in providing cancer mortality and resource information free of charge to the public through computerized databases that are available on the Internet. They are covered in the following sections.

Texas Cancer Data Center

The Texas Cancer Data Center (TCDC), created in 1986, is a project of the Texas Cancer Council and The University of Texas M. D. Anderson Cancer Center. Its mission is to empower Texans with the knowledge needed to reduce the human and economic impact of cancer by providing comprehensive and consolidated information on cancer resources, services, and statistics in Texas. The TCDC collects and maintains data regarding physicians, hospitals, freestanding cancer centers, mammography facilities, colorectal cancer screening services, home health agencies, hospices, tumor registrars, and community resources, as well as demographic and statistical information related to cancer in Texas. It collects information via direct surveys of health professionals and facilities and through other sources, including the Texas Department of State Health Services, the American College of Radiology, the State Board of Medical Examiners, and the American Cancer Society, Texas Division. Databases can be accessed at *www.txcancer.org*.

Center for Health Statistics

Additionally, in 1984, the CDC also established the Behavioral Risk Factor Surveillance System (BRFSS). Scientific research clearly showed that personal health behaviors played a major role in premature morbidity and mortality. As a result, surveys were developed and conducted to monitor state-level prevalence of the major behavioral risks among adults with the basic philosophy to collect data on actual behaviors, rather than on

attitudes or knowledge, that would be especially useful for planning, initiating, supporting, and evaluating health promotion and disease prevention programs, BRFSS data can be found at *www.cdc.gov/brfss/*.

The Texas Health Care Information Council (THCIC) was created by the Texas legislature in 1995, and in 2004, joined the newly formed Department of State Health Services.[7] THCIC's primary purpose is to provide data that will enable Texas consumers and health plan purchasers to make informed health care decisions. THCIC's charge is to collect data and report on the quality performance of health maintenance organizations operating in Texas and state hospitals. The goal is to provide information that will enable consumers to have an impact on the cost and quality of health care in Texas. The THCIC collects information from health maintenance organizations (HMOs) about patient satisfaction and quality of care, and the data it collects from hospitals range from patient diagnoses to charges for various procedures. THCIC then releases data from more than 400 hospitals each quarter. It also reports on the top 25 diagnoses statewide, which includes cancer treatment information. Each year, THCIC prepares annual reports that examine the utilization of inpatient procedures in 24 Texas regions, as well as an assessment of the performance of Texas hospitals.[8]

The American Cancer Society - Texas Division produces *The Texas Cancer Facts and Figures: A Sourcebook for Planning and Implementing Programs for Cancer Prevention and Control*. Cancer incidence and mortality for leading cancer sites by age, gender, and race/ethnicity can be found in an easy-to-read format for use by cancer stakeholders, policymakers, health care professionals, and the general public.

Objective A - Enhance Existing Cancer Data Systems To Fully Support The Needs Of Texas Health Care Professionals, Policymakers, Planners, Researchers, And The General Public

Strategy 1: Enhance awareness of the value of cancer data.

Action Steps:

a. Assess awareness of locally available cancer data resources by the public, patients, and health care professionals.

b. Assess data and information needs for implementing the *Plan* goals.

c. Encourage collaboration among data providers to better promote the available data and services.

d. Promote the importance of collaboration in data collection.

e. Promote the value of accurate and timely cancer data collection and reporting.

f. Increase awareness of cancer data sources.

g. Support and promote sources of cancer data and information regarding cancer-related health care professionals, services, and facilities and the utilization of data from these sources to address issues regarding access to care.

h. Educate legislators and policymakers on the importance of accurate and timely cancer data collection and how it may be used to address cancer health disparities.

i. Support the development of resources that aid the dissemination of cancer data and information to target audiences.

Strategy 2: Identify and address gaps in Texas cancer data.

Action Steps:

a. Encourage facilities and cancer service providers to report information regarding their services in publicly available statewide resource databases.

b. Promote data sharing and collaboration among research investigators.

c. Promote the collection of data on survivorship.

d. Promote improved reporting by local cancer registries to the Texas Cancer Registry.

e. Promote improved reporting of cancer data in underserved areas.

f. Promote the collection of more detailed BRFSS data.

g. Increase the collection of cancer and baseline data for priority populations.

Strategy 3: Promote policies that enhance the acquisition of timely, quality data.

Action Steps:

a. Promote the collection of more detailed data by region regarding race/ethnicity, disability, age, acculturation, and socioeconomic status.

b. Encourage the provision of adequate information technology resources and the infrastructure to support statewide data collection and reporting.

c. Support technical assistance and training for facilities and health care professionals to increase complete and timely reporting of cancer data.

d. Ensure that issues related to cancer data collection and reporting are considered in the adoption of electronic medical records in Texas.

e. Utilize feedback from health care facilities and professionals to improve cancer data reporting and utilization.

f. Advocate for linkage of cancer data to the state high-tech initiative.

g. Encourage the training of an adequate number of Certified Tumor Registries and other cancer reporters.

h. Support collaborative efforts to achieve the North American Association of Central Cancer Registrars (NAACCR) Gold Certification Standard of the Texas Cancer Registry.

Strategy 4: Promote support for adequate funding of Texas cancer data systems.

Action Steps:

a. Collaborate with professional societies and other health advocacy groups and stakeholders to support funding initiatives.

b. Involve and collaborate with research institutions for support, funding, and resources for cancer registry.

c. Evaluate the feasibility of obtaining research grant money to support cancer data systems.

d. Advocate for the adequate funding of a cancer registrar in each Texas public health region to help assure accurate and timely data collection.

e. Develop a communication plan related to funding issues.

Objective B - Utilize Quality Data To Support Outcome-driven Cancer Control Planning And Evaluation

Collaborative Data & Planning

There is much effort underway nationally to improve the cancer data collection effort in order to achieve a comprehensive, responsive cancer information system that can be used for planning, implementing, and evaluating programs, policies, and cancer research. Data providers must be encouraged to collaborate and share information and work to refine existing systems. Utilization of data from these sources can address a number of special issues, such as cancer health disparities and survivorship.

The American Cancer Society, for example, has created a strategic cancer control planning model that merges theory and data to help make cancer control decisions. This systematic planning process, underway since 1999, is a cooperative effort, involving every branch of the ACS, from community and state levels to each of ACS's divisions and its national organization. ACS has set long-term objectives for 2015 that are focused on decreasing

Cancer offers a wonderful opportunity to do evidence-based public health.

cancer incidence and mortality in the United States and improving quality of life for cancer patients and families. To support these goals, a nationwide program of work, outlining specific program activities, has been developed for all divisions to follow in their action planning. The divisions are developing intermediate and short-term outcomes to measure program progress, and these outcomes reflect specific state objectives and capacities that are identified through comprehensive community needs assessments. Cancer incidence, behavior, and population data then are used to calculate necessary levels of programmatic resources at state and local levels to achieve division outcomes.[9]

Through the NPCR, the CDC also is trying to address the issue of collaboration, from community to state and national levels. A 2002 meeting entitled Data for Cancer Control Planning and Evaluation: Partners' Meeting was held to bring together state and national experts with experience in cancer surveillance and control to discuss challenges and opportunities in using and disseminating data related to cancer prevention and control in the United States.[10] Among their recommendations were:

- Recognize that many different types of data content are needed for planning and evaluating cancer prevention and control programs.
- Recognize that there are a wide variety of potential users of the data, and they have different skill levels and different information needs. Provide data formats and presentations that respond to their specific needs, cultural perspectives, and data literacy levels.
- Provide data for planning and evaluating cancer control programs in an accessible, easy-to-use format for most users.
- Balance the need for timely data with the need for data of high quality.
- Balance the need for local area data with the need for stable, valid information and protect patient confidentiality.
- Do not reinvent the wheel; build on "lessons learned" by the small number of state health departments and national organizations that have cancer control plans involving effective public-private partnerships in place.
- Develop a cancer control plan for the nation. The plan should focus on changing the behaviors (individual and societal) that lead to excess morbidity and death from cancer.
- Assure the availability of uniform, high-quality data on stage of disease at diagnosis and cancer survival; these data are especially important for evaluating cancer screening programs.

Cancer offers a wonderful opportunity to do evidence-based public health, where policies are not implemented unless there is good science behind them, according to the CDC's National Comprehensive Cancer Control Program.[11] Accurate and complete data and solid research form the underpinnings for comprehensive cancer control. They help planners to understand the extent of the cancer burden and the existing infrastructure to address that burden. Data and research help ensure that politically popular strategies also are sound. They help planners to assess the social and policy environments to decide whether or not to move forward with scientifically valid approaches to cancer control.[12]

An example of how collaboration between states and federal cancer registries works well is the National Cancer Institute's State Cancer Profiles (*www.statecancerprofiles.cancer.gov*), which offers dynamic views of cancer statistics for prioritizing cancer control efforts in the nation, in states, and in counties. The site brings together data that are collected from public health surveillance systems by using either their published reports or public use files and then compares cancer rate changes between a county of a state and the entire state or between a state and the United States. These comparisons present findings in such a way that the viewer can see quickly, in every county in a state, if the trends are rising, falling, or remaining stable and how they compare to the selected comparison rates. Cancers that need more attention — those that have rising rates that are higher than the rate used for comparison — are highlighted, as are cancers that are doing the best — those that have falling rates that are lower than the rate used for comparison. The site also provides historical view of 25-year trends, 5-year rate changes in mortality, and a comparison of current death rates nationally, statewide, and in every county in the state.[13]

The target audiences are health planners, policy-makers, and cancer information providers who need

quick and easy access to descriptive cancer statistics in order to prioritize investments in cancer control. The focus is on cancer sites for which there are evidence-based control interventions, and the overall objective of State Cancer Profiles is broad to motivate action, integrate surveillance into cancer control planning, characterize areas and demographic groups, and expose health disparities.[14]

Meeting the Changing Health Care Needs of Texans

The *Texas Cancer Plan* is a document that people can reference in order to understand cancer prevention and control resources, priorities, and needs within Texas. The ever-changing field of cancer prevention and control dictates that periodic updates are required to keep Texas cancer control planners abreast of the latest data, research, best practices, and public policies. The document should, therefore, receive periodic review by individuals involved in cancer prevention and control programs and policy development, such as health care professionals, policymakers, health services planners, researchers, and cancer survivors. Future editions of the *Texas Cancer Plan* should incorporate feedback from *Plan* users and should continue to be the collaborative effort of cancer control stakeholders statewide.

