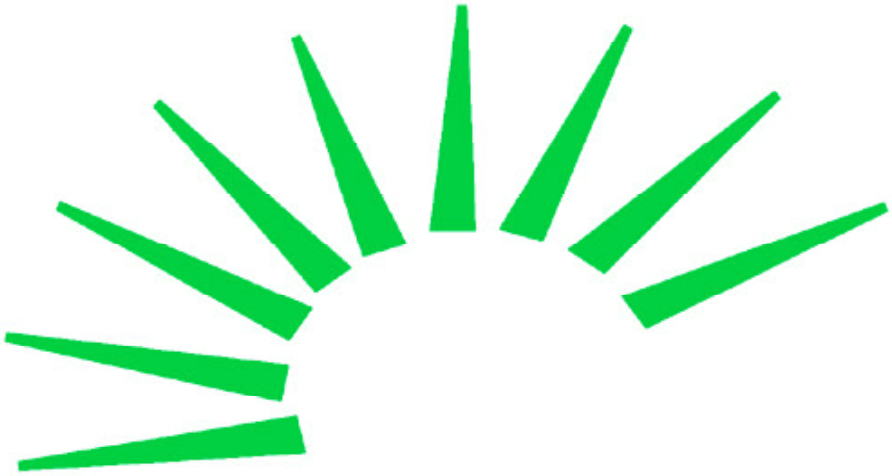

# Cancer Action Plan for Kentucky

January 2001

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# I. BACKGROUND

Kentucky is one of six states chosen by the Centers for Disease Control and Prevention (CDC) to develop a comprehensive cancer control plan. In undertaking this major endeavor, the Kentucky Department for Public Health (KDPH) contracted with the Kentucky Cancer Program (KCP) for assistance. These two state-funded entities have a history of successful collaboration on cancer control projects. Most recently, KDPH enlisted KCP to participate in CDC funded initiatives including breast and cervix cancer, tobacco control, and cardiovascular disease. Therefore, a precedent had been set for extending this relationship to the development of a cancer control action plan for the Commonwealth.

## *Cancer Control Partners in Kentucky*

Through KDPH, KCP, and the American Cancer Society (ACS), the state has a comprehensive cancer control network in place. Working together and with other partners, these organizations have established infrastructure of 120 local health departments (LHD), 10 ACS regional offices and 13 KCP offices, to support a coordinated and multifaceted cancer control agenda for the state. The missing element was a written comprehensive cancer plan of action reflecting the integrated activities of all parties. As indicated in the descriptions which follow, the respective organizations have mutual responsibilities and collaborative relationships for many cancer control activities.

**Kentucky Department for Public Health**

KDPH offers traditional and innovative public health services. The agency has been able to significantly expand activities in recent years through CDC funded initiatives. KDPH cancer control programs are as follows:

- *Breast and Cervical Cancer Screening*

Cervical cancer screening has been available through local health departments with state funds since the late 1960's. The breast cancer screening program was established with state funds in 1990 by the Kentucky General Assembly. At that time, breast cancer screening was integrated into the cervical cancer screening program through local health departments, to include Pap smears, clinical breast exams, instruction in breast self-exam, and mammograms provided through local community providers. Since that time, the program has expanded through additional state funds (now $2.6 million) and the CDC and Prevention National Breast and Cervical Cancer Early Detection Program funds (just over $2 million). This expansion has enabled the program to expand staffing for enhanced program data collection and reporting, health department service in-reach and outreach activities, program evaluation, and enhanced clinical and professional education components. These staffing expansions made it possible for the program to meet the following goals:

- Increase screening and follow up services throughout the state
- Provide new continuing education programs for health care providers
- Enhance professional education courses for LHD providers
- Expand public education activities, including statewide media campaigns
- Develop community breast and cervical cancer coalitions

All activities are coordinated through cancer control partners that include the 120 LHDs, the Governor's Office, Kentucky Cancer Registry (KCR), KCP, ACS, the Mid-South Cancer Information Service (CIS), the University of Kentucky (UK) and Louisville (UofL) Schools of Medicine, cancer screening service providers across the state, and various cancer support groups.

The KDPH Breast Cancer Advisory Committee, with membership appointed by the Governor, advises KDPH on the development and monitoring of various components of the state breast cancer screening program, now integrated with CDC funds under the name of the Kentucky Women's Cancer Screening Project. Membership on this committee includes representation of the James Graham Brown Cancer Center, the Lucille Parker Markey Cancer Center, KCR, a radiologist (fellowship-trained in breast diagnostics), the Kentucky Office of Rural Health, the Kentucky Commission on Women, and at least three breast cancer survivors.

■ *Tobacco Control*

With the highest lung cancer mortality rate in the nation, Kentucky has gone from having no public health tobacco control program just 10 years ago to having one supported with direct funding of approximately $4 million per year for tobacco control. KDPH is the recipient of a grant from CDC for over $1 million under the national tobacco prevention and control program and an additional $3 million in state tobacco settlement funds which was recommended by the governor and appropriated by the legislature in it's year 2000 session. The CDC funds support staff at the state level and local coalitions developed through 11 of the states 55 health departments. The new state funding received in the year 2000 will allow this effort to be expanded to each of Kentucky's 120 counties by providing funds to an additional 44 district or independent county health departments. Each health department receiving state or federal funds is required to designate a tobacco control coordinator, establish a coalition consisting of a group of diverse organizations, and individuals in the community, including youth, and to develop a plan for addressing the following four goals:

- Promoting cessation
- Preventing initiation
- Eliminating exposure to second hand smoke
- Eliminating disparities among populations disproportionately effected by tobacco

The approach at the state and the local level is based on the premise that, through collaborations with other agencies, organizations, programs and individuals, this state and federal funding can bring several times this amount of resources on the problem of tobacco use. For example, all state public health programs and all entities with whom KDPH contracts are required to indicate how they will address the problem of tobacco use. Needless to say, this represents an unprecedented effort in Kentucky to address the state's number one public health problem.

■ *Cardiovascular Disease*

DPH is the recipient of a grant from CDC for $865,000 to build capacity for improving cardiovascular health (CVH) in Kentucky through policy and environmental changes. KDPH contracts $450,000 to the Kentucky Department of Education (KDE) to support implementation of the enhanced school health program, Healthy Hearts = Healthy Futures. An additional $90,000 of the total grant supports a project implemented by the Jefferson County Health Department to reduce racial and ethnic disparities in burden of cardiovascular disease.

A steering committee was formed to guide the development of a statewide CVH Coalition. Several of the members of this steering committee represent programs dedicated to combating tobacco use, poor nutrition, and sedentary lifestyle, risk factors mutual to cardiovascular disease and cancer. The KDPH Breast and Cervical Cancer Program, KDPH Tobacco Control Program, KDPH Diabetes Program, KDPH Nutrition Services Branch, KDPH Arthritis Program, American Heart Association (AHA), KDE, Jefferson County Health Department, the Kentucky Dietetic Association, UK Department of Preventive Medicine, and Kentucky Children's Health Insurance Program Advisory Board are all represented on the CVH Steering Committee.

The CVH Coalition has over 100 volunteer members, among them a variety of public and private partners which include state medical societies, ACS, KCP, regional wellness coalitions, school health organizations, local tobacco control coalitions, state universities, and regional businesses and hospitals. The CVH Coalition is in the process of developing a statewide CVH Plan that will address the risk factors of tobacco use, poor nutrition and sedentary lifestyle through schools, work sites, the health care system, and communities.

KDPH contracts with LHDs who employ registered dietitians and certified nutritionists. These nutritionists and dietitians provide Medical Nutrition Therapy counseling or diet therapy to clients and families. One area of counseling addressed by these health professionals includes cancer prevention and dietary treatment issues that can be beneficial after cancer is diagnosed. Other activities provided by the dietitians and nutritionists include grocery store tours to highlight healthy foods and reading nutrition labels, Five-A-Day displays at health fairs and discussion about the importance of five fruits and vegetables each day. Within the schools, dietitians and nutritionists provide

classes concerning healthy eating and disease prevention issues. These activities may be in the form of Five-A-Day Bingo, the use of the Five-A-Day curriculum on CD-ROM by Dole, or Nutrition Jeopardy. Specific activities are designed for the needs of the community or schools as identified and will reflect current information and area trends.

The Special Supplemental Nutrition Program for Women, Infants and Children (WIC), through the new standardized nutrition risk criteria, certify applicants and participants with cancer or under treatment for cancer. Basic dietary information is provided through counseling, provided twice in a six-month time frame. Individual counseling is provided based upon the specific risk condition(s) and needs of the client.

**University of Kentucky/University of Louisville Cancer Control Programs**

Affiliated with UK and U of L, KCP alone brings a comprehensive cancer control infrastructure to the state. Housed in the Schools of Medicine at the respective institutions and in the Markey and Brown Cancer Centers, KCP also represents a wealth of
resources. Multidisciplinary teams of oncology specialists who treat patients, train health care providers, and conduct research are readily available to support program development, implementation, and evaluation. The various special initiatives and programs reflected in this network, described below, have helped position Kentucky and KCP as national models for cancer control.

- *KCP Regional Offices*

KCP has 13 regional offices across the state to provide public and professional education, patient support services, and community-based research. Cancer Control Specialists work with LHDs, ACS, and other partners to address local cancer problems.

- *District Cancer Councils (DCC)*

The 15 Area Development Districts (ADD) each have a DCC comprised of both lay and professional individuals and organizations, community leaders, government officials, and other partners. These individuals serve as advisors to KCP, reviewing regional cancer data annually for program planning and evaluation for each ADD throughout the Commonwealth.

- *Kentucky Cancer Registry (KCR)*

KCR, the state mandated registry, collects cancer incidence and treatment data on all cancer patients in the state. Cancer control organizations, researchers, community leaders, government leaders, and DCC members use registry data for program planning and evaluation. Through the registry and other sociodemographic data, research agendas are identified and evaluated.

■ *Cancer Information Service (CIS)*

The CIS, serving a six state Mid-South area is located in Kentucky. Funded by NCI, Telephone Information Specialists provide professional and patient information services to callers on all cancer-related issues. Two Partnership Program Coordinators are assigned to Kentucky to provide community outreach in conjunction with other partners.

■ *Kentucky African Americans Against Cancer (KAAAC*)

KAAAC, affiliated with the National Cancer Institute's (NCI) National Black Leadership Initiative on Cancer, has two chapters in the state. Composed of lay and health professional volunteers, this coalition develops and implements cancer control activities for the African American population.

