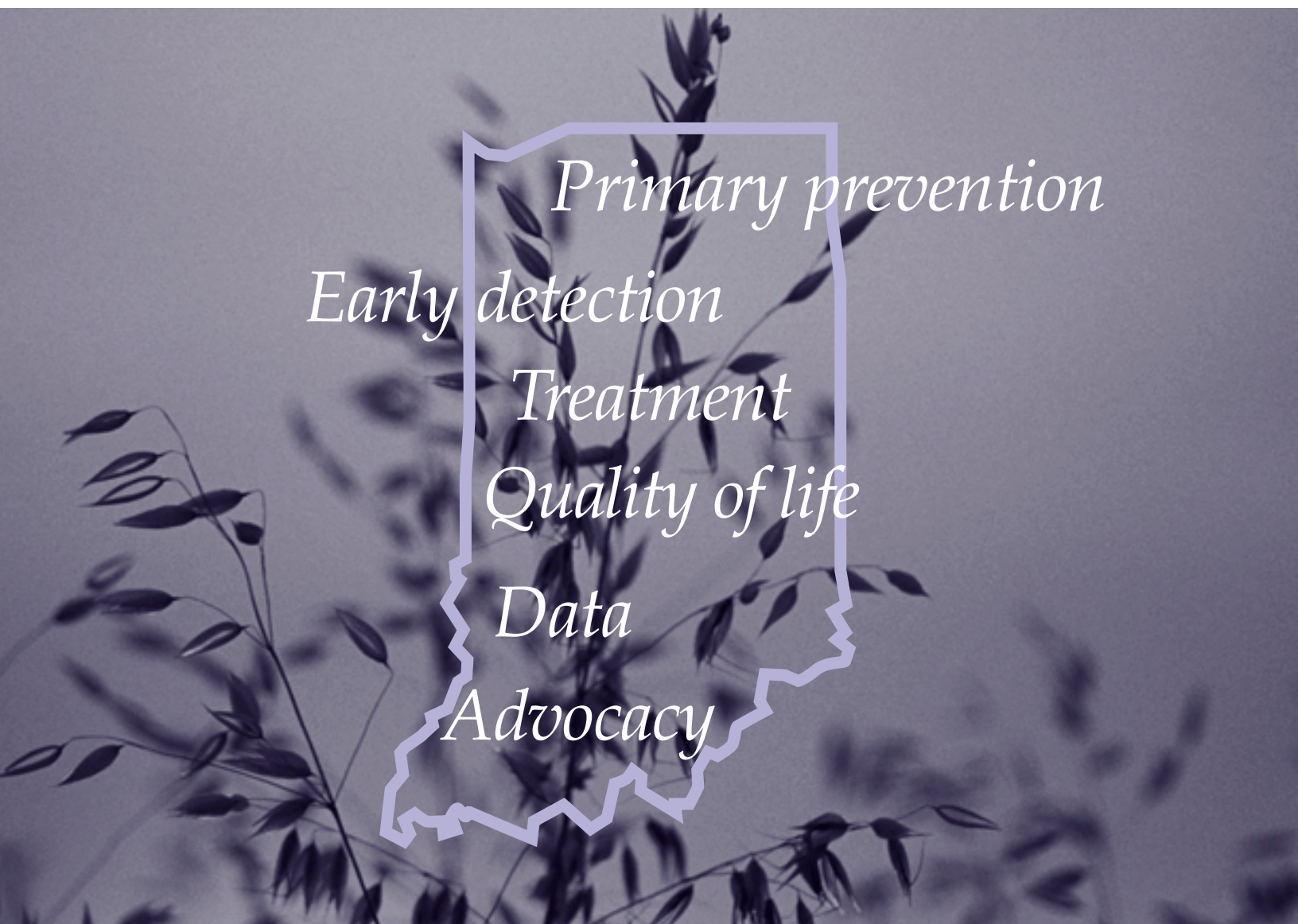


Indiana Cancer Control Plan

2005-2008



Primary prevention
Early detection
Treatment
Quality of life
Data
Advocacy

Indiana Cancer Consortium Mission

The Indiana Cancer Consortium is a statewide network of public and private partnerships whose mission is to reduce the cancer burden in Indiana through the development, implementation, and evaluation of a comprehensive plan that addresses cancers across the continuum from prevention through palliation.

Dedication

This cancer control plan is dedicated to all the Hoosiers who have been affected by cancer, and in memory of those who have died from the disease.

Cancer Control

Preventing the disease
Finding it early
Treating it promptly
Promoting quality living
Deciding with data
Advocating for change



Dear Reader,

Reducing the burden of cancer in Indiana will require close collaboration among public, private, and non profit organizations. Indiana has higher than average mortality rates for many cancers and has the fourth highest lung cancer rate in the country due to the high prevalence of smoking. Additionally, Indiana cancer data reflect significant disparities in stage at diagnosis, incidence, and mortality.

The Indiana Cancer Consortium, with over 100 participating groups, has been formed to meet this challenge. With assistance from the American Cancer Society, the Indiana Cancer Consortium has made significant progress in a few short years. The Indiana State Cancer Registry has been strengthened and has received Silver and Gold Certification status from the North American Association of Central Cancer Registries during the past two years. The first edition of the *Indiana Cancer Facts & Figures 2003*, is a consumer guide to state and county cancer statistics with recommendations for prevention and screening.

The *Indiana Cancer Control Plan* has been developed with the assistance of experts from the Indiana Cancer Consortium and its individual task forces. The plan is organized around the key areas of primary prevention, early detection, treatment, quality of life, data, and advocacy. Expert panels have assisted in developing objectives and strategies for the data-driven priorities of breast, colorectal, prostate, cervical, lung, and tobacco-related cancers.

Indiana has made great strides in the last several years in addressing public health needs related to cancer. Development and implementation of the cancer control plan will be the next major step forward in confronting the challenges of cancer in this state.

Gregory A. Wilson, M.D.
State Health Commissioner
Indiana State Department of Health

Indiana Cancer Control Plan
2005-2008



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We wish to thank the many individuals and organizations that participated in developing this *Indiana Cancer Control Plan 2005-2008 (ICCP)*. The Indiana Cancer Consortium (ICC) identified priority issues that needed to be addressed and set priorities among goals and objectives. Advisory Committees and their co-chairs spent significant amounts of time reviewing information and crafting goals, objectives, and strategies. The Consortium Steering Committee guided the plan's overall development and planning evaluation strategies.

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Executive Summary

This *Indiana Cancer Control Plan 2005-2008* was developed through the joint efforts of the Indiana State Department of Health (ISDH) and the Indiana Cancer Consortium (ICC), and funded in part by the National Comprehensive Cancer Control Program (NCCCP) at the Centers for Disease Control and Prevention (CDC). The ICC is a statewide network of public and private organizations representing multiple sectors with a shared mission of reducing the cancer burden in Indiana. This public-private collaboration is designed to maximize resources within the state, focus cancer control efforts toward areas of potentially significant impact, and reduce or eliminate disparities in the cancer burden in Indiana.

Priorities for action were identified by ICC participants, based on existing cancer incidence and mortality data, data-driven disparities, scientific research findings, and recognition of the significant role data and advocacy play in making a difference in cancer. More than 200 persons from over 100 organizations participated in developing the *Indiana Cancer Control Plan* goals. A Steering Committee and expert Advisory Committees guided the work involved in preparing this plan, and an evaluation consultant assists in ongoing evaluation of outcomes and the collaborative process.

This plan is designed to promote statewide coordination of public and private cancer control efforts, provide a framework for action to reduce the burden of cancer, and increase communication and collaboration among all those involved in working with cancer. Completion of this plan also lays the groundwork for Indiana to move into the implementation phase of the NCCCP.

Cancer in Indiana

Cancer is the second leading cause of adult deaths in Indiana, following heart disease. Although Indiana's overall cancer incidence rate in 2000 was 3% lower than the national rate, the state's mortality rate during the same year was 5% higher (1). The American Cancer Society (ACS) estimates that approximately 32,160 new cancer cases will be diagnosed in Indiana and approximately 13,250 Hoosiers will die from cancer in 2004 (2). From 1996 to 2000, the all-sites cancer incidence rate for African Americans was higher than for Caucasians (475.3 per 100,000 vs. 437.5 per 100,000). Furthermore, for the same time period, African Americans experienced a higher mortality rate than did Caucasians (278.8 per 100,000 vs. 211.0 per 100,000) (3).

The *Indiana Cancer Control Plan 2005-2008* is organized around the public health model of primary, secondary, and tertiary prevention. Within this framework, broad goals are defined for primary prevention, early detection, and treatment, along with objectives and strategies that address both general and cancer-specific issues. Likewise, goals, objectives, and strategies are identified for the cross-cutting issues of quality of life, data, and advocacy.



These goals are:

- **Primary Prevention:** Decrease cancer risk through lifestyle behavioral interventions.
- **Early Detection:** Increase early detection and appropriate screening for cancer.
- **Treatment:** Promote informed decision-making and utilization of appropriate cancer treatment.
- **Quality of Life:** Improve quality of life for patients with cancer, survivors, and their families.
- **Data:** Increase the quantity, quality, and availability of complete and timely cancer and related data.
- **Advocacy:** Enhance the capacity of the ICC, its member organizations, and other concerned individuals and organizations to articulate and advocate for ICC priority cancer-related public policy issues.

It is not possible to address all the issues associated with cancer control in one document. This plan is designed to be a living document that guides collaborative action throughout the state. It will be modified as the state moves toward the implementation phase of cancer control and as resources and needs within the state change.



Introduction

Cancer is a significant public health issue in terms of personal pain and suffering, increased medical costs, premature deaths, and loss of productive years of life. Cancer is the second leading cause of adult deaths in Indiana, following heart disease. Increased early detection and improved treatment protocols are changing the face of cancer. Depending on the type of cancer and the stage at diagnosis, cancer can be cured or become a chronic illness. Survival rates continue to increase, with a 63% national five-year survival rate for all cancers combined (2). Although progress is being made, much work remains to be done to reduce the cancer burden in Indiana.

Purpose of the *Indiana Cancer Control Plan 2005-2008*

The *Indiana Cancer Control Plan 2005-2008 (ICCP)* provides a framework for action to reduce the burden of cancer in Indiana. Its purpose is to provide statewide coordination of public and private cancer control efforts that are ongoing or needed within our state. It is intended for use by individuals and organizations in all areas of cancer control statewide.

The *ICCP* addresses all aspects of cancer, including primary prevention, early detection, treatment, quality of life issues, and end of life care. It also addresses the cross-cutting issues of data and advocacy. The goals and objectives within this plan are broad and are directed toward improving the lives of Hoosiers. Strategies for achieving these goals and objectives are quite varied and address public and professional education, collaboration among organizations, surveillance, and advocacy. As Indiana moves toward implementation of this cancer control plan, these strategies will offer interested partner organizations the opportunity to connect with comprehensive cancer control in ways that mesh with their own interests and expertise. Evaluation of goals and objectives and of the collaborative process itself is built into planning and implementation.

Indiana Cancer Facts & Figures 2003

Much of the background data for this plan comes from the *Indiana Cancer Facts & Figures 2003*, developed collaboratively by the American Cancer Society, the Indiana State Department of Health, and the Indiana Cancer Consortium. This publication represented an important first step in the development of a comprehensive cancer control plan for Indiana. Prior to this report, little up-to-date information was available to document how cancer affects the people of Indiana. The ACS and the ICC will update this publication every few years.



The Indiana Cancer Consortium

The Indiana Cancer Consortium is a statewide network of public and private partnerships whose mission is to reduce the cancer burden in Indiana through the development, implementation, and evaluation of a comprehensive plan that addresses cancer across the continuum from prevention through palliation.

Born from a vision of the ISDH, the Indiana University Cancer Center, the Indiana University School of Medicine Department of Public Health, and the ACS, Great Lakes Division, the ICC was launched in October 2001 when key stakeholders came together, united by a common mission. The ICC now has 55 formal organizational members and over 100 participating agencies deeply committed to making a difference in cancer through a collaborative process. Consortium co-chairs and a Steering Committee guide ICC planning activities, infrastructure development, partnership building, and both process and outcome evaluation. Co-chairs of the expert Advisory Committees are non-voting Steering Committee members to facilitate planning and decision-making.

The ICC is an association of diverse organizations representing health care providers and delivery systems, cancer programs, health insurance plans, employers, public health agencies, professional organizations, minority groups, health profession schools, advocacy groups, research institutions, and wellness organizations. In addition, the ICC maintains close working relationships with the ISDH and the State Health Commissioner. Their ongoing support and multiple resources for cancer control have been crucial in moving this partnership forward.

Priorities for action were identified by Consortium participants, based on cancer incidence and mortality data, data-driven disparities, scientific research findings, and recognition of the significant role data and advocacy play in making a difference in cancer. The five cancer-specific priority areas identified were breast, cervical, colorectal, prostate, and lung and other tobacco-related cancers, while data and advocacy were viewed as cross-cutting themes that impacted all planning activities. Expert volunteer Advisory Committees were convened around each of these priorities to best use issue-specific expertise and resources. These committees worked together over many months to develop cancer-specific goals, objectives, and strategies for the *ICCP*. Over 200 people were involved in this entire process.