Objective B - Utilize Quality Data To Support Outcome-driven Cancer Control Planning And Evaluation

Strategy 1: Educate cancer control stakeholders on the appropriate use of cancer data.

Action Steps:

a. Support the development and implementation of a communications plan to heighten awareness of available data.

b. Promote the development of educational resources for communities, including community-level instruction on collecting and using data.

c. Educate cancer control stakeholders on how to use data to address cancer health disparities.

Strategy 2: Promote use of cancer data for program planning.

Action steps:

a. Encourage the acquisition and provision of targeted information to meet planning needs.

b. Support programs that ensure cancer data are accessible and easy to understand and use.

c. Promote data sharing and collaboration by cancer control planners.

d. Provide data based on geopolitical boundaries for cancer control decision-making.

e. Promote awareness of data sources to grant writers and researchers.

f. Use cancer data to assess the state's progress in implementation of the *Plan*.

g. Encourage the use of measurable objectives at the regional and community levels.

h. Promote the use of Web-based data resources and provide training for their utilization.

Strategy 3: Ensure that the Texas Cancer Plan is responsive to the changing health care needs of Texans.

Action Steps:

a. Conduct ongoing reviews of the *Texas Cancer Plan* so that it continues to be a timely and comprehensive document.

b. Continue to encourage feedback from health care professionals, policymakers, planners, researchers, and the general public so that subsequent editions of the *Texas Cancer Plan* meet the needs of Texans.

c. Ensure that the *Texas Cancer Plan* is disseminated widely throughout the state and available on the Internet.

GOAL V: SURVIVORSHIP

The end of cancer treatment is not the end of the cancer experience.[1] A diagnosis of cancer is the beginning of the survivorship journey. All Texans will have an awareness and understanding of the issues and impacts of survivorship in our state.

Objective A - Increase Knowledge Of Survivorship Issues For The General Public, Cancer Survivors, Health Care Professionals, And Policymakers

Definition of *Cancer Survivor*

The definition of *cancer survivor* has evolved as knowledge and success in understanding cancer have increased. When cancer was considered incurable, the term "survivor" was used to describe family members who survived the loss of a loved one to cancer.[2] Then, physicians began to define "survivor" as someone who had survived five years following a diagnosis.

Today, due to the advocacy efforts of such organizations as the National Coalition for Cancer Survivorship (NCCS), the Lance Armstrong Foundation, and others, the term "cancer survivor" has been redefined. Many private and public organizations, including the Centers for Disease Control and Prevention (CDC), the American Cancer Society (ACS) and the National Cancer Institute (NCI), currently use the term "cancer survivor" to describe those who have been diagnosed with cancer and the people in their lives who are affected by the diagnosis, including family members, friends, and caregivers. This expanded definition acknowledges the complexity of cancer survivorship and the need for personal, familial, and extended resources.

The CDC, ACS, and NCI currently use the term "cancer survivor" to describe those who have been diagnosed with cancer and the people in their lives who are affected by the diagnosis, including family members, friends, and caregivers.

Sixty-four percent of adults whose cancer is diagnosed today can expect to be alive in five years, and one of every six people over 65 is a cancer survivor.

Importance of Survivorship Issues

Due to earlier detection and better treatments, cancer is becoming a *chronic disease* rather than an inevitably fatal one. The result of this progress is that the number of cancer survivors is increasing rapidly. While this is good news, there are still many challenges with which survivors must cope. Their lives are greatly impacted by the disease itself, its side effects and treatments, the process of dealing with a life-threatening illness, and the drain on physical, psychological, social, spiritual, and economic resources. These effects and issues can last or may occur years after treatment ends. According to recent data from NCI's Surveillance, *Epidemiology*, and End Results (SEER) program, 1.4 million survivors living today were diagnosed more than 20 years ago.

Defining a cancer survivor as anyone who has been diagnosed with cancer, from the time of diagnosis through the balance of his or her life, the President's Cancer Panel's Annual Report for 2003-2004 states that in 1971, there were only three million people with a cancer history still alive. That was 1.5 percent of the U.S. population.

In 2001, there were 9.8 million cancer survivors (3.5 percent of the population) in the United States, according to the CDC and NCI. The report also states that 64 percent of adults whose cancer is diagnosed today can expect to be alive in five years, and one of every six people over 65 is a cancer survivor. This number is expected to increase dramatically as our population ages. The President's Cancer Panel estimates that the number of cancer cases will double by 2050.

While the past 30 years have seen a steady increase in the number of cancer patients who survive the disease,[3] survival rates do vary according to the type of cancer. For example, the five-year survival rate for patients with the following cancers, no matter the stage of cancer at diagnosis, from 1992 to 1999, is:

female breast - 87 percent; colorectal - 62 percent; lung and bronchus -15 percent; prostate - 98 percent; and pancreas - 4 percent.[4]

This growing population of survivors, which ranges from children to adults, has created a burgeoning demand for:

- long-term follow-up health care
- psychological and social support services and programs
- public policies that ensure a survivor's rights to equal access to health care and employment
- consideration of cultural competency and linguistic appropriateness to ensure relevancy, understanding, and compliance with care recommendations

To address the impact of cancer survivorship, the National Cancer Institute established the Office of Cancer Survivorship (OCS) in 1996. The OCS mandate is to improve the quality of life and length of survival for people diagnosed with cancer, and to improve the health-related quality of life for family members of survivors. In addition, two important reports were released in 2004. The Centers for Disease Control and Prevention partnered with the Lance Armstrong Foundation to develop *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*, while the President's Cancer Panel, an initiative of NCI, published its 2003-2004 annual report, *Living Beyond Cancer: Finding a New Balance*. Developed to identify and prioritize cancer survivorship needs and strategies within the context of public health, intent of these reports is to ultimately improve the overall experience and quality of life of the millions of Americans who are living with, through, and beyond cancer.

The recent phenomenon of children surviving cancer is causing a host of new questions and policy issues related to:

- follow-up care of long-term and late effects of cancer and its treatments
- prevention and/or early detection of second cancers
- long-term cognitive, social, and psychological development
- sexuality and reproduction
- education
- economic, legal, and employment concerns
- health care and life insurance coverage
- transition from pediatric to adult health care

In addition to those issues faced by children surviving cancer, adults also must deal with:

- the possible loss of job and health benefits or forced early retirement
- comorbidities (other illnesses or health problems in addition to the cancer)
- lack of adequate social and/or caregiver support
- intimacy and body image issues

With long-term needs of cancer survivors — including caregivers and siblings of children with cancer — not being adequately met, there is a great need to increase the knowledge of the general public, cancer survivors, health care professionals, and policymakers concerning the five principal impacts of survivorship:

- physical
- psychological
- social
- spiritual
- economic

Each of these encompasses many complex issues of survivorship and are dealt with, in turn, on the following pages.

The five principal impacts of survivorship are: physical, psychological, social, spiritual, and economic.

Physical Impacts on Survivorship

Cancer and its treatment can present different symptoms to different people while treatments present their own set of side effects. Treatment effects are sometimes confused with the routine disease process, compounding patients' physical challenges. Patients must deal with such major physical issues as initial disease and treatment, recurrence of the original disease, development of secondary cancers, late or long-term effects of treatment, premature ageing, and organ/systems failure. There are also the rehabilitative challenges of an amputation, a colostomy, or a laryngectomy, extensive reconstructive surgery, or compromised cognitive functioning. Physical impacts also can affect caregivers, colleagues, family, and friends.

Men and women of reproductive age and parents of pediatric patients are often not informed of the risks associated with cancer treatment or the opportunities for preserving reproductive capacity.

In addition to loss of fertility, there are also long-term disease and treatment effects, such as decreased sexual functioning, early onset of menopause, and persistent lymphedema (swelling). These can result in a loss of mobility and change in bodily functions as well as change in appearance, including disfigurements from *radiation tattoos* and visible scars.

Physical symptoms, both chronic and acute, can persist for years after treatment ends. These can include pain, fatigue, weight loss, appetite changes, nausea and vomiting, shortness of breath, mental confusion, hair loss, and others depending on the cancer site. These varied symptoms call for proactive, tailored plans of pain and symptom management. A greater understanding among survivors and health care professionals of symptom management and the role of palliative care can help cancer survivors experiencing late effects, or those dealing with advanced, incurable disease, attain the maximum level of physical and mental functioning. Palliative care can provide relief from the physical and emotional distress of disease and its treatments.

Psychological Impacts on Survivorship

A diagnosis of cancer can throw a patient into a full range of emotions that extend from anger to helplessness. Many experience a loss of self-esteem and self-image that often is attached to body image and may make intimacy difficult to reestablish. These emotions may diminish with time. However, they do not necessarily disappear once treatment is over and the patient moves back into a more normal life.

Cancer and its treatment can cause stress and anxiety for the family and other caregivers. It may also provoke the fear that cancer runs in the family.

For childhood cancer survivors as distinct from adult survivors, there also may be psychological issues related to self-image, socialization, and transition back into the school/academic setting. These issues may require attention from parents, school personnel, and health care professionals for years after treatment ends. Siblings of childhood cancer patients and children of adult cancer patients also experience a major change in family lifestyle when a family member requires treatment. It is just as important to provide support, encouragement, communication, and, when needed, psychological care to the siblings.

While many survivors experience fear, stress, depression, anger, and anxiety, many also find a renewed meaning to their lives. They strive for stronger personal relationships and commit to "give back" to others. This is a valuable phenomenon among the cancer survivorship community.

Social Impacts on Survivorship

The social life of cancer survivors is also impacted. These impacts are closely tied to the psychological issues addressed above. There is often a decreased sense of social well-being as cancer survivors attempt to reintegrate into their previous lives socially and professionally. This may be due to such limitations as time, health, diminished self-image, and a perception of social stigma. Childhood survivors may have social development issues re-entering the classroom or may have special learning needs resulting from the disease or its treatment. Cultural factors among the diverse ethnic and racial populations in Texas, including beliefs, values, and traditions, may play a significant role in the social reintegration of cancer survivors into their respective communities.

For survivors, difficulties can arise at school, on the job, in social settings, and in the many daily tasks that need to be accomplished. Often the energy to interact in a social situation has been sapped by the physical fatigue caused by cancer and its treatments.

Spiritual Impacts on Survivorship

Surviving cancer affects the soul as well as the body. The spiritual impacts of survivorship may vary among cultural and racial/ethnic groups. While many gain strength and support from their faith, others feel their faith being tested; still others are filled with anger. They may wrestle with the question, "Why me?" or see cancer as a punishment. Surviving also can cause guilt. In these cases, patients ask, "Why am I the one to survive?" or "What is the meaning of my life now?"