■ *Appalachia Cancer Network (ACN)*

Funded by NCI, ACN is an outgrowth of the Appalachia Leadership Initiative on Cancer addressing the cancer control concerns of the special population in this region. ACN's initiatives include community capacity building with regard to tobacco control, cancer screening and treatment, recruitment of minority scientists, and expansion of clinical trials.

■ *Centers for Disease Control & Prevention, Prevention Research Center (PRC)*

Funded by CDC, the PRC is the only one of 23 centers in the country focused on cancer. Kentucky's cancer burden and status as one of the leading states in cancer mortality was a critical point for funding consideration. The Center, funded in 2000, will focus on intervention research related to cancer control.Mobile Mammography. Two mobile mammography units travel throughout the state to provide services to low income women through local health departments. Services are also provided to women at work sites and other community locations, increasing accessibility and reducing barriers to screening.

■ *Special Initiatives*

A number of special initiatives have been undertaken in cooperation with cancer control partners as follows: Kentucky Breast Cancer Task Force (KBCTF); county breast and cervix coalitions in cooperation with KDPH, including the Louisville & Jefferson County Partnership in Cancer Control; Providers Practice Prevention, a continuing education program for primary care providers concerning breast and cervical cancer screening, in cooperation and supported by Kentucky Medical Insurance Company (KMIC) and Kentucky Medical Association (KMA); Cooper-Clayton tobacco education and cessation program for adults; "train the trainer" program in early detection in conjunction with the Cooperative Extension Service (CES); teacher screening initiative with KDE; adolescent tobacco prevention research; physician/patient communication research; Bridging the Gap, sponsored by the Information Action Council of the National Action Plan on Breast

Cancer, to link underserved urban and rural residents to cancer information via the Internet technologies; and numerous other innovative projects.

- *Pathfinder*

The Pathfinder, a regional resource guide of cancer related services for patients and families, is distributed through cancer care providers and regional KCP offices.

**American Cancer Society (ACS)**

ACS serves Kentucky through ten offices, located in Region I and II of the Mid-South Division. Volunteers and staff work to focus and strengthen cancer control in communities across the state. ACS has established goals for cancer incidence and mortality reduction and recognizes that collaboration is necessary for their achievement. Human and financial resources must be directed toward those outcome-based, proven interventions that can impact the cancer problem at the community level. Cancer control specialists and volunteers focus on the following programs and services:

- *Tell A Friend* is designed to encourage women 40 and older, particularly the Medicare-eligible, to follow ACS breast health guidelines, with particular emphasis on mammography. Trained volunteers identify women they know who may need a mammogram and provide them with information and assistance in obtaining one. Nationwide pilot programs have shown a 40-50 percent success rate as measured by the number of women called who receive mammograms.

- *Local Tobacco Advocacy* groups which may include strengthening of compliance with youth access laws, or helping businesses and restaurants provide a smoke-free environment, is designed to move Kentuckians toward fewer cases of and deaths from tobacco-related illness. With the future health of its children at stake, more and more Kentucky communities are eager for a meaningful framework for tobacco control.

- *Make Yours a Fresh Start Family* (MYFSF) is a tobacco cessation program targeting pregnant women and mothers of young children and implemented through health care providers, thus reaching thousands more smokers than traditional smoking cessation classes. Developed and evaluated in cooperation with the Fox Chase Cancer Center, MYFSF is promoted by the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists.

- *Patient and Family Services and Education* are available or accessible across the Mid-South Division. Cancer information as well as referral to hometown resources is available 24 hours a day, seven days a week through the National Cancer Information Center at 1-800-ACS-2345. Callers speak to trained cancer

resource specialists, with oncology nurses and a physician available to address medical issues that do not violate the doctor/patient relationship. Additionally, the ACS sponsors or co-sponsors numerous support groups in Kentucky and offers the following patient service programs:

- *I Can Cope*: a comprehensive educational series for newly diagnosed cancer patients and their families.
- *Reach to Recovery*: information and support, delivered by a specially trained breast cancer survivor.
- *Man to Man:* support group and/or one-on-one visitation program for the newly diagnosed prostate cancer patient.
- *Transportation*: volunteer-provided or community-assisted transportation to and from cancer treatment is available in some areas. New effects are focusing on developing additional transportation resources to help ensure that every patient is able to complete the course of treatment.
- *Look Good...Feel Better*: a service provided by trained volunteer cosmetologists for women coping with treatment-related cosmetic changes.
- *Laryngectomy Rehabilitation and Support*: support group and/or visitation program or the laryngectomy patient.
- *Wig Bank:* ACS offices maintain wig banks across the state; the wigs, as well as some turbans and/or hats are available free of charge to any patient suffering hair loss as a result of cancer treatment.

**Other Cancer Control Partners**

In addition to the three major partners described above, Kentucky is fortunate to have a number of other public and private partner organizations, both professional and volunteer, who also focus on reducing the cancer burden.

- *Kentucky Medical Association (KMA):* KMA has a Cancer Committee focusing on cancer issues pertinent to physician and cancer care practices.
- *Kentucky Breast Cancer Coalition (KBCC):* This statewide advocacy coalition, started jointly by ACS, KCP, and KDPH is the state's equivalent and a chapter of the National Breast Cancer Coalition (NBCC).

- *Kentucky Alliance to Control Tobacco in Our Neighborhoods (Ky Action)*: Initiated by ACS, the American Lung Association, the American Heart Association, and KCP, KY ACTION represents the tobacco and health views of over 60 organizations. In addition, there are over 1800 individual members at large.

- *Oncology Nursing Society (ONS)*: ONS chapters are located across the state, supporting community oncology projects and continuing education in cancer care for nurses.

- *Cooperative Extension Service (CES)*: Located in each of the 120 counties, CES has become an important public education partner in reaching rural, underserved families on health related issues. Historically, CES has offered lay training with regard to nutrition, weight control, physical activity, and disease control.

- *Susan G. Komen Foundation:* The two Kentucky Komen affiliates sponsor research, education, screening, and treatment programs funded by proceeds from the Race for the Cure and other fund raisers.

- *Journey's End: A Kentucky Partnership for quality End-of-Life Care:* A statewide coalition funded by Robert Wood Johnson and including local cancer partners, Journey's End addresses end of life and palliative care issues through activities such as the Educating Physicians about End of Life Care (EPEC) program related to care for terminal patients and their families.

- *Health Care Excel:* The contractor for the Peer Review Organization (PRO), Health Care Excel provides quality control oversight and education for Medicare recipients in Kentucky and Indiana.

- *Hospitals:* Hospitals in local communities provide cancer control services and often invite ACS and KCP to cosponsor programs.

- *Hospice:* Hospices offer end of life services for patients and families in both outpatient and inpatient settings in all Kentucky counties.

- *Mammography Centers:* Mammography facilities are located in 92 Kentucky counties to provide mammography and diagnostic services. Several facilities also provide more accessible services through three additional mobile units.

- *Support Groups*: A number of patient and family support groups are available to patients and their families throughout the state.

## *Cancer Burden in Kentucky*

### Demographics

According to the 1998 U.S. Census Bureau Post Censal Estimates, the state of Kentucky has a population of 3,934,310 residents. In 1990, 48% of this population lived in rural areas. African Americans constitute the largest racial minority, representing 7.2% of the Kentucky population, Table 1 shows the number and percent of the population by race.

Table 1.
Kentucky Population by Race and Hispanic Origin*

| Race | Population | Percent |
|---|---|---|
| White | 3,618,693 | 91.2 |
| African American | 284,860 | 7.2 |
| Hispanic | 32,508 | .8 |
| Asian & Pacific Islander | 27,108 | .7 |
| American Indian | 5,840 | .1 |

Source:1998 U.S. Census Bureau Population Estimates
*Per 100,000 population

Although Kentucky does not have extensive minority populations by race or ethnicity, a large proportion of the state is described as poor and medically underserved. The Kentucky state profile from the US Census Bureau Statistical Abstract of the US, 1998, lists Kentucky's population as being 15.5% below the poverty level. High poverty, low literacy, lack of medical care access and a high cancer burden are major descriptors of Kentucky's population.

### Incidence

Of the cancer cases diagnosed in Kentucky from 1994 through 1997, the majority resulted from the six cancers which have scientifically proven interventions: lung, breast, prostate, colon, cervix, and malignant melanoma.[1]

Kentucky has a predominantly White population, and the percentage of reported cancer cases for Whites is between 90% and 93.5% each year. The percentage of cases for African Americans ranges from 5.7% to 6.4% each year and the number for Asians is less than 0.2% each year. Kentucky has a small but growing Hispanic population. The proportion of cancer cases that are reported to be of Hispanic origin is very small (0.3-0.4%).

Impacting the cancer incidence problem in Kentucky are alarmingly high rates of tobacco use by youth and adults. In one federal survey, 47 percent of youth in grades

9-12 reported tobacco use in the past 30 days.[2] Kentucky also has the highest overall rate of adult smoking, nearly 31 percent, compared to the national median of 23 percent.[3] Unless tobacco use is stemmed, increased cancer rates are inevitable in the future.

Table 2 shows the invasive cancer incidence rates for Kentucky compared to the rates for the Surveillance, Epidemiology and End Results (SEER) population for 1994 -1997. For all types of cancer combined, the Kentucky rate is increasing every year while the SEER rates are declining. For lung cancer, however, the Kentucky rate is one-third higher than the SEER rate and at best, holding steady each year; whereas the SEER rate is declining slightly each year. Breast cancer in Kentucky women is somewhat lower than the SEER rate, and like SEER, increasing every year from 1995-97. Kentucky prostate rates are substantially lower than the SEER rates. For colorectal cancer, the rates in Kentucky are higher than those found in the SEER population. The melanoma rates have increased over this four year period.