Organization of the *Indiana Cancer Control Plan 2005-2008*

As the planning process evolved, similar themes appeared within the various cancer-specific Advisory Committees, such as prevention, screening, barriers to screening and treatment, quality of life, and end of life issues. It also became evident that collaborative implementation of the cancer plan would be facilitated by using the public health model of primary, secondary, and tertiary prevention. At the same time, a commitment was made to maintain a focus on all priority areas identified by the Consortium. Collaborative decision-making about these changes was facilitated at Steering Committee and Consortium meetings and supplemented by electronic communication.



The public health model of **primary, secondary, and tertiary** prevention provides a framework for organizing the goals and objectives of this *Indiana Cancer Control Plan*. **Primary prevention** emphasizes preventing or reducing risks of developing disease. Risk reduction methods could include promotion of individual behavior change, using chemopreventive agents, and system level policy changes. **Secondary prevention** involves identifying disease as early as is possible, often before symptoms develop, and treating that disease promptly. Screening programs should be targeted toward groups at greatest risk for developing a disease and toward those cancers for which screening has been found effective. **Tertiary prevention** focuses on delaying disease progression, reducing risks of complications or recurrence, prolonging life, and promoting quality of life. Tertiary prevention efforts are directed toward individuals and groups of people with existing problems, rather than broad population groups.

Therefore, the *Indiana Cancer Control Plan* is organized according to the following categories:


- Primary prevention
- Early detection
- Treatment
- Quality of life
- Data
- Advocacy

Objectives and strategies within these categories address the priority cancers identified by the Consortium: breast, cervical, colorectal, prostate, and lung and other tobacco-related cancers. As planning transitions into implementation, the ICC organizational structure will be adapted to facilitate collaboration within categories while maintaining a focus on cancer-specific issues.

The collaboration that is an integral component of the ICC is an application of public health practice. Many participating organizations are sharing knowledge, resources, and expertise with the goal of making a difference in cancer through their joint and coordinated work. This collaborative process is anticipated to continue as Indiana moves toward the implementation phase of comprehensive cancer control.

Comprehensive Cancer Control Planning and Implementation

Initially, cancer control planning was funded by state level public and private funds, primarily from the ISDH, the IU Cancer Center, and the ACS, Great Lakes Division. In 2003, the Centers for Disease Control and Prevention awarded a planning grant to the ISDH, which provided funds for hiring additional cancer control staff.



The Indiana planning award is part of the CDC National Comprehensive Cancer Control Program that provides funding to assist states with cancer control planning and implementation. Comprehensive cancer control is an integrated, coordinated, and multidisciplinary public health approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation (4). The CDC's *Building Blocks* model provides a framework for assessing and addressing the cancer burden through (5):

- enhancing infrastructure and resources for planning and implementation
- mobilizing statewide support
- using data and research to assess the cancer burden
- developing broad partnerships of public and private stakeholders
- developing a plan to address the cancer burden
- evaluating outcomes and the collaborative process

The ICC is the vehicle for collaborative comprehensive cancer control planning and implementation efforts in this state. Indiana anticipates applying for implementation status in 2005, which will provide increased CDC funding, eligibility for additional federal grants, and further opportunities for partnership activities. Clearly, planning and implementation are overlapping, not discrete, entities. Some implementation already has occurred, such as publishing the *Indiana Cancer Facts & Figures 2003*, conducting an advocacy capacity survey of ICC member organizations, and working with partner organizations to advocate successfully for an increased state tobacco tax. Likewise, implementation requires continuous planning and evaluation, reorganizing the ICC infrastructure, and adapting strategies to meet changes in the economic, political, scientific, and health care environments.

Given the comprehensive nature of this plan, consideration must be given to other major health improvement planning efforts currently underway such as the *American Cancer Society's 2015 Goals*, *Healthy People 2010*, *Healthy Indiana - A Minority Health Plan for the State of Indiana*, and *Indiana Medicine and Public Health Initiative: A Plan for Community Health Improvement 2004-2007*. Goals and objectives from these plans are cross-referenced throughout the *Indiana Cancer Control Plan*.

Evaluation Strategy

The ICC has partnered with the Center for Evaluation and Education Policy (CEEP) at Indiana University to evaluate the implementation of the *ICCP* as well as the ongoing activities and operations of the Consortium. During the planning phase, CEEP provided formative feedback to ensure that it would be possible to evaluate the goals and objectives of Indiana's plan. To the extent possible, data sources and baseline indicators for the objectives were articulated. Because the dynamic nature of the *ICCP* requires an evaluation that is flexible and adaptive, CEEP will ensure that all data collection and reporting strategies are responsive to the information and




decision-making needs of the Consortium. Although specific evaluation strategies may be altered across the multiple years of plan implementation, ongoing data collection and reporting will consistently focus on the following:

- **Monitoring implementation activities:** Together, CEEP and ICC leadership will develop strategies for monitoring activities described in the *ICCP*. Relevant activities will include those performed by ICC member organizations as well as those conducted by Consortium committees and leaders. Monitoring of activities will involve the use of annual or bi-annual reports, interviews, and surveys.
- **Measuring outcomes:** CEEP and ICC leadership have begun to identify the key outcomes that will be measured to assess the success of the *ICCP*. Issues related to feasibility of measurement, cost of collecting the needed data, and meaningfulness of the indicators are being considered in the decision-making process. Subsequently, CEEP will develop a system for regularly measuring these outcomes, collecting the needed data, and reporting progress back to the ICC and relevant stakeholders. While much of the data related to measuring outcomes will come from data collected through state and national entities such as ISDH and CDC, additional data may be collected through supplemental surveys or interviews.
- **Formative feedback:** Evaluation of the ICC and the implementation of the *ICCP* also will involve a formative component through which continual feedback is provided for program improvement. Formative evaluation questions and strategies will be based on CDC's *Guidance for Comprehensive Cancer Control Planning* and will serve to assess the extent to which the Consortium continues to provide the infrastructure, partnerships, and resources necessary for supporting implementation of the *ICCP*. Data collection is likely to include document review, key stakeholder interviews, and surveys. The data collected via these means will provide information needed for continually improving the implementation process and ongoing functioning of the Indiana Cancer Consortium (5).

The Indiana Environment For Cancer Control

Cancer is the second leading cause of death in the United States and is responsible for one of every four deaths. The ACS estimates that in 2004, about 1.3 million new cases of cancer are expected to be diagnosed and more than 563,700 Americans are expected to die from cancer. Further, in 2004, Indiana is projected to diagnose 32,160 new cancer cases and document 13,250 deaths due to cancer (2). From 1996-2000, Indiana mortality rates for all cancer sites declined slightly (from 217.3 to 213.7 per 100,000) and incidence rates increased over 5% (425.3 to 448.1 per 100,000) (1). These statistics indicate some progress may have been made in early detection and adequate treatment of some cancers.

According to the National Institutes of Health (NIH), in 2003 the overall cost for cancer in the United States was \$189.5 billion, which included \$64.2 billion for direct medical costs, \$16.3 billion for lost worker productivity due to illness and \$109 billion for lost worker productivity due to premature death (2). For specific cancers in 2002, colorectal cancer treatment cost about \$6.5 billion; breast cancer, nearly \$7 billion; and cervical cancer, nearly \$2 billion (6).



Cancer screening is a good investment, and health economists generally concur that if an intervention can save one year of life for less than \$50,000, it is cost-effective. Screening costs for colorectal, breast, and cervical cancer fall within that definition: colorectal cancer screening costs \$9,424 to \$26,228 per year of life saved; having a mammogram every two years for women aged 50-79 costs \$17,297 per year of life saved; and for having Pap tests every three years, the cost is \$4,535 per year of life saved (6).

Indiana Demographics

Indiana is the 14th most populous state, with an estimated 2003 population of 6,195,643. Between 2000 and 2003, Indiana's growth of 1.9% was slightly lower than the national rate of 3.3%. Indiana's growth was due to a natural population increase from more births than deaths as well as both national and international migration (7).

In 2000, Indiana's demographic breakdown was 87.5% Caucasian, 8.4% African American, 3.5% Hispanic/Latino origin, 0.3% American Indian and Alaska Native, and 1% Asian. The greatest growth among Indiana's minority groups is within the Hispanic/Latino community, which increased 117% between 1990 and 2000 (from 98,788 to 214,536), accounting for 22% of the state's population growth. Both the African-American and Asian populations also have grown between 1990 and 2000, although at a slower rate (7).

Indiana's median age of 35 (males 34 and females 37) in 2000 was exactly the same as the U.S median age. Indiana's 65 and over population has grown 1.3% between 2000 and 2003, which is half of the nation's 65 and over growth rate of 2.6%. Unlike the nation as a whole, Indiana's younger (5-13 year olds) population has grown 1.8%, whereas the nation has shown a decline of 0.7% between 2000 and 2003 (7).

State Efforts Toward Cancer Control

The **Indiana State Cancer Registry (ISCR)** began collecting information on all reportable cancers diagnosed in Indiana beginning January 1, 1987. Reportable cancers include all malignant neoplasms, except basal and squamous cell carcinoma of the skin. Data collected include patient demographics and specific details related to the cancer diagnosis and treatment. Data are used to monitor cancer incidence, provide statistics to the public and researchers, guide cancer prevention and control programs, and make comparisons of Indiana cancer with other states and the nation. By law, all data are confidential and only data without personal identifiers are published or made available for research. The cancer registry recently was awarded "Gold Certification" from the North American Association of Central Cancer Registries (NAACCR). This certifies the data for 2001 met the highest standards for quality, completeness, and timeliness as set forth by the NAACCR.



The **Indiana State Epidemiology Resource Center (ERC)** serves as the primary center for epidemiologic analysis of health data in the state of Indiana. The ERC is comprised of Behavioral Risk Factor Surveillance System (BRFSS), Data Analysis Team, Bioterrorism, Communicable Diseases, Chronic Diseases, and other areas.


The **BRFSS** is an annual statewide random telephone survey of adults aged 18 and older that identifies health behaviors and disease risk factors. Conducted in cooperation with the CDC, the questions vary somewhat from year to year and address overall health, chronic disease, screening practices, lifestyle-related behaviors, and access to health care. BRFSS reports provide invaluable data for planning and evaluation.

The Indiana **Youth Risk Behavior Surveillance System (YRBSS)** is the counterpart annual survey for high school youths and identifies lifestyle and behavioral choices made by youth. This survey is a collaborative effort conducted by the CDC and the Indiana Department of Education.

The **Indiana Breast and Cervical Cancer Program (INBCCP)** has been operational since 1996. The INBCCP provides reimbursement for mammography and clinical breast examinations for women aged 50-64 years who meet income guidelines and are uninsured or underinsured. It also covers Pap tests and pelvic examinations for women aged 40-64 who have not had a hysterectomy and meet the same guidelines. Through June 30, 2004, the INBCCP has served 33,775 women; funded 25,375 Pap tests; 16,160 mammograms; and 30,584 clinical breast exams. The program identified 233 cases of breast cancer and 17 cases of cervical cancer. Of the women served 74% were Caucasian; 21%, Hispanic/Latino; 14%, African American; 1%, Asian/Pacific Islander; and 1%, Native American.

The **Indiana Tobacco Prevention and Cessation (ITPC)** agency exists to prevent and reduce the use of all tobacco products in Indiana and to protect citizens from exposure to tobacco smoke. Following the CDC's *Best Practices for Tobacco Control*, Indiana established a tobacco control program that is coordinated, comprehensive, and accountable (8). ITPC coordinates and allocates resources to:

- change the cultural perception and social acceptability of tobacco use in Indiana
- prevent initiation of tobacco use by Indiana youth
- assist tobacco users in cessation
- assist in reduction and protection from second-hand smoke
- support the enforcement of tobacco laws concerning the sale of tobacco to youth and use of tobacco by youth
- eliminate minority health disparities related to tobacco use and emphasize prevention and reduction of tobacco use by minorities, pregnant women, children, youth, and other at-risk populations



A Plan for Community Health Improvement 2004-2007 is a call to action for Indiana communities developed by the Indiana Medicine and Public Health Initiative, a coalition of organizations representing different aspects of health, including the ISDH. Although this plan does not contain cancer-specific objectives, it addresses the significant related public health issues of primary prevention, health promotion, access to care, and education. The goals and objectives in this plan address public health infrastructure, personal health management, children and adolescent health promotion, access to quality health care, and education and community-based programs. This plan also provides a framework for collaboration among health-related organizations.

Healthy Indiana - A Minority Health Plan for the State of Indiana is an additional Indiana plan that addresses various aspects of health. This collaborative plan provides a guide for Hoosiers working together to **HEAL** the gap in racial and ethnic health disparities for all people in Indiana. **H**Health, **E**quality, **A**ccess, and **L**eadership are key themes within the plan. The plan includes general objectives related to workforce diversity and cultural and linguistic competence, as well as disease-specific objectives addressing diseases and health issues that have significant disparities, including 15 cancer-specific objectives. The ISDH, through its Office of Cultural Diversity and Enrichment, Office of Minority Health, and the Indiana Minority Health Advisory Committee are the lead entities in the preparation, development, and implementation of this plan. There also is close collaboration with the Indiana Minority Health Coalition. The plan is an excellent source of information and provides an opportunity for comprehensive cancer control collaboration with partners in the minority community.