Research in this area is more prevalent as cancer patients seek a more holistic approach to treating and managing their disease. More than 200 studies in the United States have investigated the relationship between health and spirituality, a construct involving "faith" and/or "meaning" that can exist both within and outside of an organized religious framework.[5] Although studies continue, no single answer applies to every patient, leading to the suggestion that each survivor should explore and discover his or her individual "faith" or "meaning."

Surviving cancer calls for a reevaluation of life and often a reprioritizing of goals and ambition, a redefinition of "normal." Living with uncertainty, coping with the fear of recurrence and death, often enables survivors to reassess personal, educational, career, and social values. As a result, many find a new purpose and meaning in their lives.

Economic Impacts on Survivorship

Many patients leave cancer treatment with heavy debt. The cost of initial and continued care can become a financial burden for survivors, especially when coupled with the possible loss of employment — total or part-time — by patient and/or caregiver.

Some cancer survivors are forced into early retirement or lose their jobs during treatment. This leaves them without health insurance and often makes it difficult for them to find another job that will provide health, disability, and life insurance, when they try to reenter the work force. If cancer survivors willingly change jobs, they are often unable to qualify for health insurance or obtain a life insurance policy due to past health history. Childhood survivors also can face reduced job opportunities due to physical or cognitive disabilities. End-of-life-care costs can be a heavy drain on family resources, especially if a caregiver must give up a job to care for a patient.

For those who consider genetic testing to assess the familial impact of a cancer related to heredity, there is the fear of future uninsurability if test results confirm a genetic link. For this, and other reasons, it is important for any genetic testing to be accompanied by genetic counseling.

Stages of Survivorship

Fitzhugh Mullan, MD, a physician with cancer, was the first to discuss the cancer journey as occurring in stages.[6] He defined three stages that are experienced both by the patient and family members affected by the diagnosis.

- *Acute survival* includes from the time of diagnosis through the end of treatment. He described this stage as accompanied by fear, anxiety, and pain.
- *Extended survival* begins when treatment is completed or the patient enters remission. Psychologically, the patient must then deal with fear of recurrence and, physically, with continued limitations as a result of the illness and treatment. Survivors may be learning also to deal with chronic (long-term) side effects.
- *Permanent survival* is defined as a time when the "activity of the disease or likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested." A person at this stage may still experience aspects of the five impacts: physical, psychological, social, spiritual, and economic.

While some experts see end-of-life as a fourth stage, death actually could occur during any of these three stages. In the 21st century, end-of-life care can be purposely provided to affirm life and accept dying as a normal process. The goal of end-of-life care is to achieve the best possible quality of life for cancer survivors by managing pain and other symptoms while providing relief from distress and integrating psychological and spiritual needs.[7] Many families today are seeking information and support to enable them and their patients to "go gentle into that good night."[8] However, it is important to be culturally sensitive to how hospice care is perceived by different ethnic and racial groups.

The Lance Armstrong Foundation defines the experience of cancer survivorship as living "with," "through," and "beyond" cancer.

Expanding the concepts of Mullan, the Lance Armstrong Foundation defines the experience of cancer survivorship as living "with," "through," and "beyond" cancer.

- Living "with" cancer refers to the experience of receiving a cancer diagnosis and any treatment that may follow.
- Living "through" cancer refers to the extended state following treatment.
- Living "beyond" cancer refers to posttreatment and long-term survivorship.

Although this definition is designed to signify the experience of survivorship as a progression, this process is unique for each survivor, and movement from one phase to the next may not be clearly delineated.[9]

Objective A - Increase Knowledge Of Survivorship Issues For The General Public, Cancer Survivors, Health Care Professionals, And Policymakers

Strategy 1: Develop educational resources about cancer survivorship for survivors, the general public, health care professionals, and policy-makers.

Action Steps:

a. Promote patients' and caregivers' right to know about treatment plans and options.

b. Promote the concept of survivorship as a chronic condition in conjunction with awareness of increasing survival rates.

c. Assess the current availability of educational resources and address gaps.

d. Assist organizations in developing culturally competent and linguistically appropriate materials.

e. Develop resources to assist survivors in assessing survivorship information relevant to all stages of survivorship.

f. Identify and assess the issues that cancer survivors in Texas face.

g. Develop educational tools to help survivors communicate their needs and expectations effectively, including pain and symptom management and advance care planning.

h. Support the development of resources that consider the differences among survivors of different cancers, at different stages, of different racial and ethnic groups.

Strategy 2: Enhance and disseminate educational materials and programs on survivorship to promote knowledge and understanding of survivorship issues.

Action Steps:

a. Ensure that utilized materials are culturally competent and linguistically appropriate.

b. Identify mechanisms and experts to reach diverse audiences with culturally and medium-appropriate survivorship messages, with particular focus on accessing hard-to-reach populations.

c. Develop a user-friendly Web-based survivorship database with links to valuable educational resources.

d. Provide a speaker's bureau of experts in survivorship care to address all audiences.

e. Identify funding sources to implement successful quality-of-life and end-of-life communication campaigns or programs based on the best practices and/or best available evidence.

f. Encourage increased research on quality-of-life and end-of-life issues for underserved communities.

Strategy 3: Provide professional education and training on survivorship to ensure health care professional awareness and knowledge of survivorship issues.

Action Steps:

a. Promote the concept of survivorship as a chronic condition in conjunction with awareness of increasing survival rates.

b. Assess the current availability of professional education resources and address gaps.

c. Provide training for health care professionals to increase acceptance and practice of prescribing pain control and symptom management medications and techniques to cancer survivors.

d. Encourage the incorporation of survivorship curricula into professional training programs, including making health care professionals' aware of the role of culture and literacy in communicating difficult or complex information to survivors.

e. Provide continuing education on addressing cancer survivorship issues.

f. Provide training about research on complementary and alternative medicines and techniques for symptom management.

Objective B - Increase The Availability Of Effective Programs And Policies Addressing Cancer Survivorship

Need for Education

Cancer survivors can be effective educators, counselors and advocates when they have appropriate information and education materials. However, current programs and policies are inadequate to provide these resources to cancer survivors, also to the general public, health care professionals, and policymakers. There is little current information on late and long-term effects of cancer and cancer treatments and on complementary and preventive strategies (such as eating properly, getting enough sleep, exercising, managing stress, using sunscreen, and protecting against viruses) that can help survivors care for themselves and make informed choices.

There is little current information on late and long-term effects of cancer and cancer treatments and on complementary and preventive strategies that can help survivors care for themselves and make informed choices.

Cancer survivors are often unaware of their rights. They may lose their jobs and their health insurance without realizing that there are laws and regulations that may protect their employment, insurance, and assets. For example, Texas has an Independent Review Organization that hears appeals from Texas residents when an HMO has denied coverage. This arbitration panel is available at no cost to the patient and does not require an attorney, yet most residents do not know about it. (Information available at *www.TDI.state.tx.us*)

There are 54 million informal (unpaid and, largely, untrained) caregivers — family members and friends who care for someone who is ill — in the United States today. However, most have received little or no training and, in return, receive very little financial or practical support for home care. As more and more patients make deliberate decisions to die at home instead of in a health care facility, caregivers need to be informed about what to expect at the end of life and how to help a dying patient experience a painless transition from life to death.

Need for Research

Similarities or differences in the survivorship experience among different racial or ethnic groups or among medically underserved people are virtually unexplored.[10] An NCI review of survivorship research of underserved populations identified only 65 studies with sample sizes sufficient to permit detailed comparisons among diverse groups.[11] Populations requiring further study include diverse ethnic groups, those diagnosed at age 65 or older, rural populations, low-income groups, those with limited education, and survivors with less commonly studied types of cancer.

Populations requiring further survivorship study include diverse ethnic groups, those diagnosed at age 65 or older, rural population, low-income groups, those with limited education, and survivors with less commonly studied types of cancer.

There is a lack of information for survivors, their caregivers, health care professionals, and policymakers not only on late or long-term effects of cancer treatment and quality of life issues, but also on prevention of second cancers and survivorship-specific concerns.

Recognizing this deficit, the National Cancer Institute is promoting research on the health and functioning of the growing population of cancer survivors through interventions that seek to evaluate and improve the posttreatment cancer experience. In 2004, NCI increased the amount of funding by 30 percent to focus on interventions that improve psychosocial and health-related outcomes.

Objective B - Increase The Availability Of Effective Programs And Policies Addressing Cancer Survivorship

Strategy 1: Evaluate current status to identify gaps in existing programs and policies.

Action Steps:

a. Identify cultural issues that influence the experience of cancer among Texas's diverse populations.

b. Conduct ongoing evaluation of cancer survivorship programs and services to determine their impacts and outcomes and to ensure continuous quality improvement of services.

c. Encourage the evaluation of the impact of policies on cancer survivorship issues.

Strategy 2: Promote policies that ensure program implementation and infrastructure development.

Action Steps:

a. Educate policy- and decision-makers about the impacts of survivorship on the social and economic well-being of our state and the role and value of providing long-term follow-up care, addressing quality-of-life issues and legal needs, and ensuring access to clinical trials and ancillary services for cancer survivors, including those of diverse populations.

b. Advocate for policies that support quality and timely services for all cancer survivors.

c. Promote a policy perspective that views cancer as a chronic disease.

d. Educate insurance purchasers and benefit managers on the value of providing services needed by survivors.

e. Provide advocacy training for the public, survivors, and professionals, with special attention to training advocates from underserved communities.

Strategy 3: Develop and implement comprehensive programs and policies that address the gaps in all areas of survivorship.

Action Steps:

a. Encourage collaboration among cancer centers to ensure adequate support services for survivors.

b. Develop culturally relevant survivorship support programs and offer them in appropriate and accessible settings.

c. Develop and implement programs that address gaps in access to cancer survivorship education, information, and quality of life services.

d. Promote collaboration among organizations to identify and implement evidence-based programs, with appropriate adaptations for the needs of priority populations.

e. Ensure availability of innovative survivorship assistance programs for all citizens of Texas.

f. Identify sources of funding for program and policy development and implementation addressing issues for cancer survivors.

Objective C- Increase Access To Quality Care And Services For Cancer Survivors In Texas

Survival Disparities

Serious survival disparities exist among diverse racial/ethnic and cultural minorities, low-income and many rural populations, and recent immigrants, compared with national overall and disease-specific survival rates.[12] To address this diversity among Texas's citizens, cancer survivorship information must be designed to reach these special populations who have different education levels, cultures, social values, and health perceptions, speak different languages, and, therefore, hold diverse attitudes toward health care. Educational materials need to be developed in formats, languages, literacy levels, and contexts that are relevant to both survivors and health care professionals.