Table 2.
Kentucky vs. SEER Age Adjusted Cancer Incidence Rates*

| Cancer Type | KY 1994 | SEER 1994 | KY 1995 | SEER 1995 | KY 1996 | SEER 1996 | KY 1997 | SEER 1997 |
|---|---|---|---|---|---|---|---|---|
| All Cancers | 389.2 | 403.4 | 397.9 | 397.1 | 401.0 | 396.3 | 409.0 | 395.0 |
| Lung | 84.8 | 57.0 | 87.3 | 56.5 | 84.6 | 55.6 | 85.1 | 54.4 |
| Breast | 98.5 | 110.5 | 97.0 | 111.9 | 100.5 | 112.4 | 104.4 | 115.4 |
| Prostate | 106.9 | 148.3 | 103.6 | 139.8 | 109.3 | 138.5 | 122.3 | 139.5 |
| Colorectal | 45.4 | 44.2 | 46.7 | 42.9 | 45.9 | 43.2 | 48.1 | 43.9 |
| Melanoma | 10.3 | 13.1 | 14.6 | 13.7 | 14.8 | 14.3 | 15.4 | 14.3 |
| Cervix | 11.2 | 8.0 | 12.2 | 7.5 | 10.8 | 7.9 | 9.8 | 7.5 |

Source: SEER Cancer Statistics Review, 1973-1997 & Kentucky Cancer Registry, 2000.
* Per 100,000 population.

## Mortality

The state of Kentucky is marked by unusually high cancer mortality rates. Table 3 presents the recent five-year rates compared with the U.S. Kentucky ranked fourth in the nation in 1993-1997 for deaths due to all cancer, with a mortality rate of 191.1 per 100,000. Kentucky's lung cancer mortality rate was the highest in the country with a rate of 67.9 per 100,000. More than a third of the 9,000 cancer deaths expected in Kentucky in 2000 are attributable to lung cancer alone.[4]

Table 3.
1993-1997 Kentucky Cancer Mortality Rates and Rank *

| Cancer Type | KY Mortality Rates | KY Rank |
|---|---|---|
| All Sites | 191.1 | 4 |
| Lung | 67.9 | 1 |
| Colorectal | 19.1 | 8 |
| Breast | 24.3 | 20 |
| Cervix | 3.6 | 3 |

Source: National Center for Health Statistics, 2000
* Per 100,000 population

Table 4 shows selected 1994-1997 age-adjusted cancer mortality rates for Kentucky and the U.S. The lung cancer mortality rates provide the most striking difference. The colorectal and cervix cancer mortality rates in Kentucky are also substantially higher than those for the U.S. The breast, prostate, and melanoma cancer mortality rates for Kentucky are similar to those for the U.S.

Table 4.
Kentucky vs SEER Age-Adjusted Cancer Mortality Rates**

| Cancer Type | KY 1994 | SEER 1994 | KY 1995 | SEER 1995 | KY 1996 | SEER 1996 | KY 1997 | SEER 1997 |
|---|---|---|---|---|---|---|---|---|
| All Cancers | 190.6 | 170.6 | 185.9 | 168.6 | 188.5 | 166.6 | 189.9 | 166.7 |
| Lung | 68.6 | 49.5 | 66.7 | 49.2 | 67.8 | 48.8 | 69.1 | 48.3 |
| Breast | 26.8 | 25.5 | 23.8 | 25.2 | 22.8 | 24.3 | 23.0 | 23.3 |
| Prostate | 25.3 | 25.8 | 26.1 | 24.8 | 22.8 | 24.0 | 24.7 | 22.5 |
| Colorectal | 19.0 | 17.6 | 18.5 | 17.3 | 19.6 | 16.8 | 18.2 | 16.5 |
| Melanoma | 2.1 | 2.2 | 2.3 | 2.2 | 2.1 | 2.3 | 2.7 | 2.2 |
| Cervix | 3.5 | 2.8 | 3.9 | 3.9 | 3.4 | 2.7 | 3.6 | 2.6 |

Source: SEER Cancer Statistics Review, 1973-1997; Kentucky Cancer Registry, 2000
* Per 100,000 population

## Economic Burden

The National Institutes of Health estimates the overall annual cost for cancer is $107 billion.[5] This includes $37 billion for direct medical costs (total of all health expenditures), $11 billion for indirect morbidity costs (cost of lost productivity due to illness), and $59 billion for indirect mortality costs (cost of lost productivity due to premature death). Treatment of breast, lung, and prostate cancers accounts for over half of the direct medical costs.

# II. PLAN PROCESS

## *Plan Development*

The KBCTF, the statewide group established by the Governor to explore the problem of breast cancer in Kentucky served as the foundation of the Cancer Plan development. Chaired by the First Lady, KBCTF is composed of 60 members representing the following organizations and partners: Kentucky General Assembly, Kentucky Association of Health Plans (KAHP), Kentucky Hospital Association (KHA), Kentucky Hospice Association, Kentucky Society of Radiologists, KMA, KDPH, ACS, KBCC, KAAAC, ONS, UK Markey Cancer Center, U of L Brown Cancer Center, KCR, CIS, oncology social workers, Kentucky Breast Cancer Advisory Committee, Kentucky Primary Care Association, Kentucky Association of Family Practice (KAFP), Kentucky Commission on Women, and survivor organizations.

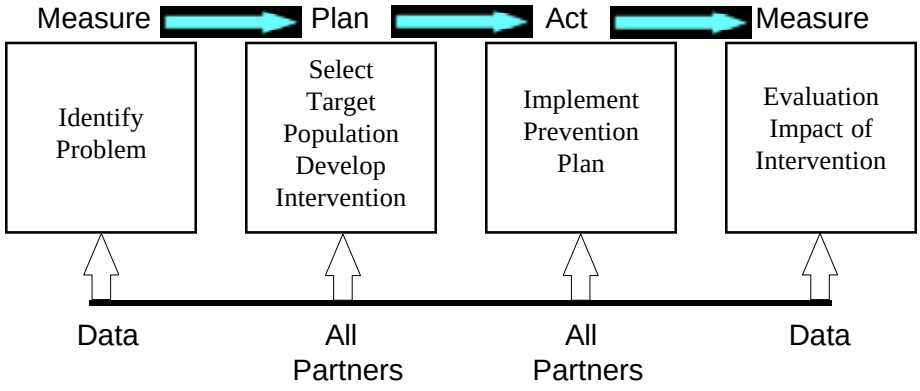
This group generated the Kentucky Breast Cancer Action Plan to address breast cancer issues in Kentucky. This two year process reflects steps outlined in the guidance document of the *Public Health Foundation, Healthy People 2010 Tool Kit, A Field Guide to Health Planning*, utilized by states for cancer plan development. The process for developing Kentucky's breast cancer plan included the following:

- Secured resources to develop the plan;
- Identified staff and expert consultants for facilitation;
- Developed a planning process including a timeline and work group structure;
- Selected cancer control partners with representation from multi disciplines, geography, political affiliation, including health care providers and survivors;
- Developed Kentucky's Breast Cancer Profile through a review of available data sources; including data on prevention, early detection, treatment, quality of life, along with information about issues related to the policy and political environment, all to be used. for plan development and evaluation;
- Conducted consensus building discussions resulting in the identification of issues and recommendations for action which were found to have broader implications for cancer control in general;
- Disseminated recommendations via a statewide press conference through the Governor's office and via regional cancer control networks to community partners;
- Activities are being monitored to measure progress in achieving recommendations and KCR data will be reviewed to evaluate outcomes.

KCP's Model of Cancer Control (Figure 2) was employed throughout the plan development. It consists of four key steps: identify the cancer control problem; select the target population and the intervention strategy; implement the intervention plan; and measure the impact of

the intervention. As shown in the model, different types of data provide input for each step. A key part of this process is using KCR data to identify cancer incidence, as well as to measure the impact of cancer control activities. Other data sources to be utilized in implementation and evaluation are discussed later in this document.

Figure 2.
Model for Cancer Control
(Cancer Control Can Be Defined As "Activities Designed
To Reduce Morbidity & Mortality From Cancer")




The following steps were undertaken in the planning process:

- **Work Group**

A work group was established to spearhead the development of the Kentucky Cancer Plan. Composed of representatives from KCP at U of L and UK, UK Center for Health Services Management and Research, and a consultant with federal cancer control experience, this work group collaborated with the Chronic Disease Branch of KDPH.

- **Cancer Plan Review**

The work group began with a review of cancer plans developed by other states. This process enabled members to examine various formats, plan contents and cancer issues common to Kentucky.

- **Review *Healthy People 2010* Kentucky Objectives**

The next step was to review the *Kentucky Healthy People 2010* priorities, which were established by KDPH. The cancer related measurable objectives presented in Figure 3 will be used to monitor the progress of this plan as designated in the recommendations.

Figure 3.
Kentucky Healthy People 2010 vs Kentucky's Cancer Plan

| ***Kentucky Healthy People 2010*** | ***Kentucky's Cancer Plan*** |
|---|---|
| Reduce cancer deaths > 220.7 per 100,000. | All Recommendations |
| Maintain lung cancer deaths to a rate > 80.7 per 100,000. | Recommendations 1-8 |
| Reduce breast cancer deaths > 22.5 per 100,000. | Recommendation 1 |
| Reduce deaths from cancer of the uterine cervix > 3.2 per 100,000. | Recommendation 5 |
| Reduce colorectal cancer deaths > 23.5/100,000. Increase to at least 35% the proportion of people ages 50 and over receiving Fecal Occult Blood testing every 1-2 years, and to at least 40% those who have ever received proctosigmoidoscopy. | Recommendation 6, 7 |
| Increase the number of men> 50, particularly African American and other high risk individuals, who receive counseling from health care providers about prostate cancer screening. | Recommendation 12 |
| Increase the % of persons >50 who have received oral, skin and digital rectal exams in the preceding year. | Recommendation 3,7 |
| Increase to at least 95% the proportion of women ages > 18 who have received a Pap test, and to at least 85% those who received a Pap test within the preceding 1-3 years. | Recommendation 6 |
| Increase to at least 85% the proportion of women ages > 40 who have ever received a CBE and mammogram, and to at least 85% those ages > 50 who have received a CBE and mammogram with the preceding 1-2 years. | Recommendation 5 |
| Increase the proportion of cancer survivors who are living > 5 years after diagnosis. | Recommendation 1,2,3,4,5,6,7,8 |
| Increase the % of KY physicians who have current knowledge about genetics and disease and who appropriately counsel or refer their high risk patients. | Recommendation 14 |

- **Survey**

A vital part of the plan development was a survey conducted among statewide partners and administered through KCP regional offices including DCCs. This open-ended survey, developed by the Illinois Partnership for Cancer Prevention and Control, was revised for Kentucky use. A total of 445 individuals from across the state completed the surveys representing over a 70% return rate. All respondents are active in cancer prevention, diagnosis, treatment, and survivorship activities and represent the following organizations: ALA, ACS, CIS, CES, Brown Cancer Center, KCR, KCP, Kentucky Center for Health Services Management & Research, KDPH, KMA, KAAAC, Kentucky Hospice Association (KHA), KBCTF, Kentucky Nurses Association (KNA), Kentucky Hospital Association, Markey Cancer Center, ONS, Survivor Organizations, UK and U of L Schools of Medicine.