Cancer Research in Indiana

Indiana has two NCI-designated Cancer Centers, one Community Clinical Oncology Program (CCOP), a private not for profit research center, and two collaborative research groups. Although basic research is conducted at all major state universities, it is focused primarily at the two NCI-designated cancer centers. Research institutions also promote interdisciplinary collaboration for developing strategies to support primary and secondary prevention, improved cancer care, and patient and professional education opportunities.

Indiana University Cancer Center is an NCI-designated Clinical Cancer Center located in Indianapolis on the Indiana University-Purdue University at Indianapolis (IUPUI) campus. The cancer center is a patient care, clinical and behavioral, research, and educational organization whose interdisciplinary programs include all the medical, surgical, and nursing specialties involved with the diagnosis and treatment of cancer. This team is supported by social service professionals, physical, occupational, and speech therapists, patient services professionals, clinical psychologists, and nutritionists. The cancer center mission is to reduce cancer incidence, suffering and mortality in Indiana and beyond. The IU Cancer Center also is the Indiana affiliate of the NCI Cancer Information Service (CIS), the nation's foremost source for the latest and most accurate cancer information for patients and their families, the public, and health professionals (9).



Purdue Cancer Center at Purdue University, is one of just eight NCI-designated basic research Cancer Centers in the United States. This cancer center is committed to helping cancer patients by identifying new molecular targets and designing future agents and drugs for effectively detecting and treating cancer. The center's research areas are cell growth and differentiation, experimental therapeutics and diagnostics, and structural biology (10).

Northern Indiana Cancer Research Consortium (NICRC) is an NCI-sponsored Community Clinical Oncology Program (CCOP). A CCOP is a comprehensive clinical trial mechanism for disseminating the latest cancer prevention and research findings to the community level, which enables those patients and physicians to participate in Phase I, II, and III clinical trials. The NICRC is supported by four member institutions, including Elkhart General Hospital, LaPorte Hospital, Memorial Hospital of South Bend, and St. Joseph Regional Medical Center (11).


Walther Cancer Institute is a private, non profit organization devoted to funding innovative research approaches in basic and behavioral sciences as well as clinical care. Funded scientists represent universities and organizations in Indiana and across the nation. The Walther Cancer Institute has collaborative basic research programs with Indiana University, Purdue University, and University of Notre Dame. The Institute's Mary Margaret Walther Program for Cancer Care Research supports interdisciplinary behavioral research focused on cancer prevention and early detection, management of symptoms and side effects of cancer treatment at diagnosis, long term survivorship issues, and problems patients and families face with advanced cancer (12).

Hoosier Oncology Group (HOG) is an innovative coalition of academics and practicing physicians who have banded together to conduct clinical and behavioral research. The HOG encourages community physicians to conduct clinical trials and increases community access to research opportunities. There are more than 400 HOG physicians from eight different states; however, the vast majority practice in Indiana. Based in Indianapolis, the HOG is funded in part by the Walther Cancer Institute (13).

Behavioral Cooperative Oncology Group (BCOG) is a cooperative study group. This coalition of academic institutions focuses on behavioral research and was formed to foster collaboration among behavioral oncology researchers and facilitate multi-site behavioral cancer research trials. BCOG members include Duke University, Indiana University, Michigan State University, Ohio State University, and University of Michigan. Based in Indianapolis, BCOG is supported in part by the Walther Cancer Institute (14).

Cancer Burden in Indiana

Indiana's incidence rate for cancer in the year 2000 was 451.4 cases per 100,000 Hoosiers, which is approximately 3% lower than the national rate of 462.9 per 100,000 (1). The state's mortality rate during the same year was 5% higher than the national rate of 213.7 vs. 202.8 deaths per 100,000 (1). The ACS estimates that approximately 32,160 new cancer cases will be diagnosed in Indiana and approximately 13,250 people in the state will die from the disease in 2004 (2).



Incidence for cancers of breast, lung (the term “lung” in this document refers to cancers of the lung and bronchus), and colon remained relatively stable from 1996-2000. Incidence for prostate, testicular, pancreatic, kidney/renal pelvis cancers, and melanoma of the skin experienced increases of 12 to 16%, and cervical, oral cavity and pharynx cancer experienced about a 7% decline. Mortality rates for all cancer sites in the same time period showed slight decreases from 217.3 to 213.7 deaths per 100,000, and declines of 12, 16 and 25% were witnessed for breast, prostate, and cervical cancers respectively. The mortality rate for lung cancer remained relatively constant at 65 deaths per 100,000, and was the highest mortality rate among all cancer sites (1).

Stage at diagnosis is an important predictor of the outcome of cancer treatment. Between the years of 1996 and 2000, 50.2% of all new cancers in Indiana were diagnosed in early stages (in situ or local stages), 22.3% were diagnosed at a regional stage, and 19.5% at a distant stage (3).

Cancer Disparities

The cancer burden in Indiana affects different racial and ethnic groups at different rates, and these differences have been described as health disparities. Health disparities are the differences in the incidence, prevalence, mortality, and related adverse health conditions that exist among specific populations. Specific efforts must be made to eliminate these disparities. Some of the differences in cancer incidence and mortality rates among racial and ethnic groups are cited in this section. According to the Institute of Medicine's recent publication, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, variables such as socioeconomic class, differences in risk factors, environmental conditions, racial discrimination, and reduced access to appropriate medical testing and treatment also must be considered (15). Religion, cultural beliefs, and age also play a key role in attitudes toward health and associated behaviors of any given population (16).

Although comprehensive cancer and related data for the African-American population exists, such data are not currently available for the Hispanic/Latino population in Indiana. Additionally, there were insufficient cancer deaths among Hispanics/Latinos in Indiana to produce stable rates. Indiana's Hispanic/Latino population, however, increased 117.2% from 1990-2000, indicating the need for more data to assist in program planning (7). Currently, only a small proportion of Hispanic/Latino residents are in high-risk age groups for cancer due to the fact that over 80% of the population is below 45 years of age. Over time, it is expected that cancer rates will become significant in this population.

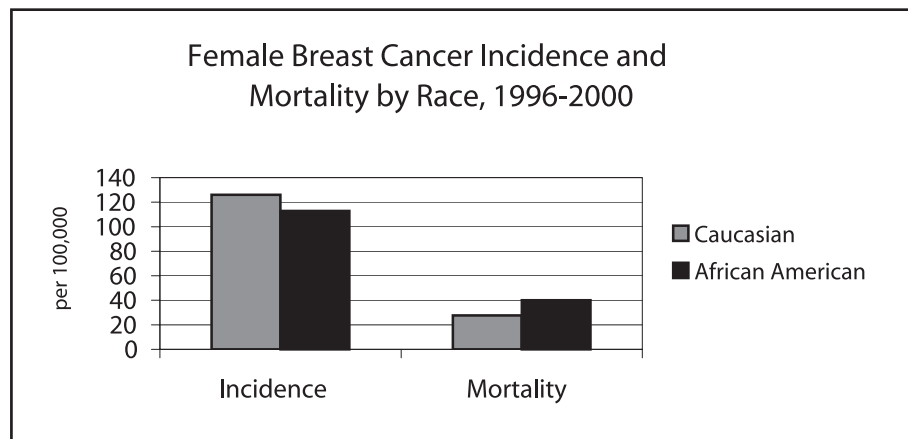
Breast Cancer Data

The average annual mortality rate for breast cancer in Indiana women from 1996-2000 was 28.4 deaths per 100,000. Between 1996 and 2000, approximately 94% of women in Indiana who developed breast cancer were aged 40 and over compared to 95% in the United States. Women aged 40 and over accounted for 96.8% of Indiana breast cancer deaths compared to



97% in the United States. In Indiana and nationally, African-American women are less likely to be diagnosed with breast cancer (112.8 vs. 126.1 cases per 100,000 women respectively) but have a higher mortality rate from breast cancer than do Caucasian women (40.1 vs. 27.6 deaths per 100,000 women respectively) (See Figure 1). In Indiana, 68.9% of women's breast cancer from 1996-2000 was diagnosed in early stages. African-American women, however, were significantly less likely to have their breast cancers diagnosed at an early stage (61.97% vs. 69.38% for Caucasian women) (1).

FIGURE 1



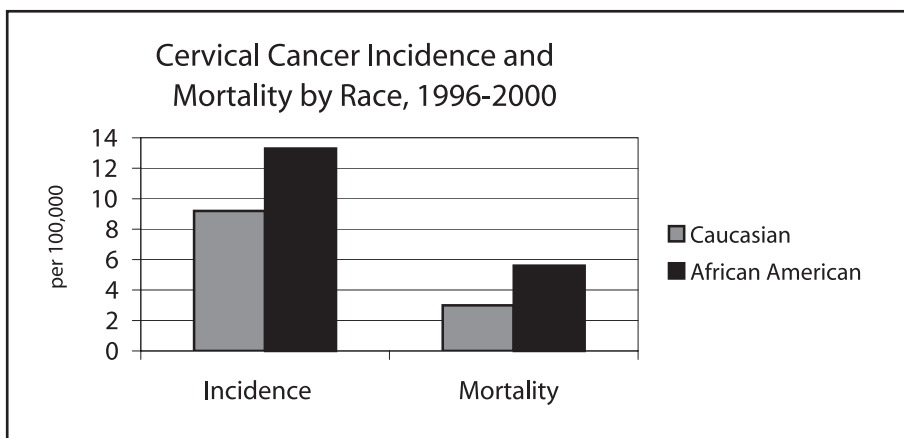
Source: Indiana State Department of Health - Indiana State Cancer Registry and the Epidemiology Resource Center, Data Analysis Team, May 2003. Rates are per 100,000 female population and age adjusted to the 2000 U.S. Population standard.

Cervical Cancer Data

Cervical cancer is almost completely preventable, especially when Pap tests are done regularly. Although Indiana cervical cancer incidence and mortality rates are low, disparities persist. In year 2000, 283 Indiana women were diagnosed with invasive cervical cancer for an age-adjusted incidence rate of 4.7 per 100,000, which is significantly lower than the national rate of 7.6 per 100,000. In 2001, 80 Indiana women died of cervical cancer for a mortality rate of 2.5 per 100,000 compared with an estimated national rate of 2.9 per 100,000. From 1996 to 2000, African-American women in Indiana experienced greater incidence and mortality from cervical cancer than Caucasian women (13.3 vs. 9.2 cases per 100,000; 5.6 vs. 3.0 deaths per 100,000) (1) (See Figure 2).

Nationally, from 1992-1999, 54% of cervical cancer cases were diagnosed early (in situ or at a local stage). The five-year national relative survival rate for women diagnosed at a local stage was 92.2% in 1992-1999. In Indiana, from 1996-2000, 87% of women's cervical cancer was diagnosed early at the in situ or local stage. African-American women in Indiana, however, are more likely to be diagnosed at a late stage than are Caucasian women. Because of small numbers, incidence and mortality rates are not available for Hispanic/Latina populations (1).

FIGURE 2



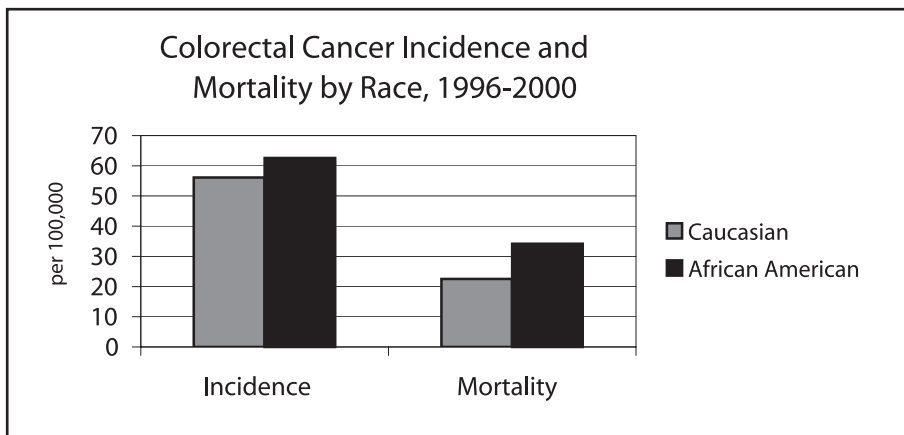
Source: Indiana State Department of Health - Indiana State Cancer Registry and the Epidemiology Resource Center, Data Analysis Team, May 2003. Rates are per 100,000 female population and age adjusted to the 2000 U.S. Population standard.

Colorectal Cancer Data

Although colorectal cancer mortality has declined 27% in Indiana over the past two decades, from 1996-2000, a yearly average of 3,286 Hoosiers developed colorectal cancer and 1,357 Hoosiers died of the disease. Mortality rates have dropped from 31.4 per 100,000 in 1976 to 21.9 per 100,000 in 2000 (17). From 1996 to 2000, African Americans in Indiana experienced higher colorectal cancer incidence and mortality rates (62.6 and 34.2 per 100,000, respectively when compared with Caucasians (56.1 and 22.5 per 100,000, respectively) (3) (See Figure 3).