Many patients leave cancer treatment without a good understanding or adequate documentation of their disease or the treatments they received.

With the growing number of survivors, there is a strong need to identify and reduce the barriers that create disparities in equal access to quality care and services. Many factors contribute to disparities: socioeconomic status; limited access to care and late diagnosis related to insurance status; geographic and transportation barriers; educational attainment and health literacy levels; cultural and language differences; provider bias; and lifestyle, among others.[13] Other factors that may create barriers are disabilities, sexual orientation, and religion.

Medical Records & Continued Health Care

Many patients leave cancer treatment without a good understanding or adequate documentation of their disease or the treatments they received. In addition, they have no guidelines or written description of recommended short- or long-term follow-up care or awareness of available resources.

An important part of education for survivors is teaching them to be their own best advocates and to know their medical and legal rights. They are entitled to request records that include the specifics of their disease, the results of tests, and treatment details from their treatment team. If a treatment facility will not provide a diagnostic/treatment summary, patients can request a copy of their medical record. There may be a charge for this service, which adds to the patient's financial burden. Since the information is key to ensuring appropriate follow-up care, opportunities to provide this service for free should be explored.

There are groups of survivors who are especially vulnerable to loss of access to continued health care due to partial or total loss of health insurance. These include those with lower incomes; the elderly; young adults and working women in the 55- to 64-year-old age group whose jobs do not provide health insurance and who have insufficient income to purchase it themselves. The latter are still too young to qualify for Medicare. The majority of survivors 65 or older are covered by Medicare. However, recent and future changes in Medicare legislation on health care for the elderly are still uncertain, making it difficult for health care consumers to have confidence in their coverage.

Objective C- Increase Access To Quality Care And Services For Cancer Survivors In Texas

Strategy 1: Identify and reduce barriers to ensure equal access to quality care and services.

Action Steps:

a. Promote the statewide dissemination of clinical trial information, with special emphasis on rural areas.

b. Create a statewide network to help with patient/survivor support.

c. Support the establishment and dissemination of clinical practice guidelines for each stage of cancer survivorship to communities across Texas, with special emphasis on rural areas.

d. Advocate for ready access to affordable medications.

e. Address issues related to access to transportation services for survivor programs.

f. Promote strategies that ensure equal access to ongoing quality care for survivors.

g. Identify and address access barriers to care and services for diverse populations.

Strategy 2: Develop and enhance patient navigation systems and pathways based on best practices to ensure optimum care for cancer survivors.

Action Steps:

a. Educate and empower cancer survivors to navigate the health care system.

b. Encourage health care facilities to provide free or reduced-cost survivorship programs.

c. Promote use of patient navigators to help ensure access to quality care for cancer survivors.

d. Support initiatives that promote quality and timely service for cancer survivors.

e. Ensure that patient navigation systems and pathways take account of the needs of diverse populations.

Strategy 3: Increase knowledge and awareness of the comprehensive support service needs of the cancer survivor during each stage of survivorship.

Action Steps:

a. Determine the necessary components of a quality survivorship assistance program.

b. Ensure availability of survivorship support programs across the state, with a particular emphasis on rural areas and underserved populations.

c. Identify barriers and gaps in support services.

d. Promote awareness of and increased access to appropriate cancer pain and symptom management.

e. Increase understanding of and access to quality end-of-life services.

f. Promote appropriate follow-up plans for all survivors.

g. Provide comprehensive education about hospice care and programs.

h. Promote increased access to the psychological and social support services needed by survivors.

i. Promote the availability of support resources.

j. Promote diverse communities' awareness and understanding of the impact that support groups can have on quality-of-life.

TERMINOLOGY

Alternative medicine: Therapeutic approaches taken in place of traditional medicine and used to treat or ameliorate disease.

Asbestos: A natural material that is made up of tiny fibers. If the fibers are inhaled, they can lodge in the lungs and lead to cancer.

BRCA1: A gene located on chromosome 17 that normally helps to restrain cell growth. Inheriting an altered version of BRCA1 predisposes an individual to breast, ovary, and prostate cancer.

Built environment: The surroundings or conditions in which people live or operate.

Carcinogen: Any substance that is known to cause cancer.

Case-control studies: A study that compares two groups of people: those with the disease or condition under study (cases) and a very similar group of people who do not have the disease or condition (controls). Researchers study the medical and lifestyle histories of the people in each group to learn what factors may be associated with the disease or condition. For example, one group may have been exposed to a particular substance that the other was not. Also called a retrospective study.

Chemotherapy regimen: A treatment program for cancer, using drugs.

Chronic disease: A disease or condition that persists or progresses over a long period of time.

Clinical trials: Research studies that involve patients. Each study is designed to find better ways to prevent, detect, diagnose, or treat cancer and to answer scientific questions.

Cognitive: Pertaining to the mental activities associated with thinking, learning, and memory.

Cohort: Any designated group followed or traced or a period, as in epidemiological study.

Cohort studies: A research study that compares a particular outcome (such as lung cancer) in groups of individuals who are alike in many ways but differ by a certain characteristic (for example, female nurses who smoke compared with those who do not smoke).

Complementary medicine: Practices often used to enhance or complement standard treatments and not recognized as standard or conventional medical approaches. Complementary medicine may include dietary supplements, mega-dose vitamins, herbal preparations, special teas, acupuncture, massage therapy, magnet therapy, spiritual healing, and meditation.

CT scan: A series of detailed pictures of areas inside the body taken from different angles; the pictures are created by a computer linked to an x-ray machine. Also called computerized tomography and computerized axial tomography (CAT) scan.

Culturally competent: Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. 'Culture' refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. 'Competence' implies having the capacity to function effectively as an individual and

an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities.

Dysplasia: Abnormal pathological development of cells indicating possibility of malignancy.

Epidemic: Affecting or tending to affect a disproportionately large number of individuals within a population, community, or region at the same time.

Epidemiology: The study of disease incidence and distribution in populations, as well as the relationship between environment and disease. Cancer epidemiology is the study of cancer incidence and distribution in the population and of how physical surroundings, occupational hazards, and personal habits such as tobacco use and diet may contribute to the development of cancer.

Ethnicity: A group that shares a common ancestry, history, or culture

Five-year survival: Five-year survival is a term commonly used as the statistical basis for successful treatment. A patient with cancer is generally considered cured after five or more years without recurrence of disease.

Genetic: Inherited; having to do with information that is passed from parents to offspring through genes in sperm and egg cells.

Genetic susceptibility: An inherited increase in the risk of developing a disease.

Health care professional: Practitioners in disease prevention, detection, treatment, and rehabilitation are known as health care professionals. They include physicians, nurses, dentists, dietitians, health educators, social workers, and therapists, among others.

Health disparities: Differences in the incidence, prevalence, mortality and burden of cancer and related adverse health conditions that exist among specific population groups in the United States.

Heterocyclic amine (HCA): Heterocyclic compounds are a major class of organic chemical compounds characterized by the fact that the atoms in their molecules are joined into rings containing at least one atom of an element other than carbon (C). These compounds are of great importance because many of the biochemical materials essential to life belong to the class. An amine is any of a class of organic compounds derived from ammonia by replacement of hydrogen with one or more alkyl groups.

High risk: When the chance for developing cancer is greater for an individual or a group of people than it is for the general population, that individual or group is considered to be at high risk. People may be considered to be at high risk from many factors or combination of factors, including a family history of disease, personal habits, or exposure to carcinogens in the environment or in the workplace.

H. pylori (Helicobacter pylori): Bacteria that cause inflammation and ulcers in the stomach. (*www.cancer.gov*)

Incidence: Incidence is the number of times a disease occurs in a given population. Cancer incidence is the number of new cases of cancer diagnosed each year. The Cancer Registry Division of the Department of State Health Services maintains cancer incidence data in Texas.

Incidence rate: A measure of the rate at which new events occur in the population. The number of new cases of a specified disease diagnosed or reported during a defined period of time, is the numerator, and the number of persons in the stated population in which the cases occurred is the denominator.

Ionizing radiation: Radiation of sufficient energy to dissociate atoms or molecules into electrically charged atoms or radicals in the irradiated material. e.g. X-rays

Linguistically appropriate: Health care services that are respectful of and responsive to linguistic needs.

Malignancy (or malignant): Cancerous; can invade nearby tissue and spread to other parts of the body.

Master Settlement Agreement: In 1998, 46 states and the four major tobacco companies signed the Master Settlement Agreement (MSA), which stipulated that the tobacco companies pay states $206 billion over 25 years and take steps to reduce youth smoking. The remaining states settled separately.

Medically underserved areas (MUA): Areas within the United States that have limited or no access to primary healthcare.

Metastatic cancer: Cancer that has spread from the place in which it started to other parts of the body.

Morbidity: Any departure, subjective or objective, from a state of physiological or psychological well-being. In this sense, sickness, illness, and morbid condition are similarly defined and synonymous.

Mortality rate: A rate expressing the proportion of a population who die of a disease, or of all causes. The numerator is the number of persons dying; the denominator is the total population (usually the midyear population) in which the deaths occurred. The unit of time is usually a calendar year. To produce a rate that is a manageable whole number, the fraction is usually multiplied by 1,000 to produce a rate per 1,000. This rate is also called the "crude death rate."

Multidisciplinary: Involving many particular fields of study.

Obesity: A condition in which a person has abnormally high amounts of unhealthy body fat; medically defined as a body mass index of 30 or greater.

Palliative care: Care that does not alter the course of a disease, but improves the quality of life.

Perforation: Abnormal opening in an organ.

Preexisting condition: A health condition (other than a pregnancy) or medical problem that was diagnosed or treated during a specified timeframe prior to enrollment in a new health insurance plan. Some pre-existing conditions may be excluded from coverage during a specified timeframe after the effective date of coverage in a new health plan.

Prevalence: In medical terminology, prevalence typically has been defined as the number of cases of a disease that are present in a population at a point in time. In the case of smoking prevalence in population, the term in used to define the number of people in that population who are regular smokers.

Primary prevention: The reduction or control of factors believed to be causative for a health problem and includes reducing risk factors such as smoking to prevent lung cancer or sex

education to reduce sexually transmitted diseases, and environmental exposures such as reducing ambient lead to prevent intellectual impairment. This category also includes health-service interventions, such as vaccinations or such preventive "therapy" tools as fluoridated water supplies or dental sealants.