Of the 445 respondents some individuals provided more than one response to single questions. Therefore, the survey was tallied according to the number of responses, not the number of respondents. The largest groups represented were nurses, 108 (24%); health educators, 56 (13%); community organizations, 56 (13%); cancer survivors, 46 (10%), physicians, 37 (8%); health administrators, 27 (6%), other health care providers, 24 (5%); tumor registrars, 17 (4%); and county extension agents, 12 (3%). The remaining 62 respondents represented a variety of occupations and interests.

The central theme emerging in the surveys was the need to address tobacco use to reduce the cancer burden for which it is responsible. Tobacco was the most frequent answer to two questions:

> "If you could change one thing to improve cancer prevention and control in Kentucky, what would it be?"

> "What two major cancer-related priorities do you believe need to be more comprehensively addressed in Kentucky?"

For the latter question, one-third of responses related to tobacco and lung cancer, with the second being screening (8%), healthy lifestyle, e.g. diet/exercise, (7%) health insurance/access, (7%), and education, (7%).

Increased screening and education also tied as the second most frequent response to the question:

> "If you could change one thing to improve cancer prevention and control in Kentucky, what would it be?"

The "education" responses dealt with cancer education for both young people and adults about the importance of early detection. For the question:

> "What are your expectations of a state cancer plan?"

The largest percentage of responses (17%) was education, followed by access/ insurance issues (14%), and early detection (11%). "Education" responses to this question focused on school and community-wide cancer education.

- **Partner Meetings**

Throughout the plan development process, the work group met with organizational partners to review their respective goals for integration into this comprehensive document. Initial consensus building sessions started with the ACS, and then moved to other partners as described in a previous section.

- **Cancer Conference**

A cancer control conference was held for a multidisciplinary audience of specialists, survivors, and volunteers, including community coalitions, DCC members, and other interested individuals. Several national experts and invitees from surrounding states' cancer programs also attended. Panelists led discussions during strategy sessions and identified ways organizations could take leadership roles in implementation. Participants were given the opportunity to recommend modifications to the draft plan during these strategy sessions. It is anticipated that key organizations will incorporate recommendations into their short and long-range plans.

In summary, the planning steps reflect CDC recommendations which include proactive leadership at all levels, use of outside experts, cross-program, cross-agency sharing and action, and accountability. The result is a blueprint for cancer control actions, recommending a range of strategies with the potential to reduce the burden of cancer in Kentucky.

## *Plan Implementation*

Implementation of this cancer plan will be a challenge requiring commitment of all cancer control partners in Kentucky. It is anticipated that staff from state and local health departments, KCP and ACS will be instrumental in moving the plan forward. CDC's continued assistance, technical and financial, will be needed. This process would be greatly enhanced by further support through a federally funded position to coordinate the implementation. A request has been submitted to CDC for a field staff assignee in Kentucky to work with cancer control organizations who have responsibility for cancer control. This plan calls for an annual review of health-related data outlined in other sections of this document. Analysis of these data and changing scientific, economic, and/or legislative factors may require future revisions of the plan.

In this era of health care cost containment and limited funding, existing resources must be integrated and maximized if optimal cancer prevention and control is to be achieved. A comprehensive approach is required to mobilize the statewide capacity for cancer prevention and control, as well as to develop and energize the leadership needed to carry out the plan. Successful implementation is contingent on effective partnerships. This document presents a plan that should serve Kentuckians well into the new century.

# III. CANCER CONTROL PLAN

Science-based cancer control approaches can improve future cancer incidence and mortality rates. Numerous effective measures exist today to prevent cancer and to minimize its consequences. The development of many cancers is related to personal lifestyles, behaviors and the environment.[6] In Kentucky, a vast number of cancer cases are attributable to tobacco use. Existing scientific research suggests that one-third of all cancer deaths occur each year due to smoking. Other cancer risk factors include adherence to traditional and unhealthy diets, a lack of physical activity, and exposure to solar radiation. Environmental factors also play a role in cancer risk, especially in occupational settings where workers have been exposed to high concentrations of certain chemicals, metals, and other exposures.

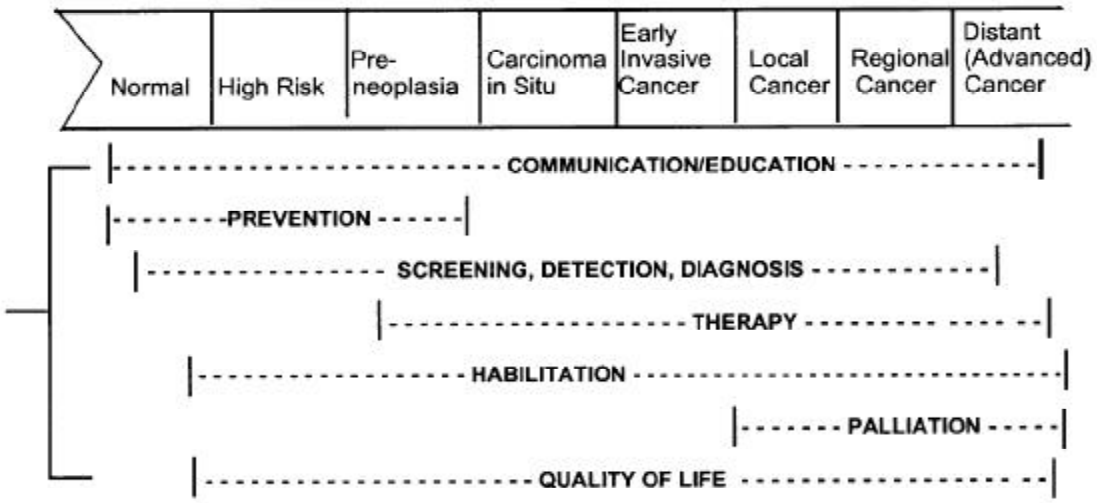
Cancer incidence rates are also influenced by the utilization and availability of tests for diagnosing the disease in its earliest stages. Regular screening examinations increase the odds that cancer will be detected at its earliest stage. Early detection and improved treatment are allowing more people who have been diagnosed with cancer to live longer and with improved quality of life.

Kentucky's unique culture, rooted deeply in tobacco and traditional Southern cooking,[7] makes cancer control more challenging. However, Kentucky also has enormous cancer control resources. These include excellent cancer treatment facilities and research institutions, and a unique state-wide cancer control partnership, involved in the prevention, early detection and treatment of cancer, and many others committed to improving the quality-of-life of patients and their families.

This plan proposes approaches to reduce the burden of cancer in Kentucky by addressing four areas along the continuum of disease (Figure 4):

- **Prevention**, with a focus on tobacco control, nutrition and physical activity, solar radiation, and environmental factors.
- **Early Detection**, with separate goals for breast, cervical, colorectal, and prostate cancers.
- **Care**, including access, standards of care, and end-of-life issues.
- **Survivorship.** The grids in each section present recommendations and priorities with monitoring and evaluation schema.

## Figure 4. The Continuum of Disease



| PREVENTION | |
|---|---|
| **RECOMMENDATIONS/PRIORITIES** | **MONITOR/EVALUATE** |
| **TOBACCO USE** | |
| 1. Reduce mortality from tobacco related cancers.<br>1.1 Increase proportion of tobacco users who successfully quit.<br>1.2 Reduce youth initiation of tobacco use.<br>1.3 Reduce/eliminate ETS. | 1. KCR, Vital Statistics<br>1.1 Cessation Groups/YRBS<br>1.2 YRBS<br>1.3 Chamber of Commerce |
| **NUTRITION & PHYSICAL ACTIVITY** | |
| 2. Reduce cancer mortality related to inadequate nutrition and lack of physical activity.<br>2.1 Increase % of Kentuckians who eat > 5 servings of fruits/vegetables daily.<br>2.2 Increase % of Kentuckians who exercise moderately on a daily basis. | 2. Data need<br>2.1 BRFSS<br>2.2 BRFSS |
| **SOLAR RADIATION** | |
| 3. Reduce the incidence and mortality of skin cancers resulting from solar radiation.<br>3.1 Increase % of people of all ages who limit sun exposure, use sun screens and wear protective clothing when exposed to sunlight and avoid artificial sources of UVA. | 3. KCR Vital Statistics<br>3.1 BRFSS |
| **ENVIRONMENTAL CARCINOGENS** | |
| 4. Increase the knowledge base on environmental carcinogens.<br>4.1 Foster research on environmental causes of cancer. | 4. Researchers<br>4.1 University sponsored projects. |

## *Prevention*

Cancer is a largely preventable illness.[8] Two-thirds of cancer deaths in the U.S. can be linked to tobacco use, poor diet, obesity, and lack of exercise. Therefore, the greatest promise of reduced cancer incidence and mortality for Kentuckians rests with tobacco use avoidance and cessation, with improved nutrition, increased physical activity, and reduced exposure to solar radiation. Prevention activities directed toward changes in personal behavior are investments in the future; unlikely to impact either cancer incidence or mortality rates for several years. However, those adopting lifestyle changes may see immediate benefits in improved health status. These are the building blocks for a healthier Kentucky and a reduced cancer burden.