Chance of survival from colorectal cancer is more than 90% when the cancer is diagnosed before it has extended beyond the intestinal wall. From 1996 to 2000, about 39% of colorectal cancers diagnosed in Indiana were early stage, compared to 74% for prostate and 69% for breast cancer (3).

FIGURE 3



Source: Indiana State Department of Health - Indiana State Cancer Registry and the Epidemiology Resource Center, Data Analysis Team, May 2003. Rates are per 100,000 population and age adjusted to the 2000 U.S. Population standard.

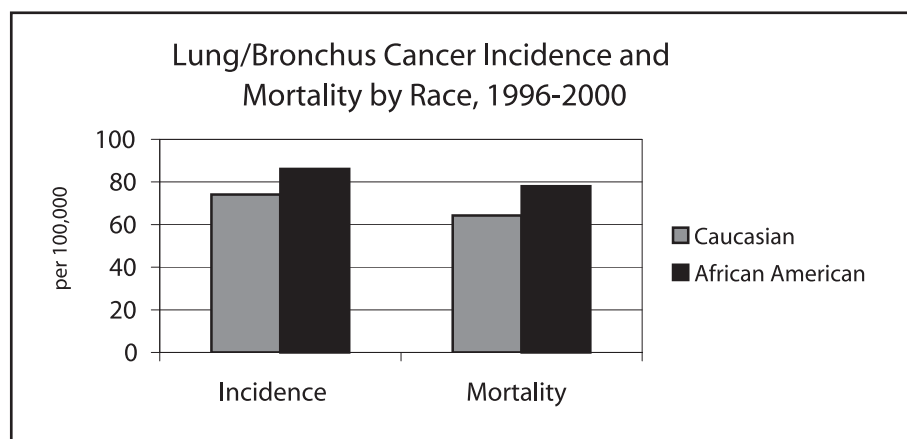


Lung Cancer Data

Nationally, the 1996-2000 lung cancer incidence rates for men averaged 85 per 100,000. For the same time period, the Indiana male lung cancer incidence rates were much higher, at 103.8 per 100,000. Female lung cancer incidence also was higher than national rates (54.4 per 100,000 vs. 51.6 per 100,000). Lung cancer is the leading cause of cancer mortality in Indiana, killing an average of 3,800 Hoosiers per year between 1996 and 2000. African-American Hoosiers have both higher lung cancer incidence and mortality rates (86.1 and 78.0 per 100,000 respectively) than Caucasians (74.1 and 64.3 per 100,000 respectively) (1) (See Figure 4).

Lung cancer most often is diagnosed at regional and distant stages, which negatively impacts the odds of survival. Five-year probability of survival is highest if lung cancer is diagnosed early, with a 48% five-year survival rate for lung cancers diagnosed at the local stage. Only 21% of lung cancers in Indiana, however, were diagnosed at the local stage between 1996 and 2000 (1).

FIGURE 4



Source: Indiana State Department of Health - Indiana State Cancer Registry and the Epidemiology Resource Center, Data Analysis Team, May 2003. Rates are per 100,000 population and age adjusted to the 2000 U.S. Population standard.

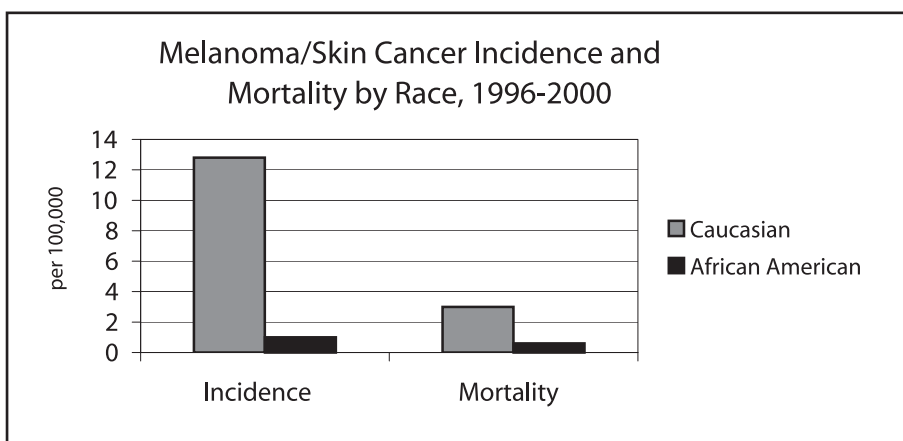
Melanoma/Skin Cancer Data

In year 2000, 1,029 Hoosiers were diagnosed with and 191 Hoosiers died of malignant melanoma. Approximately 60% of the deaths occurred in men and 40% of the deaths occurred in women (1). Due to underreporting for this cancer site, the reader must use caution when analyzing the incidence data for skin cancer. The most serious form of skin cancer is melanoma, which is expected to be diagnosed in about 1,320 Indiana residents in 2004 (2). During the 1970s, the incidence rate of melanoma increased rapidly at about 6% per year. Since 1981, however, the rate of increase slowed to a little less than 3% per year. Melanoma is primarily a disease of Caucasians, and rates are more than 10 times higher than in African Americans. Caucasian Hoosiers have both higher melanoma incidence and mortality rates (12.8 and 3.0 per 100,000 respectively) than African Americans (1.1 and 1.3 per 100,000 respectively) (3) (See Figure 5). Melanoma mortality

for the more recent period is increasing less rapidly in Caucasian men, while it has stabilized among Caucasian women.

Basal cell or squamous cell cancers (non-melanoma skin cancers) are highly curable if detected and treated early. Melanoma can spread to other body parts quickly, but it too, can be cured if detected early. The five-year survival rate nationally for patients with melanoma is 89%. For localized melanoma, the five-year survival rate is 96% nationally, with about 82% of melanomas diagnosed at the local stage. In Indiana, 85% are diagnosed at or before the local stage (1).

FIGURE 5



Source: Indiana State Department of Health - Indiana State Cancer Registry and the Epidemiology Resource Center, Data Analysis Team, May 2003. Rates are per 100,000 population and age adjusted to the 2000 U.S. Population standard.

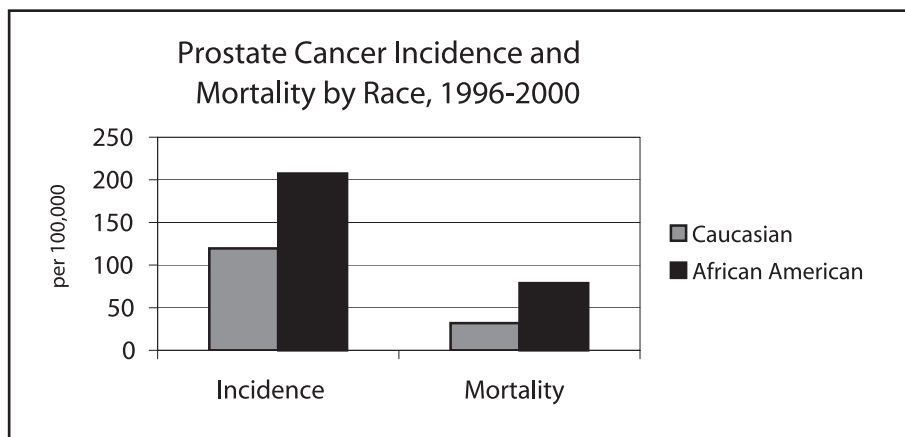
Prostate Cancer Data

There were 3,593 prostate cancer cases in Indiana in 2000 (3). Prostate cancer accounted for just over 24% of all cancer cases in Indiana men between 1996 and the year 2000. In 2000, the Indiana prostate cancer incidence rate was 134.5 compared to 170.2 in the United States. Prostate cancer deaths make up approximately 11% of all cancer deaths in Indiana men. African-American men in Indiana experience a significantly greater prostate cancer burden when compared to Hoosier Caucasian men. From 1996 to 2000, average incidence and mortality rates in African-American men were 207.4 and 78.8 per 100,000, compared with Caucasian incidence and mortality rates of 119.6 and 32.0 per 100,000, respectively (1) (See Figure 6).

From 1996 to 2000, 85% of Indiana men diagnosed with prostate cancers were diagnosed in the local and regional stages. When considering race, 86% of Caucasian men diagnosed with prostate cancer were diagnosed at a local or regional stage, compared to 81% of African Americans. Additionally, 5% of Caucasian men and 10% of African-American men were diagnosed at the distant stage, a stage where prognosis is generally less positive (1).



FIGURE 6



Source: Indiana State Department of Health - Indiana State Cancer Registry and the Epidemiology Resource Center, Data Analysis Team, May 2003. Rates are per 100,000 male population and age adjusted to the 2000 U.S. Population standard.



Primary Prevention


Primary prevention includes those steps taken by individuals, organizations, or communities to prevent the development of disease. Adopting specific lifestyle behaviors can lower cancer risk. The healthy lifestyle behaviors most effective in preventing cancer include avoiding tobacco products and secondhand smoke, minimizing alcohol intake, following a balanced diet, exercising regularly, and protecting against ultraviolet light exposure. Raising awareness about the impact people can have on their own health status through adopting healthy lifestyle behaviors is a positive first step toward cancer prevention. The recent historic collaboration among the ACS, American Diabetes Association (ADA), and American Heart Association (AHA) underscores the significance of these lifestyle changes. This collaboration encourages the prevention and early detection of cancer, diabetes, heart disease, and stroke through the initiative Everyday Choices for A Healthier LIFE. This joint initiative aims to stimulate improvements in disease prevention and early detection by increasing public awareness about healthy lifestyles, increasing the focus on prevention among healthcare providers, and supporting legislative action to increase funding for and access to prevention programs and research.

Tobacco

A recent report from the United States Surgeon General titled *The Consequences of Smoking* indicates that cigarette smoking, "...harms nearly every organ of the body, causing many diseases and reducing the health of smokers in general" (18). According to the ACS, smoking accounts for 30% of all cancers (19). This report illustrates the need to eliminate smoking in America. In a country where medical costs are very high and health insurance is not available to all people, the cancer burden caused by smoking is difficult to bear.

The rates of cigarette usage in Indiana are extremely high as it ranks fifth in the nation with 27% of Hoosier adults being smokers. An astonishing 31.6% of high school-aged children smoke and 9.9% of middle school aged children smoke (1). Furthermore, smoking rates among pregnant women are high in Indiana: 20% of women in Indiana smoked during pregnancy from the years 1996-2001 (1). High rates of cigarette use in Indiana are facilitated by their low price. Currently, the state tax on a pack of cigarettes is only 55.5 cents, which ranks 29th in the United States, compared to New Jersey, which boasts the highest cigarette excise tax of \$2.05 (20).

To improve the health of Indiana residents, a crucial step is for the public health community to promote smoking prevention among the general public. Another important step is to make smoking cessation options available to current smokers. Cigarettes contain nicotine, a highly addictive substance, which causes cessation to be difficult to achieve without assistance. Recent studies report that the ACS Quitline is a highly successful method and "nearly doubles a smoker's chances of quitting successfully compared to the use of self-help materials alone" (21).



Smokeless tobacco usage also is a major problem in Indiana. “In 1998, 15% of Hoosier adults reported using smokeless tobacco” (1). Smokeless tobacco use is not limited to adults. Currently, 4% of middle school students and 7% of high school students in Indiana chew tobacco (1). Using smokeless tobacco is a major risk factor for oral cancer. Oral cancer includes cancer of the lip, tongue, floor of the mouth, palate, gingiva, and alveolar mucosa, buccal mucosa, and oropharynx (22).

In Indiana, oral cancer rates are highest among African-American men, with an incidence rate of 18.0 per 100,000 compared to 15.1 per 100,000 for Caucasian men (23). While the cause of this difference is unclear, it may be related to higher smoking rates and/or lower dental service utilization rates among African-American males.

Nutrition/Physical Activity

Indiana faces a challenge in overcoming unhealthy lifestyles ranging from dietary habits to tobacco use. Ranked as the 10th most obese state and the 15th most overweight state, Indiana is confronted with a serious health threat. Obesity is defined as having a Body Mass Index (BMI) \geq 30.0, while being overweight is defined as having a BMI between 25.0 and 29.9. BMI is defined as weight in kilograms divided by height in meters squared (kg/m^2), and offers an easily obtainable quantification of the relationship between weight and height (24). Additionally, obesity and being overweight contribute to many health conditions besides cancer including heart disease, hypertension, and diabetes. It is imperative that people in Indiana work together to solve this growing epidemic.

Lowering fat intake and increasing daily consumption of fruits and vegetables are positive steps toward a healthier and leaner Indiana population. Statistics show, however, that Hoosiers do not follow nutritional guidelines. Currently, only 21.7% of Indiana adults eat the five to nine servings of fruits and vegetables recommended to lower colorectal cancer risk (25). Given busy lives, limited time, and the growing number of fast food options, it is easy to opt for convenient, high-fat, low nutrient meals rather than traditional meals containing fruits and vegetables prepared at home.

According to the 2002 BRFSS, 27.5 % of Indiana adults did not engage in any leisure-time physical activity (25). While leisure-time physical activity is the first step toward being active, healthy adults actually require moderate physical activity on a regular basis. *Healthy People 2010* recommends adults “...engage regularly, preferably daily, in moderate physical activity for at least 30 minutes per day” (26). Although the protective impact of physical activity on cardiovascular health appears to be well-known, many people are unaware of its cancer prevention benefits.