Priority population: The Agency for Healthcare Research and Quality's definition includes low income groups; minority groups; women; children; the elderly; and individuals with special health care needs, including individuals with disabilities and individuals who need chronic care or end-of-life health care.

Proliferation: Multiplying or increasing in number. In biology, cell proliferation occurs by a process known as cell division.

Prostate-specific antigen: A protein whose level in the blood goes up in some men who have prostate cancer or benign prostatic hyperplasia. Also called PSA.

Psychosocial: Involving both psychological and social aspects of a person

Quality of life: In cancer treatment, quality of life is the concept of ensuring that cancer patients are able to lead the most comfortable and productive lives possible during and after treatment. New treatment techniques and social and emotional support groups are adding to the quality of life for cancer patients as well as to their survival.

Radiation tattoo: The areas marked with either a temporary or permanent marker showing where the radiation should be aimed.

Radon: A radioactive gas that is released by uranium, a substance found in soil and rock. When too much radon is breathed in, it can damage lung cells and lead to lung cancer.

Randomized clinical trials: A study in which the participants are assigned by chance to separate groups that compare different treatments; neither the researchers nor the participants can choose which group. Using chance to assign people to groups means that the groups will be similar and that the treatments they receive can be compared objectively.

Risk factor: Anything that has been identified as increasing an individual's chance of getting a disease is a risk factor.

Secondary prevention: Involves early detection and treatment, such as mammography for detecting breast cancer or Pap tests for detecting cervical cancer.

Secondhand smoke: Smoke that comes from the burning end of a cigarette and smoke that is exhaled by smokers. Also called ETS or environmental tobacco smoke. Inhaling ETS is called involuntary or passive smoking.

Socioeconomic: Of, relating to, or involving a combination of social and economic factors

Stage: A distinct phase in the course of a disease. Stages of cancer are typically defined by containment or spread of the tumor: in situ, localized, regional or distant spread.

Staging: Doing exams and tests to learn the extent of the cancer, especially whether it has spread from its original site to other parts of the body.

Systems approach: Working with systems, which are defined as a network of interdependent parts that work together to try to accomplish the goals of the system. Systems have a quality of interdependence where the changes in one aspect of the system reverberate and

create impact throughout the system. Some examples of systems are a school district, a business, a community, a church, or hospital. Working with systems can provide the best utilization of volunteers, staff, and other resources in achieving a common goal.

Tertiary prevention: Involves providing appropriate supportive and rehabilitative services to minimize morbidity and maximize quality of life, such as rehabilitation from injuries. It includes preventing secondary complications.

Toxin: A poison produced by certain animals, plants, or bacteria.

NOTES

Executive Summary

1. Mokdad AH, Marks JS, Stroup DF, Gerberding JL. "Actual Causes of Death in the United States, 2000." *JAMA* 291.10 (2004): 1238-46.
2. *Texas Behavioral Risk Factor Surveillance System*. U.S. Center for Disease Control and Prevention, 2002.
3. Miniño AM, Arias E, Kochanek KD, Murphy SL, Smith BL. *Deaths: Final Data for 2000: National Vital Statistics Reports 2002*.
4. Stewart, Sherri, et al. *Cancer Mortality Surveillance - United States, 1990-2000*: Center for Disease Control, 6/4/2004.
5. Greenwald, P., Kramer, B.S., & Weed, D.L., (Eds.). *Cancer Prevention and Control*. New York, NY: Marcel Dekker, Inc.
6. Lenhard Jr., R.E., W. Lawrence Jr., and R.J. McKenna. *General Approach to the Patient*. American Cancer Society Textbook of Clinical Oncology. Eds. G.P. Murphy, W. Lawrence and R.E. Lenhard Jr. 2nd ed. Atlanta, GA: The American Cancer Society, Inc., 1995.
7. *National Healthcare Disparities Report*. 2003. Internet. AHRQ. Available: h*ttp://www.qualitytools.ahrq.gov/disparitiesreport/download_report.aspx*.
8. *The Unequal Burden of Cancer. An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*. Institute of Medicine. Eds. MA Haynes and BD Smedley. Washington, DC: National Academy Press, 1999.
9. Ibid.
10. *Cancer and the Socioeconomically Disadvantaged*. Atlanta, GA: American Cancer Society, 1990.
11. *Strategic Directions 2000-2002*. Unpublished Report: Intercultural Cancer Council - ICC, September 1999.
12. *National Health Law Program Ensuring Linguistic Access in Health Care Settings, Legal Right and Responsibilities*. 2nd Ed., August 2003.
13. Crane, J. A. "Patient Comprehension of Doctor-Patient Communication on Discharge from the Emergency Department." *J Emerg Med* 15.1 (1997): 1-7.

Goal I: Prevention Information & Services

1. Murphy, G.P., Lawrence Jr., W., Lenhard, R.E. *American Cancer Society Textbook of Clinical Oncology*. Atlanta, GA: American Cancer Society, Inc., 1995.
2. *Cancer Facts & Figures - 1998*. Atlanta, GA: American Cancer Society, Inc., 1998.
3. *Measures of Progress against Cancer: Consolidated Report*. Bethesda, MD: National Cancer Institute, 1994.
4. *The American Cancer Society's Approach to Youth Education*. American Cancer Society, Inc., 1995.
5. *Cancer at the Crossroads: A Report to Congress for the Nation*. Bethesda, MD: National Institutes of Health, National Cancer Institute, National Cancer Advisory Board, 1994.
6. Greenwald, P., Kramer, B., & Weed, D. *Introduction: History of Cancer Prevention and Control*. Cancer Prevention and Control. New York: Marcel Dekker, Inc., 1995.
7. Freeman, Harold P. "Race, Poverty, and Social Injustice: Determinants of Cancer Disparities." *CA A Cancer Journal for Clinicians* 54 (March 2004): 72, 74.
8. American Cancer Society, *The American Cancer Society's Approach to Youth Education*.
9. *Cancer Facts & Figures - 2004*. Atlanta: American Cancer Society, Inc., 2004.

10. Guidry, J. *Cancer Prevention for African Americans Project: Final Technical Report to the Texas Cancer Council*: Texas A&M University, 1995.
11. Davis, T.C., Meldrum, H., Tippy, P.K.P., Weiss, B.D., and Williams, M.V. "How Poor Literacy Leads to Poor Health Care." *Patient Care* (1996): 95.
12. Ramirez, A.G., et. al. *Practical Guidelines for the Development of Print Cancer Education Materials for at-Risk Hispanics*: University of Texas Health Science Center at San Antonio, 1995.
13. American Cancer Society, *Cancer Facts & Figures - 2004*.
14. Ibid.
15. *Texas Cancer Facts & Figures - 2004*. American Cancer Society, Inc., 2004.
16. Intercultural Cancer Council, *Strategic Directions 2000-2002*.
17. Ibid.
18. Hegarty, V, et al. "Society Racial Differences in Use of Cancer Prevention Services among Older Americans." *J Am Geriar* 48.7 (2000): 735-40.
19. American Cancer Society, *Texas Cancer Facts & Figures - 2004*, page15-16.
20. Ibid.,15.
21. Ibid.
22. Ibid.
23. Ibid.
24. *Cancer Prevention & Early Detection Facts & Figures - 2004*. Atlanta: American Cancer Society, Inc., 2004.
25. American Cancer Society, *Texas Cancer Facts & Figures - 2004*, page 16.
26. American Cancer Society, *Cancer Facts & Figures - 2004*, page 27.
27. A.G. Ramirez, et. al. "Community Level Cancer Control in a Texas Barrio." *Journal of the National Cancer Institute Monographs*, 18 (1995), 117-122.
28. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004*, page 2.
29. Ibid.
30. *National Health Education Standards*. Atlanta: Joint Committee on National Health Education Standards, 1995.
31. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004*, page 2.
32. *Comprehensive School Health Education*. ERIC Digest. Internet. Available: *http://www.ericfacility.net/database/ERIC_Digests/ed351335.html*. 10/4/2004.
33. Ibid.
34. *Schools Offer Fat Kids Slim Hope*. Internet. Education World. Available: *http://www.education-world.com/a_issues/issues318.shtml*. 2004.
35. American Cancer Society, *Cancer Facts & Figures - 2004*, page 50.
36. ERIC Digest, *Comprehensive School Health Education*.
37. 10309, Abstract. *Youth Advocacy as a Tool for Health Promotion*. Available: *http://apha.confex.com/apha/128am/techprogram/paper_10909.htm*. 9/28/2004.
38. T*exas School Health Network Factsheet*. Internet. Available: *http://www.tdh.state.tx.us/schoolhealth/sch_net.htm*. 9/28/2004.
39. Ibid.
40. *Healthy Schools-Healthy Kids*. Internet. Available: *http://63.173.64.5/hkn/schools/print_school/print_advisory.htm*. 9/28/2004.

41. *New Law Will Have Elementary School Students up and Running*. Internet. The Senate of Texas. Available: *http://www.senate.state.tx.us/75r/senate/members/dist25/pr01/p081001a.htm.* 10/5/2004.
42. American Cancer Society, *The American Cancer Society's Approach to Youth Education*, page 7.
43. Joint Committee on National Health Standards, *National Health Education Standards: Achieving Health Literacy* (American Cancer Society, Inc.: 1995), [95-50M-No.2027], 5.
44. Ibid.
45. American Cancer Society, *The American Cancer Society's Approach to Youth Education*, page 19.
46. Centers for Disease Control and Prevention. *Cigarette Smoking Among Adults - United States, 2002. MMWR* 2004;53: 427.
47. Ibid.
48. American Cancer Society, *Cancer Facts & Figures - 2004.*
49. Ibid.
50. Ibid.
51. Ibid.
52. Ibid.
53. *Tobacco Statistics Snapshot*. Internet. National Cancer Institute. Available: *http://cancer.gov/cancertopics/tobacco/statisticssnapshot/print?page=&keyword.* 9/28/2004.
54. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures 2004.*
55. Centers for Disease Control and Prevention. *State - Specific Prevalence of Current Cigarette Smoking Among Adults - United States, 2002. MMWR* 2003;52: 1277.
56. National Cancer Institute, *Tobacco Statistics Snapshot.*
57. Ibid.
58. Centers for Disease Control and Prevention. *Annual Smoking - Attributable Mortality, Years of Potential Life Lost, and Economic Costs - United States, 1995 - 1999. MMWR* 2003;52: 427.
59. *Smoke-Free Homes: Health Effects*. Internet. U.S. Environmental Protection Agency. Available: *http://www.epa.gov/iaq/ets/healthrisks.html.* 2004.
60. American Cancer Society, *Texas Cancer Facts & Figures - 2004.*
61. Ibid.
62. Ibid.
63. Ibid.
64. Centers for Disease Control and Prevention. *Cigarette Smoking Among Adults - United States, 2002. MMWR* 2004;53: 428.
65. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004.*
66. Milton, M. H., et al. "Recommendations and Guidance for Practice in Youth Tobacco Cessation." *Am J Health Behav* 27 Suppl 2 (2003): S159-69.
67. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004.*
68. Curry, S. J. "Youth Tobacco Cessation: Filling the Gap between What We Do and What We Know." *Am J Health Behav* 27 Suppl 2 (2003): S99-102.
69. "Preventing Tobacco Use among Young People: A Report of the Surgeon General." *MMWR* 43.RR-4: 1-10.
70. American Cancer Society, *Cancer Facts & Figures - 2004.*
71. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004.*