### ***Tobacco Use***

Tobacco use, especially the practice of cigarette smoking, remains the largest preventable cause of death and disability in Kentucky, which leads the nation in smoking rates for both adults and youth. Tobacco use is the single most preventable cause of cancer, responsible for a majority of the cases and deaths of cancer of these sites: lung, larynx, oral cavity, and esophagus. Lung cancer is the single largest cause of cancer mortality among both men and women and accounts for more than one in every four cancer deaths nationally. About 87 percent of lung cancer deaths and about 20 percent of all cancer deaths can be attributed to smoking.[8]

Reports have also demonstrated that smoking substantially elevates the death rates for cancers of the bladder, kidney, and pancreas in both men and women, and, possibly, cervix cancer in women. A number of published reports have suggested an association between smoking and other cancers, including cancer of the stomach, liver, prostate, colon, and rectum.[9]

Kentucky has the highest overall rate of adult smoking in the U.S., nearly 31 percent.[8] Most smokers began tobacco use before the age of 18. Kentucky's rate for tobacco use among youth is also the highest in the nation, with 47 percent of youth surveyed reporting tobacco use within the past month, compared to 36 percent nationally.[10] The risk of developing any of the smoking related cancers is dose-related; that is, the more cigarettes consumed daily, the younger the age at which one initiates smoking, and the more years one smokes, the greater the risk. Quitting smoking greatly reduces the risks for disease. For example, within a year of quitting, a former smoker's risk of heart disease is reduced by nearly 50 percent compared to someone who continues to smoke. Unfortunately, the risks for lung cancer do not decrease as rapidly, but the sooner one quits smoking, the quicker one begins to benefit. Usually, after 10 to 15 years off cigarettes, most former smoker's health status is not significantly different from that of a lifelong nonsmoker.

In addition to smoking, the use of spit tobacco products, chew and snuff, causes oral cancer, primarily of the cheek and gum, and evidence also suggests an association between the use of smokeless tobacco and cancers of the larynx and esophagus.[8] Other health consequences include damage to teeth and gums. About 28 percent of boys in Kentucky, grades 9-12, had used chewing tobacco or snuff in a 1997 survey.[10] Use of spit tobacco products is deeply rooted in Kentucky's rural culture. Environmental tobacco smoke (ETS), also called side-stream smoke, is now recognized as a significant cause of lung cancer in nonsmokers. Nonsmokers who live or work with smokers experience a 30 to 50 percent elevated risk for lung cancer. Each year, an estimated 3,000 to 6,000 nonsmoker lung cancer deaths in the U.S. are attributed to ETS.

Goals and priorities for tobacco control were developed with guidance from the CDC's *Best Practices for Comprehensive Tobacco Control Programs*.[11] According to this guidance document, the goal of comprehensive tobacco control programs is to reduce disease, disability, and death related to tobacco use by: preventing the initiation of tobacco use among young people; promoting quitting among young people and adults; eliminating non-smokers' exposure to environmental tobacco smoke (ETS); and, identifying and eliminating the disparities related to tobacco use and its effects among different population groups.

The Kentucky General Assembly made tobacco control history during the 2000 session with the allocation of tobacco settlement funds. KDPH and the Kentucky Agency for Substance Abuse Policy were awarded $10.5 million for two years for tobacco prevention and cessation programs. Plans call for the development of tobacco control coalitions in communities across the state. Also allocated were $5 million for lung cancer research over two years to be conducted by the U of L and the UK for the early detection and treatment of lung cancer.

**Recommendation 1:** Reduce mortality from tobacco-related cancers.

***Priority 1.1:*** Increase the proportion of tobacco users in Kentucky who successfully quit.

Strategies:

- Make cessation resources and programs widely available in communities including programs tailored to youth to support users who want to quit;
- Increase the capacity of physicians and other health care providers to provide cessation advice and counseling;

***Priority 1.2:*** Reduce youth initiation of tobacco use.

Strategies:

- Integrate tobacco use prevention into the school curriculum at all grade levels;
- Include tobacco use prevention in the curriculum of colleges of education at state universities and encourage those pursuing careers in teaching to become smoke free themselves;
- Distribute prevention messages through existing youth-oriented community-based channels, such as youth sports, Scouts, 4-H Clubs, youth recreational organizations, YMCA/YWCA, and church groups;
- Raise youth awareness through the media;
- Eliminate promotion of tobacco products.

***Priority 1.3:*** Reduce or eliminate environmental tobacco smoke (ETS) exposure.

Strategies:

- Encourage tobacco-free policies in work places, day care facilities, and other public locations;
- Mandate that schools be tobacco free for faculty and staff;
- Enforce existing laws relating to smoke-free environments.

## ***Nutrition and Physical Activity***

Evidence on the role of a healthy diet in cancer prevention is mounting. The deleterious consequences of obesity are considerable. “Recent estimates attribute 280,000 deaths per year in the US to ‘over-nutrition,’ making it second only to cigarette smoking as a cause of death.”[12] Eating right, plus staying physically active and maintaining a healthy weight, can cut cancer risk by 30 to 40 percent. As many as 375,000 cases of cancer, at current cancer rates, could be prevented each year in this nation through healthy dietary choices.[13]

A recent review of worldwide evidence on diet and cancer concluded that high fruit and vegetable consumption reduces the risk for at least 10 different cancers, including cancers of the lung, stomach, colon, esophagus, and larynx. Also, evidence is mounting that increased consumption of legumes and grains reduces the risk for stomach and pancreatic cancers.[14] Currently available research links diets high in fat to increased risk of various cancers, particularly breast, colon, prostate, and possibly pancreas, ovary, and endometrium.[15] Other dietary factors that have been associated with increased cancer risks include char-broiling and char-grilling of meats,[16] as well as heavy consumption of salted, pickled, or smoked foods.[17]

In a 1996 survey, only 17 percent of adults in Kentucky reported eating five or more fruits and vegetables per day. Among high school students, 21 percent had eaten five or more servings of fruits or vegetables on the day before the survey; 52.5 percent had eaten high fat foods.[10] Kentuckians are also known for high consumption of foods, such

as country ham and barbecue, that involve preparation methods (salted or smoked) mentioned above. There is enormous potential for improving nutrition among Kentuckians of all ages.

Scientific evidence about the relationship between physical activity and health status has increased, supporting the conclusion that benefits from regular moderate exercise are substantial, including a lower risk of colon cancer. Exercise may also help reduce cancers of the breast and prostate.

Physical activity burns calories, helps an individual maintain a desirable body weight, and can positively affect the distribution of body fat. Researchers are studying the role of physical activity and its relation to reduced cancer risk through enhancing the immune system, shortening the time food takes to move through the intestines, altering body composition and hormone levels.[18]

In a 1996 survey, nearly 46 percent of Kentuckians reported no leisure time physical activity; only 12 percent had regular and sustained physical activity; and 11 percent had regular and vigorous physical activity.[19] These data demonstrate an area in which widespread lifestyle changes are needed.

ACS Goals for Nutrition and Physical Activity in the Year 2000 are as follows:[20]

- Avoid overweight and weight gain during adulthood.
- Be moderately to vigorously active for at least 30 minutes on most days.
- Consume five servings of fruits and vegetables daily.
- Replace red meat with chicken, fish, nuts, and legumes, and consume dairy products at most in moderation.
- Limit alcohol consumption to one drink a day for women and two for men.
- Consider taking a multivitamin containing folic acid, particularly if alcohol is consumed daily.
- Consume cereal products in minimally refined, whole grain form.

| **Recommendation 2:** | Reduce mortality related to inadequate nutrition and lack of physical activity. |
|---|---|

***Priority 2.1:*** Increase the percentage of Kentuckians who eat five or more servings of fruits and vegetables daily.

Strategies:

- Increase awareness among Kentuckians of the nutrition goals and the health benefits of proper nutrition through the media and other communications channels;
- Incorporate nutrition education into the school curriculum at all grade levels;

- Encourage consumer education by grocers;
- Increase the capacity of physicians and other health care providers to provide nutrition advice and counseling;
- Encourage availability of healthy food choices at fast-food concessions in work sites, congregate eating sites, and other locations;

***Priority 2.2:*** Increase the percentage of Kentuckians who exercise moderately on a daily basis.

Strategies:

- Increase awareness among Kentuckians of the health benefits of exercise and ways to incorporate exercise into daily activities;
- Encourage employers to provide opportunities for exercise, including facilities whenever possible;
- Encourage school-based physical education programs.

## ***Solar Radiation***

Solar radiation exposure is the chief cause of non-melanoma (i.e., basal cell and squamous cell) skin cancer. It is also a prime factor in the etiology of malignant melanoma, which causes 75 percent of all deaths from skin cancer. This disease can spread to other organs, most commonly the lungs and liver.

Some of the risk factors for melanoma are:

- Light skin color
- Family or personal history of melanoma
- Presence of moles and freckles
- History of severe sunburn occurring early in life

Thousands of Kentuckians have outdoor occupations that necessitate exposure to the sun. These occupations include farming, construction, utility maintenance, and landscaping. People in these occupations are especially at risk for developing skin cancer.

Increasingly, Kentuckians, especially young people, are using commercial and home tanning beds. A typical indoor tanning session involves bombardment for 15, 20, or 30 minutes with UVA radiation at wavelengths of 320-400 nanometers (about two to three times the UVA in normal sunlight).[21] This exposure, like sun exposure, increases the risk of developing skin cancer.

| **Recommendation 3:** | Reduce the incidence and mortality of skin cancers resulting from solar radiation. |
|---|---|

***Priority 3.1*:** Increase the proportion of people of all ages who limit sun exposure, use sun screens and protective clothing when exposed to sunlight, and avoid artificial sources of ultraviolet light, such a sun lamps, tanning booths, and other devices.

Strategies:

- Integrate skin cancer prevention into the school curriculum at all grade levels;
- Encourage day care facilities to protect children from sun exposure;
- Encourage designers of playgrounds and outdoor recreational facilities to provide adequate shade;
- Encourage farmers, construction workers, and others in outdoor occupations to practice sun protection;
- Increase public awareness of sun safety and of the hazards of artificial light sources; and regulate businesses providing tanning services.

## ***Environmental Carcinogens***

Environmental tobacco smoke and solar radiation, discussed previously, are two major environmental carcinogens. There are many other carcinogens in the environment that contribute to the development of cancer. The degree of cancer risk a person may have depends on the concentration or intensity, and the exposure dose of a particular carcinogen.[4] Substantial increases in risk have been demonstrated in occupational settings where workers have been exposed to high concentrations of certain chemicals, metals, and other exposures as well as among radiation victims, and patients treated with drugs or therapies later found to be carcinogenic.[4]

Many chemicals have been linked in studies to increased cancer risk. Often, public concern about environmental cancer risks focuses on risks for which no carcinogenicity has been proven or on situations where known exposures are at such low levels that risks are negligible.[4] Examples are pesticides, electromagnetic radiation, and nuclear power plants.