Ultraviolet Exposure

Although Indiana has only five months of outdoor sunbathing opportunities each year, overexposure to ultraviolet rays still poses a serious threat of melanoma and other skin cancers for Hoosiers. In 2000, Indiana's melanoma incidence rate was 12.5 per 100,000 (U.S. incidence rate was 15.3 per 100,000 for 2000) (27). Basal cell and squamous cell cancers are the most common forms of skin cancer. These cancers can be prevented by protecting the skin against ultraviolet exposure. Indiana residents need to be aware of the increased risk of skin cancers from sun exposure and tanning beds. Contrary to the common belief that using tanning beds makes people look healthier, in actuality, tanning bed usage is detrimental to skin's health and can cause premature wrinkles, permanent skin damage, and skin cancer. Finally, the American Cancer Society recommends wearing protective clothing and using sunscreens with SPF (Sun Protection Factor) 15 or greater when exposed to the sun (1).

Cervical Cancer

In Indiana, African-American females have a higher cervical cancer incidence rate than do Caucasians (13.3 per 100,000 vs. 9.2 per 100,000) (1). Research has shown a direct link between the Human Papilloma Virus (HPV) and the development of cervical cancer. Cervical cancer risk can be reduced by limiting the number of lifetime sexual partners to prevent HPV infection, delaying first sexual experience, using barrier contraceptives during sexual intercourse, and avoiding cigarette use.



Primary Prevention

Goal: Decrease cancer risk through lifestyle behavioral interventions.

■ OBJECTIVE 1:

Increase the percentage of residents who follow a healthy lifestyle as recommended by leading health organizations.

Cross Reference: *HP 2010 Objectives:* 3-9, 19-1, 19-2, 19-3, 19-3c, 19-5, 19-6, 22-1, 22-2, 22-3, 22-7, 22-8; *Healthy Indiana-Minority Health Plan Strategies:* CVD S3.8; *ACS 2015 Nationwide Objectives:* Nutrition, Physical Activity, Sun Protection

Baseline: 21.7% of adults report eating five or more servings of fruits and vegetables per day
20.3% of youth eat fruits and vegetables five or more times per day

Target: 30% for adults and youth

Baseline: 23.1% of adults are obese

Target: 15% for adults

Baseline: 35.6% of adults are overweight

Target: 15% for adults

Baseline: 11.5% of youth are overweight

Target: 5% for youth

Baseline: 14.2% of youth are at risk of being overweight

Target: 5% for youth

Baseline: 72.5% of adults during the past month, other than their regular job, did participate in physical activity or exercise
31.9% of youth participate in an insufficient amount of physical activity

Data Sources: Youth Risk Behavior Survey, Indiana 2003 (28); Behavioral Risk Factor Surveillance System Indiana 2002 (25)

STRATEGIES:

1. Advocate for policies that promote increased physical activity and healthy food choices in schools, the workplace and communities.
2. Increase the proportion of adolescents who engage in vigorous physical activity that promotes cardiorespiratory fitness three or more days per week for 20 or more minutes per occasion.
3. Increase the proportion of adults who engage regularly, preferably daily, in moderate physical activity for at least 30 minutes per day.
 - Create point-of-decision prompts (such as, motivational signs placed by elevators and



escalators encouraging stair use for health/weight control).

- Create avenues for non-family exercise support (such as, walking groups, workout buddies).
4. Support transportation policy and infrastructure changes to promote non-motorized transit (such as, creating and/or enhancing bike lanes, requiring sidewalks and adding bicycle racks to buses).
 5. Promote the adoption of healthy eating habits.
 - Raise awareness about healthy food preparation, balanced nutritional intake and appropriate portion sizes.
 - Empower caregivers to have children eat less fat, more fruits, vegetables, and whole grains by providing time-saving ideas and recipes.
 - Provide informed and easily accessible education programs in the home and community that focus on developing knowledge and skills related to nutrition and meal planning, food purchasing, preparation, safety, and food budgeting.
 - Promote “5 to 9 a day” program for Hoosiers.
 6. Educate the public about the causes of skin cancer and methods of prevention.
 - Promote the American Cancer Society’s “Slip! Slop! Slap!” program in Indiana schools and workplaces.
 - Conduct a public education campaign about skin changes.
 - Encourage primary care providers to have a discussion with their patients about the need for limited exposure to ultraviolet rays.

■ OBJECTIVE 2:

Eliminate disparities and barriers to adopting the recommended cancer risk-reduction lifestyle behaviors.

Cross Reference: *Healthy Indiana-Minority Health Plan* Objective: CAN-S1.1, Strategies: CAN-S2.6-CAN-S3.6

STRATEGIES:

1. Disseminate information to health care providers and the general public about modifiable and non-modifiable cancer risk factors, using culturally and literacy-level appropriate education materials.
2. Involve insurers and employers in planning solutions that impact consumer lifestyle factors.
3. Disseminate risk-reduction public education materials that are culturally and literacy-level appropriate for target audiences, identify gaps in those materials and develop materials as needed.
4. Identify disparities and barriers in adopting lifestyle factors and risk-reducing behaviors related to cancer prevention.



5. Conduct public media campaigns about breast and colorectal cancer risk, risk-reduction and prevention (such as, radio and television public service announcements).
6. Increase awareness among health care providers and women of all ages about the importance of risk-based cervical cancer screening and lifestyle risk factors.

■ **OBJECTIVE 3:**
Increase the percentage of adults and youth who attempted to and successfully quit using tobacco.

Cross Reference: *HP 2010 Objectives:* 27-1a, 27-10, 3-10; *A Plan for Community Health Improvement 2004-2007 Objectives:* 4-1, 4-3; *ACS 2015 Nationwide Objectives:* Adult Tobacco Use

Baseline: 48.5% of adults attempted to quit

Target: 81% of adults attempted to quit

Baseline: 10.3% of adults successfully quit

Target: 31% successfully quit

Baseline: 71% of adults work in a smoke free workplace

Target: 96% of adults work in a smoke free workplace

Baseline: 14.5% of smokers reported their health coverage pays for smoking cessation services

Target: 40% of smokers reported their health coverage pays for smoking cessation services

Baseline: 55.5 cents tax per pack

Target: \$2.00 tax per pack

Baseline: \$2.76 per capita spent on tobacco control programs

Target: \$5.93 per capita spent on tobacco control programs

Baseline: 30.4% of youth are currently using tobacco

25.6% of youth currently smoke cigarettes

72% of youth (grades 6-12) report being in the same room or car with someone who is smoking during at least one of the past 7 days

30% of youth (grades 6-12) are exposed to secondhand smoke daily

57% of middle school cigarette smokers attempted to quit

62.1% of high school cigarette smokers attempted to quit

Data Sources: *Indiana Adult Tobacco Survey 2002* (29); Federation of Tax Administrators (20); *Indiana Youth Tobacco Survey 2002* (30); *Indiana Youth Behaviors Risk Factor Survey 2003* (28); Centers for Disease Control and Prevention. *Best Practices for Comprehensive Tobacco Control Programs* (8)



STRATEGIES:

1. Educate employers about smoking cessation and the benefits of a smoke-free workplace.
2. Educate health care professionals, including pediatricians, about the importance of tobacco prevention education.
3. Increase the percentage of health care providers who offer tobacco cessation counseling to patients and their families at the time of diagnosis for all cancers.
4. Offer incentives to health care providers and employers for smoking cessation efforts.
 - Honor businesses that have innovative smoking prevention, smoking cessation and smoke-free workplace programs.
 - Develop a program through which a smoke-free “seal of approval” is provided for business owners to put on their door.
5. Use mass communication (such as, television, radio and print media) to target the public with smoking prevention and cessation messages.
6. Provide information to the public about the cancer risks of using smokeless tobacco.
 - Encourage school sports coaches and physical education teachers to discuss the hazards of smokeless tobacco with students, especially males.
 - Provide information to schools about smokeless tobacco cessation programs.
 - Encourage dental providers to discuss the hazards of smokeless tobacco with their adult and youth patients.
7. Support organized efforts toward decreased exposure to secondhand smoke in the home and the workplace.
8. Create expanded access to smoking cessation programs.
 - Increase the percentage of smokers who can receive tobacco cessation insurance benefits.
 - Explore adoption of the American Cancer Society Quitline.
 - Create innovative methods of offering smoking cessation programs at the community level.
9. Advocate for tobacco control policies affecting both adults and youth.
 - Support an increase in no-smoking ordinances throughout all counties in Indiana.
 - Increase Indiana’s cigarette excise tax from 55.5 cents to \$2.00 by 2008.
 - Increase the level of support for state-wide tobacco control programs to CDC recommended level of per capita spending.



■ **OBJECTIVE 4:** **Decrease tobacco use among youth.**

Cross Reference: *HP 2010 Objectives:* 27-3, 27-2b; *A Plan for Community Health Improvement 2004-2007 Objectives:* 4-4, 4-7; *ACS 2015 Nationwide Objectives:* Youth Tobacco Use

Baseline: 13.6% non-compliance among tobacco retailers selling products to minors

Target: 0% non-compliance among tobacco retailers selling products to minors

Data Sources: Tobacco Retailer Inspection Program 2003 (31)

STRATEGIES:

1. Eliminate non-compliance among tobacco retailers selling products to minors.
2. Support evidence-based tobacco prevention and cessation programs targeted at youth.



Early Detection

Cancer occurs when abnormal cellular activity produces a tumor or growth in the body. For certain cancers, screening tests can detect cancerous or pre-cancerous changes at an early stage, which allows prompt treatment and a greater likelihood of a positive outcome. Early detection through regular screening examinations saves lives by identifying cancers when they are most curable and treatment is most likely to be successful. Cancers that can be detected through early screening include breast, colon, rectum, cervix, prostate, testis, oral cavity, and skin, and account for about half of all new cancer cases. Early detection of certain cancers, however, is not without risk, therefore, each cancer site should be addressed individually (1).

Breast Cancer

Improved survival rates are related to early detection and adequate treatment. Nine out of 10 women remain in remission 10 years after diagnosis when the tumor is detected early (in situ or local stage). From 1996 to 2000 the breast cancer stage at diagnosis among Hoosier women was 15.0% in situ, 54.0% local, 25.0% regional, 4.0% distant, and 2.0% unstaged/unknown (1).

The ACS recommends all women aged 40 and older receive yearly mammograms and clinical breast examinations. Monthly breast self-examination is an option for women, starting in their twenties, although its efficacy is unclear. At this time, mammography is the most effective breast cancer screening tool and can detect breast cancer about 1.7 years earlier than clinical examination or breast self-examination alone (1). According to the 2002 BRFSS data for women aged 40 and older, however, only 57% of Caucasian women and 54.9% of African-American women had a mammogram in the past year (25).

Indiana has mandated insurance coverage for mammography. Medicare covers annual mammography for women aged 65 and older and the INBCCP provides free mammograms for income-eligible women aged 50 to 65. These systems, however, leave gaps in coverage for uninsured and underinsured women and low income women between ages 40 and 50 who are not Medicaid eligible.

Racial disparities in breast cancer are a major concern in Indiana. Although the difference in mammography use is relatively small, the mortality rate for African-American women is 40.1 per 100,000 compared to 27.6 per 100,000 for Caucasians. This alarming difference indicates a need to raise awareness about breast cancer and promote routine screening among African-American women in Indiana (1).



Colorectal Cancer

Colorectal cancer can almost always be cured if detected early and treated adequately. Screening tests can detect colon polyps (tissue growths) before they become cancerous, as well as early-stage colorectal cancers. Screening guidelines are specifically aimed at adults aged 50 and older who are at average risk, or younger individuals with a family history of colorectal cancer or personal history of chronic inflammatory bowel disease, colon polyps, or colorectal cancer. Screening methods include colonoscopy, flexible sigmoidoscopy, double-contrast barium enema, and stool blood tests. The preferred method of screening for individuals at average risk is fecal occult blood testing and sigmoidoscopy. The preferred method for individuals at high risk is a colonoscopy (1).

Efforts to increase colorectal cancer screening must be combined with addressing the challenge of having enough screening facilities and trained providers. Because colorectal cancer screening requires specific skill sets, continuing education and training for health care providers are necessary to meet the needs of the aging Indiana population.

The incidence rate of colorectal cancer from 1996-2000 in Indiana was 56.1 per 100,000, while the mortality rate for colorectal cancer was 23.2. For the same timeframe, African Americans in Indiana experienced increased colorectal cancer incidence and mortality rates (62.6 and 34.2 per 100,000) when compared to Caucasians (56.1 and 22.5 per 100,000) (3). This considerable disparity needs to be addressed by increased screening among African Americans to prevent late stage diagnosis.

Prostate Cancer

Prostate cancer is the most commonly diagnosed cancer in Hoosier men, and is the second leading cause of cancer death for them. From 1996 to 2000, the prostate cancer mortality rates of African-American men were dramatically higher than Caucasian men on a national level (73 per 100,000 vs. 31.2 per 100,000) (32). For the same timeframe, the disparity is even greater in Indiana (78.8 per 100,000 vs. 32 per 100,000) (1). Although late stage diagnosis and treatment barriers are thought to be key factors, much remains to be learned about this disproportionate prostate cancer burden among African-American men.