72. Centers for Disease Control and Prevention. *Cigarette Use Among High School Students - United States, 1991 - 2002. MMWR* 2004;53: 499-502.
73. American Cancer Society, *Cancer Facts & Figures - 2004.*
74. Centers for Disease Control and Prevention. *Cigarette Use Among High School Students - United States, 1991 - 2002.*
75. Ibid.
76. Milton, M. H., et al. "Recommendations and Guidance for Practice in Youth Tobacco Cessation." *Am J Health Behav* 27 Suppl 2 (2003): S159-69.
77. Centers for Disease Control and Prevention. *Cigarette Use Among High School Students - United States, 1991 - 2002.*
78. Milton, M. H., et al. "Recommendations and Guidance for Practice in Youth Tobacco Cessation." *Am J Health Behav* 27 Suppl 2 (2003): S159-69.
79. Curry, S. J. "Youth Tobacco Cessation: Filling the Gap between What We Do and What We Know." *Am J Health Behav* 27 Suppl 2 (2003): S99-102.
80. Ibid.
81. Ibid.
82. Ibid.
83. C.N. D'Onfrio and D.G. Altman. "Children and Youth." Tobacco Use: An American Crisis. (Washington, DC: American Medical Association, January 1993), 38.
84. Ibid.
85. Levinson, A. H. "Tobacco Sales to Minors: Has Familiarity Bred Contempt for Youth Access Programs?" *Am J Public Health* 94.5 2004: 696.
86. Ibid.
87. C.N. D'Onfrio, 36.
88. Centers for Disease Control and Prevention. *Usual Sources of Cigarettes for Middle and High School Students - Texas, 1998 - 1999. MMWR* 2002;51: 900-901.
89. Ibid.
90. U.S. Department of Health and Human Services, *Preventing Tobacco Use among Young People: A Report of the Surgeon General.*
91. Ibid., 8.
92. *Ratliff-Sadler Act.* Senate. 74th Texas Legislature. 1. May 1994.
93. Section 1926, Federal Public Health Service Act. U.S.C.
94. S.L. Nightingale. (1996). "From the Food and Drug Administration." *Journal of the American Medical Association* 276 (1996), 1128.
95. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004.*
96. Ibid.
97. *Office of Tobacco Prevention and Control Frequently Asked Questions.* 2004. Internet. Texas Department of Health. Available: *www.worthit.org/resources.* 2004.
98. Centers for Disease Control and Prevention. *State - Specific Prevalence of Current Cigarette Smoking Among Adults - United States, 2002.*
99. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004.*
100. Centers for Disease Control and Prevention. *Cigarette Smoking Among Adults - United States, 2002.*
101. Centers for Disease Control and Prevention. *State - Specific Prevalence of Current Cigarette Smoking Among Adults - United States, 2002.*

102. Ibid.
103. Ibid.
104. *Best Practices for Comprehensive Tobacco Control Programs*. Internet. Centers for Disease Control. Available: *http://www.cdc.gov/tobacco/bestprac.htm*. 2004.
105. *Online Guide to Quitting*. Internet. Available: *www.smokefree.gov*. 10/4/2004.
106. Centers for Disease Control, *Best Practices for Comprehensive Tobacco Control Programs*.
107. Marwick, C. "Intensive Smoking Cessation Efforts Cost-Effective." *JAMA* 276.16 (1996): 1291.
108. Centers for Disease Control and Prevention. *State - Specific Prevalence of Current Cigarette Smoking Among Adults - United States, 2002*.
109. Ibid.
110. Ibid.
111. Ibid.
112. Centers for Disease Control and Prevention. *Declines in Lung Cancer Rates - California, 1988 - 1997. MMWR* 2000;49: 1066-1069.
113. Centers for Disease Control, *Best Practices for Comprehensive Tobacco Control Programs*.
114. *Cancer Facts*. Internet. National Cancer Institute. Available: *http://cis.nci.nih.gov/fact/3_9.htm*. 6/22/2004.
115. Ibid.
116. Centers for Disease Control and Prevention. *Impact of Smoking Ban on Restaurant and Bar Revenues - El Paso, Texas, 2002. MMWR* 2004;53: 150-152.
117. Calle, E. E., et al. "Overweight, Obesity, and Mortality from Cancer in a Prospectively Studied Cohort of U.S. Adults." *N Engl J Med* 348.17 (2003): 1625-38.
118. McKay, Betsy. "Obesity Is Linked to Cancer Risk - Extra Weight Sharply Increases Likelihood of Disease in Breasts, Colon and Organs." *Wall Street Journal* August 24, 2004: D1 & D3.
119. Bianchini, F., R. Kaaks, and H. Vainio. "Overweight, Obesity, and Cancer Risk." *Lancet Oncol* 3.9 (2002): 565-74.
120. Colditz, G. A. "Economic Costs of Obesity and Inactivity." *Med Sci Sports Exerc* 31.11 Suppl (1999): S663-7.
121. *The Burden of Overweight and Obesity in Texas*, 2000-2004 Executive Summary. Internet. Texas Department of Health & Texas Department of Argiculture's Food and Nutrition Division. Available: *http://www.tdh.state.tx.us/sshp/Cost_Obesity_ExecSumm.pdf*. 2004.
122. *Cancer Facts*, Obesity and Cancer. Internet. National Cancer Institute. Available: *http://cis.nci.nih.gov/fact/3_70.htm*. 10/10/2004.
123. Ibid.
124. Department of Health & Texas Deparment of Agriculture's Food and Nutrition Division. *The Burden of Overweight and Obesity in Texas, 2000-2004 Executive Summary*.
125. Hoelscher, D. M., et al. "Measuring the Prevalence of Overweight in Texas Schoolchildren." *Am J Public Health* 94.6 (2004): 1002-8.
126. *Obesity*. Internet. Harvard School of Public Health. Available: h*ttp://www.hsph.harvard.edu/cancer/publications/reports/vol1_full_text/print_ready/obesity.html*. 6/29/2004.
127. *Wall Street Journal*, August 24, 2004.
128. National Cancer Institute, *Cancer Facts, Obesity and Cancer*.
129. Ibid.
130. Ibid.
131. *Healthy People 2010*. Center for Disease Control, National Health Institute.

132. *Wall Street Journal*, August 24, 2004.

133. *5 a Day for Better Health Program Evaluation Report: Introduction*. Internet. National Cancer Institute Cancer Control & Population Sciences. Available: *http://dccps.nci.nih.gov/5ad_2_evi.html*. 2004.

134. Ibid.

135. Ibid.

136. McCann, J. "Obesity, Cancer Links Prompt New Recommendations." *J Natl Cancer Inst* 93.12 (2001): 901-2.

137. Hoelscher, D. M., et al. "Measuring the Prevalence of Overweight in Texas Schoolchildren." *Am J Public Health* 94.6 (2004): 1002-8.

138. Ibid.

139. Briggs, M., S. Safaii, and D. L. Beall. "Position of the American Dietetic Association, Society for Nutrition Education, and American School Food Service Association—Nutrition Services: An Essential Component of Comprehensive School Health Programs." *J Am Diet Assoc* 103.4 (2003): 505-14.

140. Ibid.

141. Fisher, J. O., et al. "Parental Influences on Young Girls' Fruit and Vegetable, Micronutrient, and Fat Intakes." *J Am Diet Assoc* 102.1 (2002): 58-64.

142. Bianchini, F., R. Kaaks, and H. Vainio. "Overweight, Obesity, and Cancer Risk." *Lancet Oncol* 3.9 (2002): 565-74.

143. *Schools Offer Fat Kids Slim Hope*. Internet. Education World. Available: *http://www.education-world.com/a_issues/issues318.shtml*. 2004.

144. Department of Health & Texas Deparment of Agriculture's Food and Nutrition Division. *The Burden of Overweight and Obesity in Texas, 2000-2004 Executive Summary*.

145. Briggs, M., S. Safaii, and D. L. Beall. "Position of the American Dietetic Association, Society for Nutrition Education, and American School Food Service Association—Nutrition Services: An Essential Component of Comprehensive School Health Programs." *J Am Diet Assoc* 103.4 (2003): 505-14.

146. Bianchini, F., R. Kaaks, and H. Vainio. "Overweight, Obesity, and Cancer Risk." *Lancet Oncology* 3.9 (2002): 565-74.

147. Ibid.

148. Ibid.

149. Ibid.

150. Nies, M. A., H. L. Chruscial, and J. T. Hepworth. "An Intervention to Promote Walking in Sedentary Women in the Community." *Am J Health Behav* 27.5 (2003): 524-35.

151. Education World, *Schools Offer Fat Kids Slim Hope*.

152. Klebanoff, R, and N Muramatsu. "A Community-Based Physical Education and Activity Intervention for African American Preadolescent Girls: A Strategy to Reduce Racial Disparities in Health." *Health Promotion Practice* 3.2 (2002): 276-85.

153. Ibid.

154. Nies, M. A., H. L. Chruscial, and J. T. Hepworth. "An Intervention to Promote Walking in Sedentary Women in the Community." *Am J Health Behav* 27.5 (2003): 524-35.

155. Ibid.

156. Bianchini, F., R. Kaaks, and H. Vainio. "Overweight, Obesity, and Cancer Risk." *Lancet Oncology* 3.9 (2002): 565-74.

157. Nies, M. A., H. L. Chruscial, and J. T. Hepworth. "An Intervention to Promote Walking in Sedentary Women in the Community." *Am J Health Behav* 27.5 (2003): 524-35.

158. Nelson, Nancy. *The Majority of Cancers Are Linked to the Environment*. 7/14/2004. Internet. National Cancer Institute - Environment Report. Available: *http://www.cancer.gov/newscenter/benchmarks-vol4-issue3*. 10/5/2004.