Pesticides are widely used in producing and marketing our food supply. These chemicals are found in some foods in very low concentrations, well within established safety levels. However, environmental pollution by slowly degrading pesticides, such as DDT, a result of past agricultural practices, can lead to food chain bio-accumulation and to persistent residues in body fat. Such residues have been suggested as a possible risk factor for breast cancer. Studies have shown that concentrations in tissue are low, and the evidence has not been conclusive.[4] Although evidence that pesticides cause cancer in humans is not conclusive, a prudent course would be to minimize exposure through use of protective practices and appropriate personal hygiene. Research is continuing to clarify cancer risks from specific pesticides and to determine mechanisms of actions.

**Recommendation 4:** Increase the knowledge base on environmental carcinogens.

***Priority 4.1:*** Foster research on environmental causes of cancer.

Strategies:

- Support research on the etiology of environmental cancers;
- Encourage Kentucky researchers to apply for federal and nonprofit funding for research projects on environmental carcinogens;
- Monitor cancer incidence and potential environmental exposures via the KCR.

# EARLY DETECTION

| RECOMMENDATIONS/PRIORITIES | MONITOR/EVALUATE |
|---|---|
| **BREAST** | |
| 5. Reduce mortality from breast cancer by early detection through increased screening.<br>5.1 Raise awareness among Kentucky's women about breast cancer risks and benefits of early detection.<br>5.2 Provide all women > 40 with access to screening mammography.<br>5.3 Improve availability and accessibility of screening services in areas of state with proportion of late stage disease, and among subgroups of high-risk women. | 5. KCR<br>5.1 ACS, KBCC, KBCTF, KCP, KDPH<br>5.2 KDPH<br>5.3 Community coalitions, ACS, KCP, KDPH |
| **CERVIX** | |
| 6. Reduce mortality from cervical cancer by early detection through increased screening.<br>6.1 Raise awareness about risks, and benefits of early detection.<br>6.2 Increase % of women who obtain regular Pap tests and pelvic exams.<br>6.3 Ensure the quality of Pap tests in pathology labs. | 6. KCR<br>6.1 ACS, KCP, KDPH<br>6.2 BRFSS<br>6.3 Pathologists/Pathology lab certification |
| **COLORECTAL** | |
| 7. Reduce mortality from colorectal cancer by early detection through increased screening.<br>7.1 Promote, increase and optimize the appropriate use of high quality colorectal cancer screening.<br>7.2 Improve colorectal screening methods. | 7. KCR<br>7.1 KMA, Medicare, KAHP<br>7.2 KMA, Providers Practice Prevention |
| **PROSTATE** | |
| 8. Reduce mortality from prostate cancer, especially among African Americans.<br>8.1 Raise awareness of prostate cancer risks.<br>8.2 Increase % of at risk men >50 who are screened regularly.<br>8.3 Improve screening and treatment. | 8. KCR<br>8.1 ACS, KAAAC, KCP, KDPH<br>8.2 KMA, Urologists<br>8.3 KMA, KY Physicians Practice Survey, Cancer Committee |

## *Early Detection*

Early detection of cancer, through screenings, may extend life, reduce treatment requirements, and improve the quality of life for cancer patients. As with prevention, the benefits of early detection are not recognizable on a statewide level for years to come. In fact, increased screening efforts may lead to temporary increases in cancer incidence rates. With effective screening, however, cancers will be detected at earlier stages when treatment is more likely to be successful.

The technology for early detection is improving daily with more screening methods being developed, for an expanding array of cancers. However, even the most advanced screening methods are useless unless asymptomatic people seek screening according to established guidelines. A major problem in Kentucky is that large percentages of residents do not seek screening exams for early detection when they have no symptoms. As a result, cancers are too often detected at more advanced stages and thus successful treatment is often diminished.

Cancers discussed herein include breast, cervical, colorectal, and prostate, those for which screening techniques are currently available. Screening guidelines vary among various medical organizations, and they are subject to change with advancements in science. Such changes may necessitate alterations in screening-related goals within this plan.

### ***Breast Cancer***

Breast cancer is the second most often diagnosed cancer in Kentucky, with an estimated 2700 cases expected in 2000. Only lung and bronchus cancers are estimated to be diagnosed more often with 3400 cases expected. Nationally, breast cancer is diagnosed more often than lung cancer, with 182,800 new cases of breast cancer cases expected, compared to 164,100 cases of lung and bronchus cancers. Risk factors for breast cancer include:[22]

> *Gender*: Simply being a woman is the main risk factor for developing breast cancer. Breast cancer can affect men, but this disease is about 100 times more common among women than men.
>
> *Aging*: A woman's risk of developing breast cancer increases with age. About 77 percent of women with breast cancer are over age 50 at the time of diagnosis. Women aged 20-29 account for only 0.3 percent of breast cancer cases.
>
> *Genetic risk factors*: Recent studies have shown that about 10 percent of breast cancer cases are hereditary and that most of these result from mutations (changes) of the BRCA1 and BRCA2 genes. Normally, these genes help to prevent cancer by making proteins that keep cells from growing abnormally. However, if a person has inherited a mutated gene from either parent, chances

of developing breast cancer increase. About 50 percent to 60 percent of women with inherited BRCA1 or BRCA2 mutations will develop breast cancer by the age of 70. Women with these inherited mutations also have an increased risk for developing ovarian cancer.

*Inherited mutations of the p53 tumor suppressor gene* can also increase a woman's risk of developing breast cancer, as well as leukemia, brain tumors, and/or sarcomas (cancer of bones or connective tissue). The Li-Fraumeni syndrome, named after the two researchers who described this inherited cancer syndrome, is a rare cause of breast cancer.

*Previous breast biopsy*: Women whose earlier breast biopsies were diagnosed as proliferative breast disease without atypia or usual hyperplasia have a slightly higher risk of breast cancer (1.5 to 2 times greater than other women do). A previous biopsy result of atypical hyperplasia increases a woman's breast cancer risk 4 to 5 times. Having a biopsy diagnosed as fibrocystic changes without proliferative breast disease does not affect breast cancer risk.

*Family history of breast cancer*: Breast cancer risk is higher among women whose close blood relatives have this disease. Blood relatives can be from either the mother's or father's side of the family. Having one first-degree relative (mother, sister, or daughter) with breast cancer approximately doubles a woman's risk, and having two first-degree relatives increases her risk 5-fold. Although the exact risk is not known, women with a family history of breast cancer in male family members also have an increased risk of breast cancer.

*Personal history of breast cancer*: A woman with cancer in one breast has a 3- to 4-fold increased risk of developing a new cancer in the other breast. This is different from a recurrence of the first cancer.

*Race*: Although white women have a higher incidence rate of breast cancer than do African American women, African Americans have a higher mortality rate. Asian and Hispanic women have a lower risk of developing breast cancer.

*Previous breast irradiation*: Women who have had chest area radiation therapy as a child or young woman, as treatment for another cancer (such as Hodgkin's disease or non- Hodgkin's lymphoma) are at significantly increased risk for breast cancer.

*Menstrual periods*: Women who started menstruating at an early age (before age 12) or who went through menopause at a late age (after age 50) have a slightly higher risk of breast cancer.

*Other suspected risk factors:* for breast cancer include lifestyle-related factors, including use of oral contraceptives, not having children, induced abortion, estrogen replacement therapy, not breast feeding, use of alcohol, obesity and high-fat diets, and lack of physical activity.[22]

Kentucky has made enormous strides recently in identifying ways in which to address the burden of breast cancer in the Commonwealth. The Kentucky Breast Cancer Task Force, established by Governor Paul Patton in 1998, developed the "Kentucky Breast Cancer Action Plan."[23] The plan described the breast cancer problem in Kentucky and made numerous far-reaching recommendations. Some of the most significant recommendations dealt with breast cancer screening. During the second year of the Breast Cancer Task Force activities, the Implementation Plan was developed. [24]

Regular mammography screening, when combined with timely and appropriate treatment, can reduce mortality from breast cancer by 30 percent in women over the age of 50 and 16 percent in women ages 40-49 years. In 1997, about 27 percent of Kentucky women ages 50 and older reported that they had not received a mammogram in the last two years.[3] This was equal to the national median percentage. In the same survey, only 73 percent of women age 50 and older reported having had a clinical breast exam within the past two years, compared with 77 percent nationally.

The Kentucky Breast Cancer Action Plan calls for all women age 40 and older to have a mammogram and clinical breast examination each year. Despite significant growth in mammography facilities over the past decade, 38 Kentucky counties (32%) still do not have a certified mammography facility. These counties account for 11 percent of all Kentucky women ages 40 and older. Also, Medicare data show low mammography utilization among women ages 65 and older. Between 1994 and 1995, for example, only 23 percent of Kentucky's female Medicare beneficiaries received screening mammograms. Variations were also found in screening rates among ethnic, income, and education differences. White women were more likely to had "ever received" a mammogram than African American women, as were women with incomes greater than $25,000 per year. Women with less formal education were less likely to have had a mammogram or clinical breast examination in the past two years.

| **Recommendation 5:** | Reduce mortality from breast cancer by early detection through increased screening. |
|---|---|

***Priority 5.1:*** Raise awareness among Kentucky's women about breast cancer risks and the benefits of early detection.

Strategies:

- Establish an integrated, ongoing public information program to foster a

high degree of knowledge among women of all ages about breast cancer risks and benefits of early detection;
- Encourage health care providers to routinely counsel women in their care to undergo breast cancer screening;
- Integrate reminder systems into physician practices;
- Promote community-level programs, such as breast cancer coalitions, to increase breast cancer education opportunities and to educate women about the risk of breast cancer and the need to return for re-screening at appropriate intervals.

***Priority 5.2:*** Provide all women ages 40 and older with access to screening mammography.

Strategies:
- Utilize available mechanisms for financing regular screening for uninsured and under-insured women;
- Encourage in-state self insured companies and in-state branches of out-of-state companies to provide screening mammography coverage in accordance with current ACS guidelines;
- Ensure that age-eligible women in counties without mammography facilities have adequate access to breast cancer screening through facilities in adjoining counties and/or mobile mammography units;
- Encourage hospitals and other health service organizations to offer free or low-cost breast cancer screening.

***Priority 5.3:*** Improve availability and accessibility of breast cancer screening services in geographic areas with high proportions of late-diagnosed breast cancers and among subgroups of women with lower screening rates (e.g., African American women; women with less than 12 years of education; women who are non-English speaking; and women who are low-income, uninsured, and/or > 70 years of age.)

Strategies:
- Expand community coalitions to increase breast cancer education and screening;
- Implement special interventions for at-risk populations.