The Prostate-Specific Antigen (PSA) test and the digital rectal exam (DRE) are the most common tests used to detect prostate cancer before symptoms occur; however, only a biopsy provides a definitive diagnosis. Although there is supportive evidence that PSA screening can detect early-stage prostate cancer, evidence is mixed and inconclusive regarding whether early detection improves health outcomes. Additionally, prostate cancer screening can cause anxiety related to follow-up testing from frequent false-positive results. Even when detected early, treatment is controversial. Significant side effects are associated with treatment regimens and untreated prostate cancer might not affect an individual patient's health or longevity.



Since current evidence is insufficient to determine whether the potential benefits of prostate cancer screening outweigh its potential harms, there is no scientific consensus that widespread screening is beneficial. Age, family history, and race are the principal risk factors for prostate cancer and many providers and health organizations look at these factors when making recommendations about prostate cancer screening.

The key to early detection for prostate cancer is to employ shared and informed decision-making between health care providers and patients. It is recommended that men discuss prostate cancer screening with their health care provider (shared decision-making) and/or learn about the pros and cons of screening on their own (informed decision-making) before making a decision to be screened.

Lung and Other Tobacco-Related Cancers

At this time, there is no evidence that early detection of lung cancer, including bronchus cancer, is an effective means of decreasing lung cancer mortality. Eliminating tobacco use could nearly eliminate lung cancer. Of all cancers in Indiana, lung cancer has the highest mortality rate: 65 per 100,000 for the years 1996-2000. There is a disparity between Caucasians and African Americans, particularly among men (92.2 per 100,000 vs. 117.7 per 100,000). Unfortunately, the majority of lung cancer cases are diagnosed in late stages, which negatively impacts survival odds. In Indiana, only 21% of lung cancers were diagnosed at the local stage between 1996 and 2000 (1).

Lung cancer in Indiana is related to the state's high smoking rate. Indiana ranks fifth in the country for adult smokers, which means lung cancer will continue to place a huge burden on Hoosiers for many years. Additionally, cigarette use among Indiana youth, grades nine to 12, is similar to Indiana adults, ranking higher than the national average (1). Non-smoking efforts must continue and include increased cigarette taxes, non-smoking ordinances, and media campaigns. Although there is no reliable screening mechanism that can detect lung cancer early, the Spiral CT study shows promise as a new screening tool that ultimately may help reduce lung cancer mortality rates.

Oral cancer rates in Indiana are low, but there is a direct link between oral cancer and all forms of tobacco use. Inspection of the oral mucosa, counseling about eliminating tobacco use, and limiting alcohol consumption should be standard components of preventive dentistry and primary medical care, as these are important steps toward oral cancer early detection. Unfortunately, not everyone receives regular dental care due to financial barriers and/or a lack of understanding of the value of good dental health. Efforts should be made to increase access to and utilization of regular professional dental care.



Cervical Cancer

Cervical cancer is highly preventable. Routine Pap tests and pelvic exams can detect abnormalities called pre-cancerous changes before cervical cancer has developed. When a Pap test is abnormal, further tests are needed to determine the level of abnormality and the kind of treatment method needed. Cervical cancer rates have decreased as more women have received regular screening. Although mortality rates in Indiana are relatively low, incidence rates show some disparity between Caucasian women and African-American women. From 1996 to 2000, Caucasian incidence rates were 9.2 per 100,000 compared with 13.3 per 100,000 for African Americans (1). The INBCCP provides free Pap tests for income-eligible women who are 40-64 years of age. Because of this program and other low cost options, cervical cancer incidence rates should continue to decline as women receive screening and necessary follow-up for abnormal Pap tests. Continued efforts need to be targeted at populations with higher incidence rates such as African-American females and under screened women such as those in the Hispanic/Latina population.



Early Detection

Goal: Increase early detection and appropriate screening for cancer.

■ OBJECTIVE 1:

Increase the percentage of women aged 40 and older who receive regular breast cancer screening.

Cross Reference: *HP 2010 Objectives:* 3-13; *Healthy Indiana -Minority Health Plan Objectives:* Can-5, *Strategies:* CAN S4.1-CAN S7.1, CAN S4.5-CAN S7.5; *ACS 2015 Nationwide Objectives:* Breast Cancer Early Detection

Women aged 40+ have had a mammogram within the past year

Baseline: 56.8% All Indiana women aged 40+

57% White, non-Hispanic women aged 40+

54.9% Black, non-Hispanic aged 40+

48.1% Other/multi-race, non-Hispanic aged 40+

62.8% Hispanic aged 40+

Target: 80%

Women aged 40+ have had a clinical breast exam within the past year

Baseline: 60.9% All Indiana population aged 40+

60.7% White, non-Hispanic aged 40+

65.2% Black, non-Hispanic aged 40+

55% Other/multi-race, non-Hispanic aged 40+

63.1% Hispanic aged 40+

Target: 80%

Data Source: Behavioral Risk Factor Surveillance System, Indiana 2002 (25)



STRATEGIES:

1. Promote interventions that target women not receiving annual mammography and clinical breast exams.
 - Expand the use of provider reminder systems for annual mammograms and clinical breast exams.
 - Support efforts to increase funding for programs providing free screening to low income, uninsured or underinsured women.
2. Disseminate information related to breast cancer screening through lay health advisors and community outreach workers.
3. Promote media campaigns to inform the public of the need for regular breast cancer screening.

■ OBJECTIVE 2:

Increase the percentage of residents aged 50 and older who receive risk-based colorectal cancer screening and follow-up using accepted professional guidelines.

Cross Reference: *HP 2010 Objectives: 3-12; Healthy Indiana-Minority Health Plan Objectives: Can 10, Strategies: CAN S8.1-CAN S10.1; ACS 2015 Nationwide Objectives: Colorectal Cancer Early Detection*

Ever had a blood stool test using a home kit (individuals aged 50+)

Baseline: 41.7% All Indiana individuals aged 50+

43.5% White, non-Hispanic individuals aged 50+

29.1% Black, non-Hispanic individuals aged 50+

26.2% Other/multi race, non-Hispanic individuals aged 50+

31.6% Hispanic individuals aged 50+

Target: 75%

Ever had a sigmoidoscopy or colonoscopy (individuals aged 50 and older)

Baseline: 43.7% All Indiana individuals aged 50+

44.1% White, non-Hispanic individuals aged 50+

45.1% Black, non-Hispanic individuals aged 50+



37.6% Other/multi race, non-Hispanic individuals aged 50+

17.8% Hispanic individuals aged 50+

Target: 75%

Have had a blood stool test using a home kit in the past year (individuals aged 50 and older)

Baseline: 16.9% All Indiana individuals aged 50+

17.7% White, non-Hispanic individuals aged 50+

11.2% Black, non-Hispanic individuals aged 50+

7.3% Other/multi race, non-Hispanic individuals aged 50+

13.4% Hispanic individuals aged 50+

Target: 50%

Have had a sigmoidoscopy or colonoscopy in the past 5 years (individuals aged 50 and older)

Baseline: 33% All Indiana individuals aged 50+

33.4% White, non-Hispanic individuals aged 50+

36.4% Black, non-Hispanic individuals aged 50+

28.7% Other/multi race, non-Hispanic individuals aged 50+

13.7% Hispanic individuals aged 50+

Target: 50%

Data Sources: Behavioral Risk Factor Surveillance System, Indiana 2002 (25)

STRATEGIES:

1. Enhance colorectal cancer screening capacity.
 - Explore screening facility capacity issues.
 - Provide training opportunities for existing providers.
 - Explore ways to increase the number of providers trained to provide colorectal screening.
2. Conduct campaigns to increase public awareness of colorectal cancer risk and the benefits of screening and early detection.



3. Support Indiana's participation in the CDC national Colorectal Capacity Study.
4. Develop a resource guide for colorectal cancer screening facilities and services.
5. Disseminate culturally appropriate decision-making information regarding screening guidelines.
6. Employ interventions that promote patient utilization of colorectal cancer screening.

■ OBJECTIVE 3:

Promote informed decision-making related to prostate cancer screening for all men.

Cross Reference: *Healthy Indiana-Minority Health Plan* Strategies: CAN S11.1; ACS 03-04: Prostate Cancer Ends Statement 1 & 2; ACS 2015 *Nationwide Objectives*: Prostate Cancer Early Detection

STRATEGIES:

1. Support efforts that promote informed decision-making followed by opportunities for free prostate cancer screening.
2. Offer culturally sensitive education to the public regarding prostate cancer.
 - Identify educational materials in both English and Spanish.
3. Develop unique ways to deliver information about prostate cancer and screening issues to communities.
 - Utilize community centers to hold informational sessions about prostate cancer.
 - Organize church-based educational programs and health fairs to promote informed decision-making.
 - Create an educational program utilizing community health workers to deliver important messages about prostate cancer and screening.
 - Develop computer programs to increase appropriate decisions regarding prostate cancer screening.

■ OBJECTIVE 4:

Eliminate disparities and barriers related to cancer screening and diagnostic services.

Cross Reference: *HP 2010 Objectives*: 3-11; *Healthy Indiana-Minority Health Plan* Strategies: CAN SU2.1, CAN SU2.3



STRATEGIES:

1. Increase health care providers' awareness of current cancer screening guidelines and follow-up recommendations.
2. Analyze legislative mandates and insurance coverage for cancer screening to determine gaps in coverage.
3. Disseminate culturally appropriate guides related to informed decision-making for cancer screening.
4. Promote culturally sensitive and family-friendly screening experiences.
5. Disseminate information about low-cost or free cancer screening services to medically underserved populations.
6. Explore geographic disparities in mammography use.
7. Identify barriers in access to dental care.
8. Increase access for persons without dental insurance or access to dental care by increasing the number of mobile dental clinics and identifying providers who offer free/low cost care.
9. Promote the need for regular cervical cancer screening and diagnostic services to the public.
 - Increase public awareness of the need for age-appropriate and risk-based Pap tests.
 - Increase the percentage of women who receive timely and culturally relevant follow-up for abnormal cervical cancer screening tests.
10. Analyze screening data to elucidate current scope of cancer screening and diagnostic patterns.

■ OBJECTIVE 5:

Encourage primary care practitioners to incorporate clinical practice guidelines to promote early detection of cancer.

STRATEGIES:

1. Distribute information to primary care physicians and primary care extenders about prostate cancer risk and screening.
2. Disseminate information to primary care physicians and extenders about clinical practice guidelines that promote optimal early detection of breast cancer through mammography, clinical breast exams and breast self-exams.
3. Explore trial use of the Cancer Risk Information System (CRIS) computer program in primary care settings.



Treatment

Between 1996 and 2000, approximately 130,000 Hoosiers were diagnosed with cancer each year. Treatment for these cancers varies with the type of cancer, stage at diagnosis, age, and general health and personal decision factors. As cancer treatment becomes more effective and complex, it also becomes more costly and tends to be offered in larger population centers.

Successful treatment involves a partnership among health care providers, patients and families/caregivers. Although patients and families vary in the degree to which they wish to participate in treatment decisions, having that option is essential. Patients who fully understand their treatment program experience greater satisfaction with their care and are more likely to complete treatment despite inevitable side effects.

When patients understand the nature and risks of their cancer diagnosis and the potential risks and benefits of treatment, they can make informed decisions that are congruent with their personal preferences and values. Shared decision-making occurs when a health care provider and an informed patient make decisions together about treatment to whatever extent the patient desires (33). The significance of informed and shared decision-making is well illustrated with prostate cancer treatment. Current therapies for prostate cancer include surgery, radiation, chemotherapy, and hormonal treatment. The physical and psychological post-treatment side effects depend in part on the type of therapy and may include incontinence, proctitis, bowel urgency, diarrhea, and sexual dysfunction. Any one of these can be devastating and may be life-long, having a significant impact on men and their partners. When patients and partners are fully informed about potential treatment side effects and potential solutions to alleviate them, they can make a decision that is right for them.

Access to excellent cancer treatment may be limited by lack of health insurance, cost of care, geographic location, travel time, transportation, education, cultural and language barriers, immigration status, sexual orientation, and child care. These barriers can impact treatment decisions and completion of the care plan. Approximately 54% of Hoosiers who did not use medical care during the past year cited cost as the primary barrier (25).

Indiana was one of the first 10 states to take advantage of the Federal Breast and Cervical Cancer Prevention and Treatment Act of 2000 (BCCPTA). This allows states to provide treatment for uninsured income-eligible women diagnosed with cancer through the Indiana Breast and Cervical Cancer Program by enrolling them in Medicaid for the duration of their treatment. This legislation has helped address the ethical issue of offering free screening without viable treatment options.



For many Hoosiers, cultural values, fatalistic views, and religious beliefs play a major role in treatment decisions. Cultural differences can impact access to care among minority populations when mainstream medical care is mismatched with cultural values or when care is sought only after traditional healing methods fail. The rapidly growing Hispanic/Latino population in Indiana also presents significant language challenges for both patients and providers.