159. Ibid.
160. American Cancer Society. *Cancer Facts & Figures - 1998*, 30.
161. National Cancer Institute. *Measures of Progress Against Cancer: Consolidated Report* (Bethesda, MD: 1994), 60.
162. Ibid.
163. Ibid.
164. American Cancer Society, *Cancer Facts & Figures - 1998*, page 30.
165. Ibid.
166. National Cancer Institute. *Measures of Progress Against Cancer: Cancer Prevention*, 27.
167. *NCI Cancer Facts: Heterocyclic Amines in Cooked Meats*. 9/15/2004. Internet. National Cancer Institute. Available: *http://cis.nci.nih.gov/fact/3_25.htm*. 10/5/2004.
168. National Cancer Institute, *The Majority of Cancers Are Linked to the Environment.*
169. *NCI Cancer Facts: Radon and Cancer - Questions and Answers*. 7/13/2004. Internet. National Cancer Institute. Available: *http://cis.nci.nih.gov/fact/3_52.htm.* 10/5/2004.
170. Ibid.
171. National Cancer Institute, *The Majority of Cancers Are Linked to the Environment.*
172. *Prevention and Early Detection: Unproven Risks*. 12/02. Internet. American Cancer Society. Available: *http://www.cancer.org/docroot/PED/content/PED_1_3X_Unproven_Risks.asp?sitearea=PED*. 2004.
173. Ibid.
174. Ibid.
175. National Cancer Institute, *The Majority of Cancers Are Linked to the Environment.*
176. *1993 Toxics Release Inventory Public Data Release Executive Summary*. Washington, DC: US Environmental Protection Agency, Office of Pollution Prevention and Toxics, 1995.
177. Latest Texas TRI Data. Internet. Texas Natural Resource Conservation Commission. Available: *http://www.tnrcc.state.tx.us/exec/oppr/tri/summary.html#assistance.* 2004.
178. *Cancer Rates and Risks*. 4th ed: National Cancer Institute.
179. National Cancer Institute, *Measures of Progress against Cancer: Consolidated Report*.
180. National Cancer Institute, *The Majority of Cancers Are Linked to the Environment.*
181. *Texas Community Right-to-Know Acts*. Internet. Texas Department of State Health Services. Available: *http://www.tdh.state.tx.us/beh/HazCom/RulesMainPage.htm.* 2004.
182. Ibid.

Goal II: Early Detection & Treatment

1. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004.*
2. Ibid.
3. *Cancer Screening Overview*. Internet. National Cancer Institute. Available: *http://www.nci.nih.gov/cancertopics/pdq/screening/overview.* 10/12/2004.
4. *Prevention & Early Detection*. Internet. American Cancer Society. Available: *http://www.cancer.org/docroot/PED/content/PED_2_3X_Early_Detection.asp?sitearea=PED.* 10/12/2004.
5. American Cancer Society, *Texas Cancer Facts & Figures - 2004.*
6. *Guide to Clinical Preventive Services*. 1996. Internet. AHRQ. Available: *http://www.ahrq.gov/clinic/cpsix.htm.* 2004.

7. *Cancer Screening Overview*. Internet. National Cancer Institute. Available: *http://www.nci.nih.gov/cancertopics/pdq/screening/overview*. 10/12/2004.
8. Ibid.
9. Ibid.
10. Ibid.
11. Ibid.
12. *Screening for Prostate Cancer*. December 2002. Internet. U.S. Preventive Services Task Force. Available: *http://www.ahrq.gov/clinic/3rduspstf/prostatescr/prostatwh.htm*. 10/6/2004.
13. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004*.
14. *Screening for Lung Cancer*. May 2004. Internet. U.S. Preventive Services Task Force. Available: *http://www.ahrq.gov/clinic/uspstf/uspslung.htm*. 10/6/2004.
15. American Cancer Society, *Prevention & Early Detection*.
16. Ibid.
17. Brenner, D. J., and C. D. Elliston. "Estimated Radiation Risks Potentially Associated with Full-Body Ct Screening." *Radiology* 232.3 (2004): 735-8.
18. American Cancer Society, *Texas Cancer Facts & Figures - 2004*.
19. Ibid.
20. Ibid.
21. Ibid.
22. *Colorectal Cancer Screening: What Are States Doing?* Internet. National Conference of State Legislatures. Available: *http://www.ncsl.org/programs/health/colonrectal.htm*. 2004.
23. *Breast and Cervical Cancer Update*. Internet. National Conference of State Legislatures. Available: *http://www.ncsl.org/programs/health/brescerv.htm*. 2004.
24. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004*.
25. Boohaker, E.A., Ward R.E., Uman J.E., and McCarthy B.D. "Patient Notification and Follow-up of Abnormal Test Results." *Archives of Internal Medicine* 156 (1996): 327-31.
26. *Action Plan on Breast & Cervical Cancers for Texas*. August 2003. Internet. Texas Cancer Council. Available: *http://www.texascancercouncil.org/pdfs/bcactionplan.pdf*. 2004.
27. *National Lung Screening Trial*. Internet. National Cancer Institute. Available: *http://cancer.gov/nlst/what-is-nlst/print?page=keyword=*. 10/11/2004.
28. Risser, D.R. and Condon K.W. "Stage of Cancer Diagnosis in Rural Versus Urban Areas of Texas: Implications for Changing the Disparity through Health Services." *Texas Journal of Rural Health* Third Quarter (1995): 21.
29. *Rural Health in Texas: A Report to the Governor and the 75th Texas Legislature*. Austin: Center for Rural Health Iniciatives, 1997.
30. Ibid., 37.
31. W.J. Mayer and R.W. Beardall. "Translating Science into Practice: Cancer Prevention in Primary Care Medicine." In P. Greenwald, B.S. Kramer, and D.L. Weed (Eds.) *Cancer Prevention and Control* (New York, NY: Marcel Dekker, Inc., 1995), 419.
32. *Texas: At-a-Glance*. Internet. Kaiser Family Foundation. Available: *www.statehealthfacts.org*. 2004.
33. Mayer and Beardall, 419.
34. *Screening Mammograms: Questions and Answers*. 5/3/2002. Internet. National Cancer Institute. Available: *http://cis.nci.nih.gov/fact/5_28.htm*. 10/12/2004.

35. *Nonfinancial Barriers to Health Care in Texas: Report to the Texas Legislature*. Health Law Policy Institute, University of Houston, 1995.

36. Ibid., 23.

37. Guidry, Jeff et. al. "Transportation as a Barrier to Cancer Treatment." *Cancer Practice* 5 (1997): 364.

38. Black, B. *The Triad Study: Use of Community Services for Cancer Patients and Their Families*: American Cancer Society, Commission on Cancer, National Cancer Registries Assn., 1997.

39. Sheridan, S. L., R. P. Harris, and S. H. Woolf. "Shared Decision Making About Screening and Chemoprevention. A Suggested Approach from the U.S. Preventive Services Task Force." *Am J Prev Med* 26.1 (2004): 56-66.

40. Rimer, B. K., et al. "Informed Decision Making: What Is Its Role in Cancer Screening?" *Cancer* 101.5 Suppl (2004): 1214-28.

41. Chan, E. C., et al. "Cultural Sensitivity and Informed Decision Making About Prostate Cancer Screening." *J Community Health* 28.6 (2003): 393-405.

42. Barry, M. J. "Health Decision Aids to Facilitate Shared Decision Making in Office Practice." *Ann Intern Med* 136.2 (2002): 127-35.

43. Ibid.

44. *Clinical Trials: What Are States Doing*. September 2004. Internet. National Conference of State Legislatures. Available: *http://www.ncsl.org/programs/health/2004clinicaltrials.htm.* 2004.

45. *Facts and Figures About Clinical Trials*. National Cancer Institute. Available: *http://cancer.gov/clinicaltrials/facts-and-figures/print?page=&keyword.* 10/12/2004.

46. Ibid.

47. *Clinical Trials: What Are States Doing*. September 2004.

48. *Plans & Priorities for Cancer Research*. Internet. National Cancer Institute. Available: *http://2001.cancer.gov/main.htm.* 2004.

49. *ASCO: Access to Quality Cancer Care*. Internet. American Society of Clinical Oncology. Available: *http://www.asco.org/ac/1,1003,_12-002177-00_18-0011731-00_19-0011734-00_20-001,00.asp.* 2004.

50. Ibid.

51. National Cancer Institute, *Plans & Priorities for Cancer Research.*

52. Ibid.

53. National Cancer Institute, *Screening Mammograms: Questions and Answers*.

54. *Health & Safety Code :Chapter 401. Radioactive Materials and Other Sources of Radiation*. Internet. Available: *http://www.capitol.state.tx.us/statutes/docs/HS/content/htm/hs.005.00.000401.00.htm.* 2004.

55. *ACOS: Public Information*. Internet. American College of Surgeons. Available: *http://www.facs.org/.* 2004.

Goal III: Professional Education & Practice

1. Janz, N. K., et al. "Colorectal Cancer Screening Attitudes and Behavior: A Population-Based Study." *Prev Med* 37.6 Pt 1 (2003): 627-34.

2. Lemkau JP, Grady K, Carlson S. "Maximizing the Referral of Older Women for Screening Mammography." *Archives of Family Medicine* 5.3 (1996): 174-8.

3. Cummings DM, Whetstone L, Shende A, Weismiller D. "Predictors of Screening Mammography: Implications for Office Practice." *Archives of Family Medicine* 9.9 (2000): 870-5.

4. Smith, R. A., V. Cokkinides, and H. J. Eyre. "American Cancer Society Guidelines for the Early Detection of Cancer, 2003." *CA Cancer J Clin* 53.1 (2003): 27-43.