## ***Cervix***

There are several known risk factors for cervix cancer. These include early age at first intercourse, multiple sex partners, smoking, and exposure to the Human Papiloma Virus (HPV).

Cervix cancer is detected through the Pap test, a simple, painless test to detect abnormal cells in and around the cervix. If all women had pelvic exams and Pap tests

regularly, most precancerous conditions would be detected and treated before cancer develops. Precancerous changes of the cervix usually do not cause pain. In fact, they generally do not cause any symptoms and are not detected unless a woman has a pelvic exam and a Pap test.

According to incidence and mortality rates, screening for cervix cancer should start in the late teens when these rates begin their upward trend. Carcinoma in situ describes a pre-invasive cancer that involves only the surface cells and has not spread into deeper tissues. Cervix cancer occurs when abnormal cells spread deeper into the cervix or to other tissues or organs. Rates for carcinoma in situ reach a peak for both African American and White women between 20 and 30 years of age. Women who have never had a Pap test or who have not had one for several years have a higher-than-average risk of developing invasive cervix cancer. Mortality from cervix cancer increases with advancing age. Extra effort is warranted to reach older women who have not been screened. Women ages 65 and older account for nearly 25 percent of all cervix cancer cases and 41 percent of cervix cancer deaths in the United States, but they have much lower screening rates than younger women.[25]

In the 1997 Behavioral Risk Factor Surveillance Survey, nearly 82 percent of Kentucky women surveyed reported having had a Pap test in the past three years, compared to a national median of nearly 85 percent. Among older women in Kentucky, fewer reported screening: ages 55-64, 69 percent; ages 65-74, 77 percent; and age 75 and older, 59 percent.

These numbers underscore the importance of special screening efforts targeted to reach women who do not receive regular screening.

**Recommendation 6:** Reduce mortality from cervical cancer by early detection through increased screening.

***Priority 6.1:*** Raise awareness among Kentucky women of all ages about cervical cancer risks and the benefits of early detection.

Strategies:

- Establish an integrated, ongoing public information program to foster a high degree of knowledge among women about cervical cancer risks and early detection. Ensure that older women are targeted with the message.

***Priority 6.2:*** Increase percentage of women who obtain regular Pap tests and pelvic exams.

Strategies:

- Increase the number of health care providers who perform or refer women for regular Pap tests and pelvic exams;

- Reduce access barriers to screening;

***Priority 6.3:*** Ensure the quality of Pap tests in laboratories serving Kentucky women.

Strategies:

- Monitor laboratories in reading Kentucky Pap tests for compliance with rules and regulations of CLIA (Clinical Laboratory Improvement Amendments of 1988);
- Develop and implement standards of care for patient reporting, tracking, and follow up.

## ***Colorectal Cancer***

Together, cancers of the colon and rectum are among the most common cancers in the United States. They occur in both men and women and are most often found among people who are over the age of 50. This cancer is a highly treatable and often a curable disease when localized to the bowel. Exact causes of colorectal cancer are not known. However, studies show that certain factors increase a person's chance of developing colorectal cancer: [26]

*Age:* Colorectal cancer is more likely to occur as people get older. Most people who develop colorectal cancer are over the age of 50. However, the disease can occur at any age.

*Diet:* The development of colorectal cancer seems to be associated with a diet that is high in fat and calories and low in foods with fiber, such as whole grains, fruits, and vegetables. Researchers are exploring how these and other dietary components play a role in the development of colorectal cancer.

*Polyps:* Polyps are benign growths (not cancer) on the inner wall of the colon or rectum. They are relatively common in people over age 50. Because most colorectal cancers develop in polyps, detecting and removing these growths may be a way to prevent colorectal cancer. Familial polyposis is a rare, inherited condition in which hundreds of polyps develop in the colon and rectum. Unless this condition is treated, it is extremely likely to develop into colorectal cancer.

*Personal history:* A person who has already had colorectal cancer may develop colorectal cancer a second time. Also, research studies show that women with a history of ovarian, uterine, or breast cancer have a somewhat increased chance of developing colorectal cancer.

*Family history:* Close relatives (parents, siblings, or children) of a person who has had colorectal cancer are somewhat more likely to develop this type of cancer themselves, especially if the relative developed the cancer at a young age. If many family members have had colorectal cancer, the chances increase even more.

*Ulcerative colitis*: Ulcerative colitis is a condition in which the lining of the colon becomes inflamed. People who have ulcerative colitis are more likely to develop colorectal cancer.

Colorectal cancer screening tests are used to detect cancer, polyps that may eventually become cancerous, or other abnormal conditions. Most people who undergo colorectal screening do not have any colorectal abnormality. For those who do, diagnosis and treatment can occur promptly. The following tests are used to detect colon cancer: [26]

A *fecal occult blood test* (FOBT) is a test for hidden blood in the stool. This test has been proven to reduce the death rate from colorectal cancer.

A sigmoidoscopy is an examination of the rectum and lower colon with a lighted instrument.

A *colonoscopy* is an examination of the rectum and entire colon with a lighted instrument.

A *double contrast barium enema* is a series of x-rays of the colon and rectum. The x-rays are taken after the patient is given an enema with a white, chalky solution that contains barium to outline the colon and rectum on the x-rays.

A *digital rectal exam* (DRE) is a test in which the doctor inserts a lubricated, gloved finger into the rectum to feel for abnormal areas.

Between 1989 and 1994, only 37 percent of colorectal cancers in the U.S. were detected in the earliest stage.[18] Eighteen percent of Kentuckians, age 50 and older, surveyed in 1997reported having used a fecal occult blood test in the past year, a rate equal to the national median percentage.[3] Percentages were greater among older Kentuckians who reported having had the test within the preceding two years, but remained comparable in each age group to the national median. Only 25 percent of Kentuckians, age 50 and older, reported having had a sigmoidoscopy within the last five years. This was less than the national median of 30 percent.[3] Percentages of older Kentuckians who reported ever having received a proctoscopy or sigmoidoscopy were lower in each age group than the national medians.

**Recommendation 7:** Reduce mortality from colorectal cancer by early detection through increased screening.

***Priority 7.1:*** To promote, increase, and optimize the appropriate use of high quality colorectal cancer screening.

Strategies:

- Increase access to regular colorectal screening for all Kentuckians, age 50 and older;
- Encourage healthcare providers to offer or refer patients for regular screening.

***Priority 7.2:*** Improve colorectal screening methods.

Strategies:

- Support research to determine the most effective screening methods.

***Prostate Cancer***

Prostate cancer is the most common of all cancers for men, with the exception of skin cancer, and is the second leading cause of cancer death in the United States. The incidence of prostate cancer has increased for all men since 1973. African American men are at high risk, in fact, African Americans in the U.S. have the highest rates of this cancer in the world. Although the incidence among whites is quite high, it is distinctly lower than among blacks. Sixty percent of all newly diagnosed prostate cancer cases and almost 80 percent of all deaths occur in men 70 years of age and older. Mortality rates for prostate cancer are much lower than the incidence rates, because survival for men with this cancer is generally quite high.

Unlike cancers discussed above, the benefits of prostate screening are the subject of debate. In general, cancer screening is considered useful when there is evidence that treatment at an earlier stage of disease will result in fewer overall deaths or reduce the need for aggressive treatment. However, in prostate cancer, scientific uncertainty about the natural progression of the disease and the efficacy of specific treatments makes it unclear whether early treatment will result in lower mortality.

It is often very difficult to distinguish between prostate cancers that may become life-threatening and those that may not. Some men have prostate cancer that is aggressive, but most prostate cancer is slow-growing. Autopsy studies reveal that a large percentage of older men who died of other causes also had undiagnosed prostate cancer. Increased screening is certain to lead to more treatment, and thus treatment-related morbidity, including impotence and incontinence.

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| **Recommendation 8:** | Reduce mortality from prostate cancer especially among African Americans and others who may be high risk. |

***Priority 8.1:*** Raise awareness of prostate cancer risks.

Strategies:

- Develop targeted education and outreach programs for African American men that focus on prevention, early detection, and state-of-the-art information on prostate cancer treatment;
- Provide access to state-of-the art information on prostate cancer treatment;
- Encourage men to talk to their health care providers about early detection of prostate cancer.

***Priority 8.2:*** Increase the percentage of men age 50 and older, at high risk for prostate cancer, who are screened regularly.

Strategies:

- Encourage health care providers to counsel age-eligible men and provide prostate cancer screening.

***Priority 8.3:*** Improve screening and treatment of prostate cancer.

Strategies:

- Support research on the etiology of prostate cancer;
- Support research to find effective means of detecting prostate cancer;
- Support research to improve prostate cancer treatment, with reduced negative side effects.

| CANCER CARE | |
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| 9. Reduce the inequity of the cancer burden in Kentucky's poor, uninsured and underinsured.<br>9.1 Increase financial access of Kentuckians to NCCN Practice Guidelines. | 9. KCR<br>9.1 Legislature |
| 10. Reduce the inequity in cancer burden among rural populations.<br>10.1 Increase access to cancer screening and treatment in geographically underserved areas. | 10. All providers<br>10.1 KAHP, KCR, KDPH |
| 11. Improve treatment outcomes by increasing the number of patients receiving care according to established professional treatment guidelines.<br>11.1 Increase the number of health care providers who follow NCCN Practice Guidelines.<br>11.2 Increase patient access to information on standards of care across the continuum of disease.<br>11.3 Increase patient participation in clinical trials.<br>11.4 Expand community capacity for providing patient access to cancer information. | 11. KCR, KMA, Providers<br>11.1 KCR, KMA, Physician Survey<br>11.2 ACS, CIS, KCP, Providers<br>11.3 CIS, KCP<br>11.4 ACS, CES, CIS, Libraries |
| 12. Improve communication among cultural and limited literacy groups in the understanding of physician advice and cancer information.<br>12.1 Increase demand for cancer screening and treatment in culturally unique and limited literacy populations.<br>12.2 Increase availability of patient information and advice for non-English speaking and limited literacy patients.<br>12.3 Improve provider community with culturally diverse and limited literacy patients | 12. CIS, ACS, Health Care Training, Programs<br>12.1 KAAAC, Migrant<br>12.2 KDP, CIS, KDPH, ACS, CES, FRC<br>12.3 Health Care Training Programs |
| 13. Ensure quality of care at the end-of-life, the management of cancer-related pain and timely referral to palliative and hospice care.<br>13.1 Increase capacity of patients and care givers for handling of end-of life issues.<br>13.2 Increase resources available to help patients and their families deal with end-of-life issues. | 13. Journey's End (EPEC)<br>13.1 KMA, Journey's End, Universities<br>13.2 Support Groups |
| 14. Ensure adequate availability of services and equitable quality of life for cancer survivors.<br>14.1 Increase number of patients who are referred to support services.<br>14.2 Enforce laws relating to discrimination against patients. | 14. Support Groups<br>14.1 KMA<br>14.2 Legislators |

## *Cancer Care*

In order to be well-served across the continuum of care, Kentuckians must have both financial coverage for and access to providers of cancer-related preventive, diagnostic, treatment, and supportive services

### ***Financial Access***

Over 44 million people (16 percent) in the U.S. have no health insurance at all, including 545,000 Kentuckians (14 percent).[27] Eighty million more nationwide have health insurance insufficient to cover the costs of a catastrophic illness such as cancer.