Clinical trials provide an avenue for increased access to state-of-the-art treatment. Clinical trials offer benefits to all those involved, including the researchers, health providers, and patients. For patients, clinical trials can offer opportunities to access free treatment and potentially link them to support services relating to their diagnosis. According to the NCI, over 25,000 cancer patients were enrolled in NCI treatment clinical trials in the United States for the years 1997-2001. This statistic, however, represents a small fraction of total cancer patients. From 1998 to 1999, approximately 2.5% of adult cancer patients participated in clinical trials. From 1997 to 2001, about 60% of clinical trial participants were women and 40% were men, although slightly more men than women were newly diagnosed with cancer during that time period. An analysis of NCI Cooperative Group trial enrollment from 1998-1999 identified that only about 35% of participants were aged 60 or older. Recent directives will permit the Centers for Medicare and Medicaid Services (CMS) to pay for patient care costs of Medicare patients enrolled onto clinical trials. This policy change may result in increased participation from that population (34).

Reasons for underutilization of clinical trials include lack of physician and patient awareness about existing clinical trials, lack of trust that the clinical trial therapy will be effective, a perception that clinical trial processes are highly complex, and lack of insurance coverage for routine patient care costs associated with clinical trials (35). A 2002 review of patients accrued to NCI clinical trials during 1998-1999 revealed that patients enrolled onto clinical trials were significantly less likely to be uninsured and more likely to be on Medicare. Geographic areas with higher socioeconomic status, more oncologists, and approved cancer programs had higher accrual rates. Overall, the highest observed accrual was from suburban counties (36).

The same study found that African-American, Asian American, and Hispanic/Latino adult patients with cancer were entered onto clinical trials at lower rates than Caucasian patients of the same age. Various barriers contribute to these disparities. Within the African-American community some lack of trust continues, based on past research exploitation. Hispanics/Latinos and other minorities may be more comfortable with providers of similar ethnicity, or at least with those who understand and appreciate their culture. Finding ways to increase minority participation in clinical trials is especially important because of the disparate effect of cancer on minorities.



Treatment

Goal: Promote informed decision-making and utilization of appropriate cancer treatment.

■ OBJECTIVE 1:

Eliminate barriers and increase access to receiving clinically effective treatment services and appropriate follow-up.

STRATEGIES:

1. Support legislation to expand access to cancer treatment for uninsured and underinsured patients.
2. Increase availability of cervical cancer treatment options for Hispanic/Latina women enrolled in the INBCCP Program who do not possess the necessary U.S. documentation to qualify for Medicaid.
3. Provide opportunities for health care providers to become more culturally sensitive and effectively communicate with patients from diverse populations.
4. Assist patients and families to better navigate the health care system.
5. Increase awareness among patients, providers, and the general public about myths related to cancer and cancer treatment.

■ OBJECTIVE 2:

Increase participation in cancer clinical trials.

STRATEGIES:

1. Address the barriers to participation in clinical trials experienced by individuals in diverse populations.
 - Explore avenues to increase minority physician participation in clinical trials.
 - Explore avenues to allay fears and apprehension minority groups have related to past events involving clinical trials.



- Encourage health care providers to suggest clinical trials as a means of receiving treatment for patients newly diagnosed with cancer.
 - Provide information about clinical trials in a culturally sensitive manner, including consent forms that are tailored to meet the patients' reading levels.
 - Expand opportunities for clinical trial participation across the state.
 - Adjust clinic hours to accommodate various patient employment schedules.
2. Explore insurance issues related to participation in clinical trials.
 3. Increase public awareness about purposes, benefits, and enrollment procedures for clinical trials, particularly among minority populations.

■ **OBJECTIVE 3:**

Increase the percentage of patients with cancer who receive evidence-based treatment and follow-up based on acceptable standards of care.

STRATEGIES:

1. Promote the awareness and use of existing Internet resources to provide balanced, unbiased information about cancer treatment options, outcomes and quality of life.
2. Increase patient and family awareness of treatment-related symptom management to promote successful treatment plan completion.
3. Disseminate professional educational information about treatment options for various stages of breast cancer diagnoses.
4. Distribute educational tools to assist clinicians in helping women diagnosed with breast cancer and their families understand treatment recommendations and options.
5. Encourage health care providers to offer educational opportunities regarding surgical options of breast conserving therapy and mastectomy to women with breast cancer.
6. Publicize information about treatment options for various stages of breast cancer diagnoses.
7. Assess treatment pattern variations that impact access to appropriate treatment options for breast cancer.
8. Compile and disseminate existing prostate cancer quality of care guidelines published by professional organizations for radiation therapy, urology, and medical oncology.
9. Promote informed decision-making in high risk groups regarding prostate cancer treatment.



Quality of Life


Quality of life issues cut across every aspect of the cancer care continuum, from prevention and detection, through diagnosis and treatment, to survivorship and end of life. Most health care providers and researchers conceive quality of life as a multidimensional concept that encompasses social, psychological, emotional, spiritual, physical, and economic dimensions of a person's life. Quality of life is subjective and is best assessed from the patient's perspective, rather than equated with objective circumstances. The impact of cancer on the quality of life of patients and their families can be severe, and often is exacerbated by the toxicity and side effects that accompany cancer therapies. Cancer may affect quality of life in both the short and long term, and the same type and stage of cancer may have very different effects on quality of life, depending upon each individual's unique characteristics and resources (37). Although quality of life is relevant across the cancer care continuum, the importance of quality of life concerns has recently been highlighted in several areas.

Survivorship

Advances in early detection and treatment have resulted in steady increases in cancer survivorship. The number of people living with cancer increased from 3.0 million (1.5% of the U.S. population) in 1971 to 9.8 million (3.5%) in 2001; an estimated one of every six persons over age 65 is a cancer survivor (38). Given the aging U.S. population, quality of life for cancer survivors becomes an increasingly important concern. Survivors and their families must contend with a host of physical, psychological, and socioeconomic issues, including long term side effects and late effects, ongoing concerns over recurrence, and lasting difficulties with insurance and employment. Minimal resources have been devoted toward preventing or reducing the quality of life burdens experienced by cancer survivors.

Palliative Care

The increasing attention paid to quality of life concerns has resulted in significant improvements in the delivery of palliative care during active treatment, which involves control of pain and other physical symptoms, as well as psychological, social, and spiritual distress. Ideally, palliative care should be available during treatment, survivorship, and end of life care and involve; 1) comprehensive assessment using validated symptom measures; and 2) collaborative efforts from a multi-disciplinary team to enhance comfort and improve quality of life (39). Multi-disciplinary teams should consist of physicians, nurses, social workers, chaplains, caregivers, and others, depending



on the individual needs of each patient. Providing quality palliative care requires professional communication skills, assessment and treatment of the disease and treatment-related symptoms, psychosocial, spiritual, and bereavement support.

End of Life Care

End of life care includes palliative care and other activities/delivery systems that help facilitate the process of comfortable dying when cure is not possible, preserving patient autonomy, respecting patient and family wishes, providing grieving support, and facilitating bereavement processes for families. Hospice is one system of effective end of life care that can be provided at home or within an institution. Significant insurance and reimbursement issues, however, are associated with hospice care, including the Medicare distinction between treatment, cure, and prolonging life (regular Medicare), and comfort care (hospice Medicare) (40).

Barriers

Barriers to incorporating quality of life concerns into cancer care identified by the 2001 Institute of Medicine report *Improving Palliative Care for Cancer* are:

- separation of palliative and hospice care from potentially life-prolonging treatment within the health care system, which is both influenced by and affects reimbursement policy
- inadequate training of health care personnel in symptom management
- inadequate standards of care and lack of accountability in caring for dying patients
- disparities in care, even when available, for African Americans and other ethnic and socioeconomic segments of the population
- lack of information resources for the public dealing with palliative and end of life care
- lack of reliable data on the quality of life and the quality of care of patients dying from cancer (as well as other chronic diseases)
- low level of public sector investment in palliative and end of life care research and training (41)



Encouraging Developments

In recent years, encouraging developments include an increased recognition on the part of health care providers and consumers of quality of life research, concomitant increases in federal funding for quality of life and survivorship studies, greater use of interdisciplinary teams to provide cancer patient care, development of standards of care for hospice and palliative medicine, and expanded opportunities for medical and nursing education in palliative and end of life care. The National Consensus Project for Quality Palliative Care (NCP) recently released new voluntary practice guidelines for palliative care specialists and other health care professionals. These guidelines are intended to assist the growing number of palliative care programs established in hospitals, nursing homes, hospices, and health systems in delivering high-quality, state-of-the-art care for seriously ill patients and their families (42). The Education on Palliative and End of life Care (EPEC) for physicians teaches fundamental palliative care skills in communication, ethical decision-making, psychosocial considerations, and symptom management (43). The End of life Nursing Education Consortium (ELNEC) is a Robert Wood Johnson funded project designed to develop a core of expert nursing educators, coordinate national nursing education efforts in end of life care, and foster strong collaboration with medical colleagues (44). The National Comprehensive Cancer Network (NCCN), composed of the world's leading cancer centers, has also developed and disseminated in-depth practice guidelines for cancer palliative care.

Challenges

Challenges remain, despite these encouraging developments. Quality of life research has yet to be translated into clinical practice. Cultural, ethnic, and religious perspectives relevant to cancer care continue to challenge professionals to find creative ways to provide appropriate and culturally competent palliative care and promote comfortable dying among diverse groups of people. Geographic barriers continue to present significant problems, especially for Indiana's large rural population.



Quality of Life

Goal: Improve quality of life for patients with cancer, survivors, and their families.

■ OBJECTIVE 1:

Increase utilization of symptom management and psychological, social, and spiritual support for patients and families during cancer treatment.

STRATEGIES:

1. Expand health care provider participation in educational opportunities designed to increase communication skills with patients and families regarding cancer treatment issues.
2. Increase patient and family understanding of treatment side effects and the role adjuvant therapy plays in the overall cancer treatment plan.
3. Encourage health care providers to provide anticipatory symptom management guidance and access to supportive care during treatment.
4. Increase health care provider participation in educational opportunities regarding effective methods of assessment and palliation for cancer symptoms and cancer treatment side effects.
5. Provide information to health care providers, patients, and families about support networks for newly-diagnosed patients.
6. Disseminate information about website links with credible information about cancer treatment.
7. Identify existing data for tracking progress on pain and symptom management.
8. Disseminate a synthesis of published data about the potential side effects of cancer treatment.
9. Provide information to health care providers and patients about quality of life issues for people of varied cultural, racial, ages, and economic backgrounds.



■ OBJECTIVE 2:

Increase access to information and support services that enhance quality of life for survivors of cancer and their families.

Cross Reference: *HP 2010 Objectives:* 3-15

STRATEGIES:

1. Compile and disseminate information about effective methods of alleviating the prostate cancer post-treatment symptomatology burdens of bowel incontinence, proctitis, urgency, diarrhea, and sexual dysfunction.
2. Compile and disseminate information about dealing with post-treatment physical, psychological and social issues related to breast, cervical, colorectal, and tobacco-related cancers.
3. Explore employment and insurance issues related to cancer survivorship.
4. Disseminate web links providing accurate information about survivorship issues, wellness, and support networks.

■ OBJECTIVE 3:

Increase Indiana residents' utilization of end of life care that enhances patient quality of life and assists patients and families in the grieving process.

STRATEGIES:

1. Encourage health care providers to proactively discuss end of life concerns with patients and their families.
2. Develop an educational campaign about patient rights regarding end of life care and advance directives, targeting the public and families of patients with cancer.
3. Facilitate the process of comfortable dying, preservation of autonomy, and providing grieving support for the family.
4. Increase professional participation in educational opportunities related to palliative, hospice and end of life care, such as:
 - End of life Nursing Education Consortium (ELNEC) for professional nurses
 - Education on Palliative and End of life Care (EPEC) for physicians



5. Disseminate information about hospice and end of life services to providers, patients, and families.
6. Increase the number of physicians, nurses, and home-health aides certified in hospice and palliative care.
7. Identify patterns of hospice use by minority populations.
8. Support efforts to recruit more minorities into the health professions.
9. Explore issues related to treatment while in hospice care.
10. Disseminate information to health care providers, patients, and families about hospice eligibility and services.
11. Identify cultural, ethnic, provider system, and individual barriers to using hospice and end of life care.
12. Explore cultural, psychosocial, and spiritual issues related to end of life issues, hospice care, and symptom management.
13. Convene an expert panel to review insurance issues related to hospice and palliative care.
14. Expand health care provider awareness about the benefits of an interdisciplinary team approach to providing end of life care that enhances quality of life for patients and families.



Data

Cancer Data Collection

Cancer is a reportable disease, and Indiana cancer data are collected by the Indiana State Cancer Registry at the ISDH. Incident cases, with staging and other cancer-related data (cancer-related data are data that facilitate understanding and interpretation of the cancer burden) are submitted to the ISCR by hospitals, health care facilities, medical laboratories, physicians, and dentists throughout the state. Cancer mortality data are obtained from the Epidemiology Resource Center (ERC) Data Analysis Team. The ISCR, in collaboration with the ERC and the Chronic and Communicable Disease Division, analyzes these cancer data and publishes annual reports containing the necessary statistics for tracking cancer trends. The Comprehensive Control Program at the ISDH works closely with the ISCR and ERC to obtain and understand cancer data for cancer control planning, implementation and evaluation purposes.