5. Ibid.
6. Mayer and Beardall, 416.
7. Hamblin, J., and P. D. Connor. "Cancer Screening Guideline Preference Surveys: Physicians' Perceptions of the American Cancer Society." *Tenn Med* 91.1 (1998): 17-20.
8. Ashford, A., et al. "Cancer Screening and Prevention Practices of Inner-City Physicians." *Am J Prev Med* 19.1 (2000): 59-62.
9. Sheinfeld Gorin, S., et al. "Cancer Education among Primary Care Physicians in an Underserved Community." *Am J Prev Med* 19.1 (2000): 53-8.
10. Herman, C. J., E. J. Lengerich, and G. Stoodt. "Variation in Recommendations for Breast and Cervical Cancer Screening among Primary Care Physicians in North Carolina, 1991." *South Med J* 89.6 (1996): 583-90.
11. Lurie, N., et al. "Why Do Patients of Female Physicians Have Higher Rates of Breast and Cervical Cancer Screening?" *J Gen Intern Med* 12.1 (1997): 34-43.
12. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004*.
13. *Fulfilling the Potential of Cancer Prevention and Early Detection*. Eds. SJ Curry, T Byers and M Hewitt. Washington, DC: The National Academies Press, 2003.
14. Lobb, R., et al. "Implementation of a Cancer Prevention Program for Working Class, Multiethnic Populations." *Prev Med* 38.6 (2004): 766-76.
15. American Cancer Society, *Cancer Prevention & Early Detection Facts & Figures - 2004*.
16. Mayer and Beardall, 352-62.
17. Klabunde, C. N., et al. "A National Survey of Primary Care Physicians' Colorectal Cancer Screening Recommendations and Practices." *Prev Med* 36.3 (2003): 352-62.
18. Gutierrez, G. "Medicare, the Internet, and the Future of Telemedicine." *Crit Care Med* 29.8 Suppl (2001): N144-50.
19. R.J. McKenna, D. Wellisch, and I.F. Fawzy. *Rehabilitation and Supportive Care of the Cancer Patient*. American Cancer Society Textbook of Clinical Oncology. Eds. G. P. Murphy, W. Lawrence and Jr. R. E. Lenhard. 2nd ed. Atlanta, GA: American Cancer Society, Inc., 1995.
20. Easter, D. W., and W. Beach. "Competent Patient Care Is Dependent Upon Attending to Empathic Opportunities Presented During Interview Sessions." *Curr Surg* 61.3 (2004): 313-8.
21. Mayer and Beardall, 420.
22. Leiner, M., G. Handal, and D. Williams. "Patient Communication: A Multidisciplinary Approach Using Animated Cartoons." *Health Educ Res* 19.5 (2004): 591-5.
23. Sivesind, D., et al. "Communicating with Patients in Cancer Care; What Areas Do Nurses Find Most Challenging?" *J Cancer Educ* 18.4 (2003): 202-9.
24. Sepucha, K. R., et al. "Consultation Planning to Help Breast Cancer Patients Prepare for Medical Consultations: Effect on Communication and Satisfaction for Patients and Physicians." *J Clin Oncol* 20.11 (2002): 2695-700.
25. McGrath, V. "The Importance of Follow-Up: Why Is It My Responsibility?" *J Med Pract Manage* 17.2 (2001): 90-2.
26. Novick, Lloyd F. "Put Prevention into Practice." *Journal of Public Health Management and Practice* 10.2 (2004): 93-4.
27. Tyler, D. O., M. A. Taylor-Seehafer, and M. Murphy-Smith. "Utilizing "Ppip Texas Style!" in a Medically Underserved Population." *J Public Health Manag Pract* 10.2 (2004): 100-8.
28. M.N. Raber and J.S. Bailes. "Clinical Oncology in a Reforming Heath Care Environment." In J. F. Holland, E. Frei, III, R. Bast, Jr., D. Kufe, D. Morton, & R. Weichselbaum (Eds.). *Cancer Medicine*: Vol. 1 (4th ed.) (Baltimore, MD: Williams & Wilkins, 1997), 1448.

29. B.U. Philips, Jr., and L.M. Alperin. *Collaboration among Texas Medical Schools to Improve Education in Cancer Prevention and Detection*. Austin, TX: Report to the Texas Cancer Council, 1995.
30. *Grant #1 R25 CA65618*. Internet. Available: *http://snapper.utmb.edu:800/ccenter/INDEX.HTML*. June 26, 1996.
31. Internet. *Cancer Teaching and Curriculum Enhancement in Undergraduate Medicine*. Available: *www.catchum.utmb.edu*. 2004.
32. Ibid.
33. Ibid.
34. Ibid.
35. Ibid.
36. "American Society of Clinical Oncology Policy Statement Update: Genetic Testing for Cancer Susceptibility." *Journal of Clinical Oncology* 21.12.
37. *Use of Genetic Information in Employment, Occupational Licenses and Health Insurance*. 75th Texas Legislature. House Bill 391997.
38. November 2004. Internet. National Center for Complementary and Alternative Medicine. Available: *www.nccam.nih.gov*. 2004.
39. Ibid.
40. *NCI Cancer Facts: Cam*. Internet. National Cancer Institute. Available: *http://cis.nci.nih.gov/fact/9_14.htm*. 10/15/2004.
41. Ibid.
42. *Doctors, Patients Face Different Barriers to Clinical Trials*. Internet. National Cancer Institute. Available: *http://www.cancer.gov/clinicaltrials/developments/doctors-barriers0401*. 9/28/2004.
43. Ibid.
44. Ibid.
45. Ibid.
46. *2003-2004 Texas State Health Plan Update*. Internet. Statewide Health Coordinating Council. Available: *http://www.texasshcc.org/complete.pdf*. 2004.
47. *Center to Reduce Cancer Health Disparities*. Internet. National Cancer Institute. Available: *http://crchd.nci.nih.gov/*. 2004.
48. *Making Cancer Health Disparities History*. March 2004 2004. Internet. Available: *http://www.hhs.gov/chdprg/pdf/chdprg.pdf*. 2004.
49. Ibid.
50. Ibid.
51. *Unequal Treatment: What Healthcare Providers Need to Know About Racial and Ethnic Disparities in Health-Care*. March 2002. Internet. Institute of Medicine. Available: *http://www.iom.edu/Object.File/Master/4/175/0.pdf*. 2004.
52. Ibid.
53. Ibid.
54. Statewide Health Coordinating Council, *2003-2004 Texas State Health Plan Update*.
55. Ibid.
56. *The Health Care Workforce Shortage*. Internet. American Association for Clinical Chemistry. Available: *http://www.aacc.org/divisions/management/images/article_havens.pdf*. 2004.

57. Alexia Green, K. Lynn Wieck, Jim Willmann, Chris Fowler, Wanda Douglas, and Clair Jordan. "Addressing the Texas Nursing Shortage: A Legislative Approach to Bolstering the Nursing Education Pipeline." *Policy, Politics, & Nursing Practice* 5.1 (2004): 41-48.

58. *State of the Healthcare Workforce* 2003. American Federation of Teachers, 2003.

59. *Missing Persons: Minorities in the Health Professions*. The Sullivan Commission.

60. *Rural Health in Texas: A Report to the Governor and the 75th Texas Legislature*. Austin, TX: Center for Rural Health Initiatives, January 1997.

61. Risser and Condon, 21.

62. *Cancer Pain Resource Center for Physicians*. Internet. Texas Medical Association Physician Oncology Education Program (POEP). Available: *http://www.texmed.org/has/prs/pop/cancer_pain.asp.* 2004.

63. Ibid.

64. McKenna, Wellisch, and Fawzy, 644.

Goal IV: Cancer Data Aquisition & Utilization

1. American Cancer Society, Cancer Facts and Figures - 2004.

2. *Cancer Registries: The Foundation for Cancer Prevention and Control*. Department of Health and Human Services - Centers for Disease Control and Prevention, 2004/2005.

3. 2003. Internet. Available: *http://www.naaccr.org.* 10/18/2004.

4. *Improving the Collection and Use of Racial and Ethnic Data in HHS*. December 1999. Internet. Available: *http://aspe.hhs.gov/datacncl/RaceRpt/index.htm#toc.* 11/16/2004.

5. Ibid.

6. Ibid.

7. Texas Health Care Information Council. 2004. Internet. Available: *http://www.thcic.state.tx.us/AboutTHCIC.htm.* 10/18/2004.

8. Ibid.

9. *American Cancer Society Nationwide Strategic Cancer Control Planning Model: Merging Theory and Data to Make Cancer Control Decisions*. 2001. Internet. Available: *http://apha.confex.com/apha/129am/techprogram/paper_29729.htm.* 10/18/2004.

10. *Data for Cancer Control Planning and Evaluation: Partners' Meeting*. 2002. Internet. Available: *http://www.cdc.gov/cancer/npcr/partnersmtg/index.htm.* 2004.

11. *Guidance for Comprehensive Cancer Control Planning Volume 1: Guidelines*. Internet. Available: *http://www.cdc.gov/cancer/ncccp/guidelines/part2/section5.htm.* 10/18/2004.

12. Ibid.

13. *Death Rate/Trend Comparison by Cancer, Death Years through 2001texas Counties Versus United States.* Internet. Available: *http://www.statecancerprofiles.cancer.gov/cgi-bin/quickprofiles/profile.pl?48&001#RT_ForAStateCounty.* 2004.

14. *State Cancer Profiles*. 2004. Internet. Available: *http://www.statecancerprofiles.cancer.gov.* 2004.

Goal V: Survivorship

1. US Department of Health and Human Services, National Institutes of Health, National Cancer Institute. *President's Cancer Panel, 2003-2004 Annual Report*.

2. *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*. Centers for Disease Control and Prevention, April 2004.
3. *Texas Cancer News Newsletter, Houston Edition*. American Cancer Society, Fall 2004.
4. American Cancer Society, *Texas Cancer Facts & Figures - 2004*, 9.
5. Breitbart, W. "Spirituality and Meaning in Supportive Care: Spirituality- and Meaning-Centered Group Psychotherapy Interventions in Advanced Cancer." *Support Care Cancer* 10.4 (2002): 272-80.
6. Mullan, F. "Seasons of Survival: Reflections of a Physician with Cancer." *N Engl J Med* 313.4 (1985): 270-3.
7. Centers for Disease Control and Prevention. *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*.
8. Thomas, Dylan. "Do Not Go Gentle into That Good Night." The Poems of Dylan Thomas. *New Directions*, 1953.
9. Centers for Disease Control and Prevention. *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*.
10. Ibid., 6.
11. *National Cancer Institute Cancer Control & Populations Sciences*. Cancer Survivorship Research Web site. Available: *http://dccps.nci.nih.gov/ocs/healthdisp.html*. 2004.
12. US Department of Health and Human Services, National Institutes of Health, National Cancer Institute. *President's Cancer Panel, 2003-2004 Annual Report*.
13. Ibid.

Index

Q

R

S

T

U

W

Y

Sandra Balderrama, MPA, BSW, Executive Director
P.O. Box 12097
Austin, Texas 78711
(512) 463-3190 • Fax (512) 475-2563
Email: tcc@tcc.state.tx.us
Homepage: *http://www.tcc.state.tx.us*

Printed On Recycled Paper