Another invaluable source of data is the Behavioral Risk Factor Surveillance System. Indiana has the distinction of being a pioneer among the states participating in the BRFSS. Since 1984, the ISDH has joined with the CDC to develop and implement the BRFSS survey in Indiana. This statistically reliable random telephone survey monitors modifiable risk factors associated with chronic and communicable diseases, including cancer, by collecting information from adults aged 18 years and older about health behaviors and preventive practices. The surveys are conducted on a continuous basis and serve as a key source of evaluation data for cancer control programming (25).

Data obtained from other sources also aid in understanding cancer risks and trends, and hence cancer control efforts. The Surveillance, Epidemiology and End Results (SEER) program at the NCI supplies data for cancer incidence and survival in the United States, and provides a good benchmark for comparing Indiana data to the nation. Indiana census data identify population trends and can potentially be linked with disease data to provide valuable cancer control planning and implementation information (45). The CDC's Wide-ranging OnLine Data for Epidemiologic Research (WONDER) is a valuable resource for a wide array of public health statistical data, guidelines, and scientific references (46). Additionally, the NCI Physician Data Query (PDQ®) database provides evidence-based treatment summaries that could be used to assess cancer treatment patterns in Indiana (47). The ACS's Community Assessment E-tool serves many functions related to cancer control planning including demographics, prevention, early detection, incidence and mortality data analysis and reports, medical and educational resources, and much more (48).



Why Cancer Data Are Important

Comprehensive, timely, and accurate cancer-related data are essential for evaluating progress toward cancer prevention and control. Staging data and incidence, mortality, and survival rates help identify populations at greater risk for developing or dying from cancer, monitor epidemiologic trends, and provide information for evaluating progress toward goals. In the CDC's *Building Blocks of Comprehensive Cancer Control* model, data are the basis for determining planning goals and objectives (5). Current cancer incidence, mortality, and staging data made it possible for the ICC to review the current burden of cancer in the state, set priorities, and begin cancer control planning. In addition to gathering cancer data for short, intermediate, and long term evaluation of the goals and objectives in this plan, specific efforts will be focused on improving access to and increased usability of cancer and related data in Indiana. Access to accurate, timely, and user-friendly data enables the public, providers, insurers, advocates, and policy makers to make informed decisions.

Data Gaps and Challenges

Although there are many sources of Indiana cancer and related data, there is opportunity to enhance their use. Increasing the timeliness and accuracy of cancer incidence, mortality, staging and related data submitted to the ISCR by hospital registries would allow earlier availability of complete data. Providers, insurers, health departments, universities, research institutions, and other organizations produce data that are not accessible in one location. Facilitating the sharing and integration of these cancer and related data would greatly improve any efforts to plan, evaluate or craft policy in relation to cancer. Additionally, the use of mapping techniques to display cancer trends, resources, and other methods to aid comprehensive cancer control would help identify gaps. While BRFSS data are very valuable, they are self-reported; data collected by cancer screening providers are usually unavailable. Creating a system to collect actual cancer screening data would offer more robust data for decision-making.

Role of the Data Advisory Committee

The ICC Data Advisory Committee supports ICC data needs in many ways. This committee conducted the initial assessment of the cancer burden in Indiana to help determine ICC priorities, assumed the responsibility for preparing the *Indiana Cancer Facts & Figures 2003*, assisted other ICC Advisory Committees with their data needs, and continues to identify gaps and disparities in cancer data. The committee also supports the ISCR in its efforts to enhance cancer data collection and registry and is working to facilitate data sharing among public and private organizations that collect significant quantities of cancer and related data. It is anticipated that this process will help reduce data gaps and provide opportunities for synergy and collaboration, thereby providing a more complete picture of cancer and related issues in Indiana. Last, but certainly not least, the Data Advisory Committee will develop strategies to effectively market and distribute cancer and related data in a fashion that is easily interpretable and usable by the intended audiences.



Data

Goal: Increase the quantity, quality and availability of complete and timely cancer and related data.

■ OBJECTIVE 1:

Increase the quality, accuracy, and timeliness of required data that are reported to the Indiana State Cancer Registry.

Cross Reference: *HP 2010 Objectives: 3-14*

STRATEGIES:

1. Support creation of information technology needed to enhance data collection.
2. Support efforts to improve the quality of data submitted from hospitals across the state.
3. Develop a mechanism to increase awareness about opportunities for Cancer Tumor Registrars.
4. Examine national staffing and structure of cancer registries and Surveillance, Epidemiology and End Results (SEER) program.
5. Expand training program opportunities for Cancer Tumor Registrars.

■ OBJECTIVE 2:

Increase availability of accurate and timely cancer data to the public, people at risk, patients, health professionals, and policy-makers.

STRATEGIES:

1. Identify gaps in available data.
2. Support regular publication of cancer and related data.
3. Explore mechanisms for sharing cancer and related data between public and private systems.
4. Disseminate information to help individuals more easily find public-use data.



■ OBJECTIVE 3:

Organize cancer and related data to facilitate interpretation and understanding of cancer issues.

Cross Reference: *HP 2010* Objectives: 23-3; *A Plan for Community Health Improvement 2004-2007* Objectives: 1-4

STRATEGIES:

1. Compile a resource list of readily available data sources.
2. Develop creative avenues to present cancer data (such as, utilizing Geographic Information Systems [GIS] data maps).



Advocacy

Cancer is a political, as well as a medical, social, psychological, and economic issue. Every day, legislators and other policymakers make decisions that affect the lives of cancer survivors, their families, and all potential cancer patients (49). The *ICCP* includes advocacy as a significant strategy to influence policy decisions in a way that benefits those affected by cancer.

Advocacy is action directed toward influencing the way the public and policy-makers at all levels think and act regarding a given issue. An advocate is anyone who participates in the process of influencing policy. By informing and educating the public and policy makers, cancer control advocates can positively influence the laws, regulations and rules that impact the experience of cancer from prevention through palliation.

The advocacy focus for this plan is to expand the capacity of both the ICC and its member organizations to advocate for policies that enhance programs to help prevent cancer, broaden access to quality cancer treatment, and improve the quality of life for those affected by cancer. The advocacy power of a collaborative group such as the Consortium lies in the combined resources and expertise that can provide essential information to policy makers for decision-making. Given that many ICC member organizations do not have paid government relations staff or lobbyist services, it is crucial for the Consortium to enhance its members' ability to communicate effectively regarding cancer related issues.

The Consortium's Advocacy Advisory Committee will develop mechanisms to keep Consortium members informed about current policy and legislative issues, provide advocacy training and assist in developing a proactive legislative agenda. The committee will also create an electronic network for conveying essential legislative information to members in a timely manner so they can take appropriate action. The committee will work with other Consortium Advisory Committees to "put a human face on cancer" and develop advocacy strategies for cancer-specific issues such as those identified in other sections of this plan.

Advocacy-related achievements have already occurred in this state. Indiana has:

- mandated insurance coverage for breast, colon, and prostate cancer screening
- adopted the Breast and Cervical Cancer Prevention and Treatment Act
- worked both legislatively and administratively on improving its cancer registry
- raised the state tobacco tax and increased penalties for those who sell tobacco to minors

Emerging cancer-related legislative issues include school nutrition and physical activity, continued funding for agencies and programs that work to prevent and treat cancer, and maintaining current screening mandates.



Advocacy

Goal: Enhance the capacity of the Indiana Cancer Consortium, its member organizations and other concerned individuals and organizations to articulate and advocate for ICC priority cancer-related public policy issues.

■ OBJECTIVE 1:

Promote increased awareness about Indiana's cancer burden, the ICC mission and priority issues, and effective advocacy methods.

STRATEGIES:

1. Develop a concise user-friendly communication method to help member organizations explain the ICC and its priorities, goals, and strategies.
2. Develop partnerships with the news media, well-known cancer survivors, health related organizations, and community groups.
3. Provide policy-makers with information about the ICC and its priorities.

■ OBJECTIVE 2:

Advocate for cancer-related policy and legislative issues.

Cross Reference: *A Plan for Community Health Improvement 2004-2007* Objectives: 11-4

STRATEGIES:

1. Communicate priority legislative issues to stakeholders and policy-makers.
2. Develop guidelines and policies to use when working with policy makers and legislators.
3. Provide member organizations with bill summarization and interpretation for key legislation related to ICC priorities.
4. Develop position papers to clarify issues and promote informed decision-making.
5. Create legislative toolkits and provide periodic training.
6. Provide information to ICC members for advocacy within their own organizations.



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Acronyms

ACS

American Cancer Society

BCCPTA

Breast and Cervical Cancer Prevention and Treatment Act of 2000

BCOG

Behavioral Cooperative Oncology Group

BMI

Body Mass Index

BRFSS

Behavioral Risk Factor Surveillance System

CCOP

Community Clinical Oncology Program

CDC

Centers for Disease Control and Prevention

CEEP

Center for Evaluation and Education Policy

CIS

Cancer Information Service

CMS

Centers for Medicare and Medicaid Services

CRIS

Cancer Risk Information System

DRE

Digital Rectal Exam

ELNEC

End-of-Life Nursing Education Consortium Project

EPEC

Education on Palliative and End-of-life Care

ERC

Epidemiology Resource Center

FOBT

Fecal Occult Blood Test

FTA

Federation of Tax Administrators

GIS

Geographic Information Systems

HOG

Hoosier Oncology Group

HP

Healthy People

HPV

Human Papillomavirus

ICC

Indiana Cancer Consortium

ICCP

Indiana Cancer Control Plan

INBCCP

Indiana Breast and Cervical Cancer Program

ISCR

Indiana State Cancer Registry

ISDH

Indiana State Department of Health

ITPC

Indiana Tobacco Prevention and Cessation

IU

Indiana University

IUPUI

Indiana University-Purdue University Indianapolis

NAACCR

North American Association of Central Cancer Registries

NCCCP

National Comprehensive Cancer Control Program

NCCN

National Comprehensive Cancer Network

NCI

National Cancer Institute

NCP

National Consensus Project for Quality Palliative Care

NICRC

Northern Indiana Cancer Research Consortium

NIH

National Institutes of Health

PDQ®

Physician Data Query

PSA

Prostate-Specific Antigen

SEER

Surveillance, Epidemiology, and End Results

TIPS

Tobacco Information and Prevention Source

TRIP

Tobacco Retailer Inspection Program

WONDER

Wide-ranging OnLine Data for Epidemiologic Research

YRBS

Youth Risk Behavior Surveillance System



Glossary of Terms

Baseline: An initial or known value (e.g., Body Mass Index) to which later measurements can be compared.

Body Mass Index (BMI): Weight in kilograms divided by height in meters squared (kg/m^2), and offers an easily obtainable quantification of the relationship between height and weight.

Cancer Burden: Number of new cases and/or deaths from cancer or overall impact of cancer in a community.

Five-year Survival: Percentage of people with a given cancer who are expected to survive five years or longer with the disease.

Incidence: Frequency of new occurrences of a condition within a defined time interval. The incidence rate is the number of new cases of specific disease divided by the number of people in a population over a specified period of time, usually one year.

Morbidity: Disease or the effects of disease within a population.

Mortality Rate (Death Rate): The rate of deaths in a given population, for a given time.

Prevalence Rate: Proportion of people with a certain disease at a given time.

Public Health Model of Prevention:

Primary Prevention: Preventing or reducing risks of developing disease, done through promotion of individual behavior change or at the system level through policy changes.

Secondary Prevention: Identifying disease as early as is possible, often before symptoms develop, and treating that disease promptly. Screening programs should be targeted toward groups at greatest risk for developing a disease.

Tertiary Prevention: Delaying disease progression, reducing risks of complications or recurrence, prolonging life, and promoting quality of life. Tertiary prevention efforts are directed toward individuals and groups of people with similar problems, rather than broad population groups.

Risk Factor: Something that may increase the chance of developing a disease. Some examples of risk factors for cancer include age, a family history of certain cancers, use of tobacco products, certain eating habits, obesity, exposure to radiation or other cancer-causing agents, and certain genetic changes.

Informed Decision-Making: Occurs when an individual understands the nature and risks of their cancer diagnosis and treatment options. Informed decisions are congruent with personal preferences and values.

Shared Decision-Making: Occurs when a health care provider and an informed patient together make decisions about treatment to whatever extent the patient desires.

Spiral CT Scan: A detailed picture of areas inside the body. The pictures are created by a computer linked to an x-ray machine that scans the body in a spiral path. Also called helical computed tomography.

Staging:

In situ Cancer: Early neoplasm which has not penetrated the membrane surrounding the tissue of origin.

Localized Cancer: Invasive malignant cancer confined entirely to the organ where the cancer began.

Regional Cancer: Cancer that has extended beyond the original (primary) organ to nearby organs or tissues, or has spread via the lymphatics to regional lymph nodes or both.

Distant Cancer: Cancer that has spread from the original (primary) organ to distant organs or distant lymph nodes.

Target: The goal measure intended to be attained.

To request a copy of the ***Indiana Cancer Control Plan*** 2005-2008

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