The problem of access is severe among the poor. Over 20 percent (689,138) of Kentuckians live in poverty, according to the U.S. Census Bureau. The poor, who typically experience substandard living conditions, lower educational levels, risk-raising lifestyles, and insufficient access to care, have a higher incidence of many cancers, are diagnosed with more advanced disease, and have lower survival rates. Even the poor on Medicaid may fare no better than the uninsured. Similarly the elderly who have the highest cancer incidence and mortality rates, lack coverage under Medicare for certain cancer prevention services, and until just recently were not covered for care provided in qualified clinical trials. They are frequently not offered, and do not seek, state-of-the-art cancer care. Many of the elderly are unaware of the available cancer care services or how to obtain cancer-related information.

While poverty affects access, the poor are not alone in their lack of insurance coverage. It is interesting to note that among all uninsured in the U.S. in 1998, less than 13 percent were poor. Among racial groups, Hispanics had the highest chance of not having health insurance coverage in 1998. The uninsured rate for Hispanics was 35.3 percent, compared with 11.9 percent for non-Hispanic whites. Among the poor, Hispanics also had the highest non-coverage rates, with 44.0 percent of that population uninsured in 1998.[27] Blacks are the second largest uninsured group (22 percent) among all people. When only the poor are considered, whites are the second most uninsured group (34 percent). In all of these groups, many have pre-existing conditions, including cancer, that render them uninsurable under the current health care system, or eligible only for hopelessly unaffordable coverage. Anecdotal evidence indicates that even those with insurance delay seeking diagnostic and other medical care for fear of employment discrimination, future insurability, and financial ruin should be cancer be discovered, or due to the lack of co-payment/deductible resources.

| **Recommendation 9:** | Reduce the inequity of the cancer burden of Kentucky's poor, uninsured and under insured. |
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***Priority 9.1:*** Increase financial access of Kentuckians to state-of-the-art cancer screening and treatment.

Strategies:

- Encourage in-state self-insured companies and in-state branches of out-of-state companies to provide cancer screening coverage in accordance with current ACS guidelines;
- Encourage hospitals and other health service organizations to offer free or low-cost cancer screening;
- Enroll people who are currently eligible for health-care services through Medicaid, and expand the eligibility;
- Promote insurance reimbursement for routine screenings and insurance incentives for compliance;
- Promote insurance coverage of treatment under clinical trials;
- Work with policy makers to include screening and diagnostic services as included in health plans;
- Optimize the use of cancer funds raised by nonprofit organizations within a county to serve the target population locally.

## ***Geographic Access***

Access to effective cancer services and technologies is unequal across population groups and geographic localities. Rural residents with cancer are especially challenged. In seeking cancer care, they face a lack of specialized local care, cost, and travel requirements. Rural physicians, nurses, social workers, and pharmacists have limited resources to provide or coordinate the quality of care needed for these patients. In most of Kentucky's communities, no individual or entity is responsible for ensuring cancer care. Even the well-insured and well-educated frequently experience problems accessing needed health services. Cancer care resources, equipment, and providers must be better distributed in communities.

A variety of options for improving cancer care in underserved areas must be explored. One of these is telemedicine, the application of modern telecommunications to the practice of medicine. Telemedicine holds great potential for improved care in rural and under served areas. Applications of telemedicine include administrative video conferences between a central headquarters and remote branches; networking Continuing Medical Education (CME) offerings, including instruction in sophisticated procedures formerly not possible; video-consultations permitting examination, diagnosis, and treatment of a patient remotely; teleradiology; telepathology; patient medical records; and medical data banks.

Kentucky TeleCare, a program started in 1993 by the UK Chandler Medical Center, uses two-way interactive video to bring health care providers and patients in rural areas of Eastern Kentucky together with medical specialists at secondary and tertiary care centers such as the UK Chandler Medical Center. The program is currently being expanded to link six primary care medical facilities, five rural public school sites, St. Claire Medical Center in Morehead, and the UK Chandler Medical Center to improve

school health delivery services, increase access to secondary and tertiary care services, provide much-needed access to behavioral health resources and create a regionally integrated health care delivery system. Barriers to widespread implementation of telemedicine, such as reimbursement issues, must be overcome in order to bring this technology to areas in which it is needed. In several rural Kentucky communities, local physicians have partnered with urban health providers in order to give their patients access to specialists, including oncologists and surgeons. More communities must be encouraged to develop arrangements that bring specialized care to Kentucky's rural areas.

Resource guides need to be more readily available to Kentucky residents. For example, Pathfinder guides compiled by KCP offices list resources available to cancer patients and their families within each Area Development District (ADD). These are widely available in the health care community. The Kentucky Breast Cancer Task Force has recommended expanded distribution of this resource. The guide lists regional cancer resources including support services, transportation, prosthesis, cosmetic services, treatment and rehabilitation. Despite few resources, creative collaboration and community partnerships may provide patients and healthcare professionals with needed resources in rural areas. Transportation for cancer patients, for example, might be obtained through local community organizations. All of these options and more must be explored in order to improve access of patients to quality care.

**Recommendation 10:** Reduce the inequity in cancer burden among rural populations.

***Priority 10.1*** Increase access to cancer screening and treatment in geographically underserved areas.

Strategies:

- Expand the Kentucky TeleCare Program to cover rural areas throughout the state;
- Encourage health care providers in remote areas to work collectively to increase access to screening facilities, and to arrange for treatment specialists to establish office hours in their areas;
- Increase free or low-cost transportation and housing options for persons in remote areas to travel elsewhere for screening and treatment services;
- Focus on health initiatives to improve the overall health status of Kentuckians by investing in local health departments and other community-based resources;
- Improve KCP Pathfinder and other geographic resource guides for cancer patients and their families and promote availability;

- Encourage county health departments to play a major role in fostering opportunities for work site and community cancer screenings.

## ***Standards of Care***

Poor quality care can be worse than no care. Often, differences in cancer care occur because existing practice standards are not uniformly applied, or because standards have not been established. For example, up to 90 percent of cancer pain would be alleviated if the Agency for Healthcare Research and Quality (formerly Agency for Health Care Policy and Research)[28] pain management guidelines were followed.

To ensure that advances in cancer care are incorporated into clinical practice, standards of care must be developed, implemented, and evaluated where they do not exist, are not uniformly applied, or are not widely known by the consumers. Standards are needed and should be applied across the entire continuum of cancer: early detection; treatment; hospice; rehabilitation; recovery; and, of life. For example, the Mammography Quality Standards Act (MQSA) of 1992,[29] helps ensure that patients receive safe and effective services in appropriate settings. It deals with both screening and treatment issues. Efforts must be made to inform health care providers of the resources from which professionally accepted treatment guidelines can be obtained. Healthcare professionals may use various national cancer and rural health organizations and Internet sites as resources for updated oncology literature and for information on upcoming oncology conferences and partnerships with urban cancer care providers. Physicians Data Query (PDQ), the comprehensive cancer database of the National Cancer Institute (NCI), contains peer-reviewed summaries on cancer treatment, screening, prevention, genetics, and supportive care; a registry of approximately 1,800 open and 10,300 closed cancer clinical trials from around the world; and directories of physicians, professionals who provide genetics services, and organizations that provide cancer care. It can be accessed via the worldwide web, CancerFAX, or through 1-800-4-CANCER. In addition to improving physician access to treatment standards, it should be easier for patients themselves to access and understand treatment information. Patients who have more information, vs limited information, frequently receive better care. Their interest in receiving optimum care increases the likelihood that their provider will follow practice guidelines. One proven method for assisting patients is the use of patient navigators.[30] These individuals, whether paid or volunteer, professional or lay, are trained to assist patients in seeking and obtaining care. The navigators also serve as a liaison between patients and providers.

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| **Recommendation 11:** | Improve treatment outcomes by increasing the number of patients receiving care according to established professional treatment guidelines. |

***Priority 11.1:*** Increase the number of health care providers who follow practice guidelines of national professional organizations (i.e. National Comprehensive Cancer Network.[31]

Strategies:

- Increase awareness and use of PDQ for all health professionals;
- Integrate professionally-accepted practice guidelines into health professional school curriculum;
- Raise public awareness of the need to seek optimum care;
- Develop relationships with medical specialists and academic medical facilities for specialized treatment;
- Encourage local physicians to adhere to treatment guidelines;
- Increase the number of certified nurses, social workers, and other healthcare professionals.

***Priority 11.2:*** Increase patient access to information on standards of care across the continuum of care.

Strategies:

- Establish a network of patient navigators, including volunteers, and trained social workers;
- Promote the use of the Cancer Information Service (1-800-4-CANCER).

***Priority 11. 3:*** Increase patient participation in clinical trials.

Strategies:

- Encourage physicians to inform all cancer patients about the availability of clinical trials and to offer participation in clinical trials as a choice;
- Increase patient education on the purpose and benefits of clinical trials;
- Remove financial and geographic barriers to participation in clinical trials.

***Priority 11.4:*** Expand community capacity for providing patient access to cancer information.

Strategies:

- Work with local libraries to increase their awareness of cancer information resource so that they may better serve community;
- Increase the capacity of home health workers and others having contact with patients, to provide information and referrals;
- Promote community information resources***.***

### *Cultural and Low-Literacy Access*

In Kentucky, there are many patients who are at a disadvantage in seeking screening and other services, and in communicating with their healthcare providers. Often special populations are under served and may hold cultural beliefs that discourage active participation in the health care system. In addition to African American populations in

several areas, Kentucky has a growing Hispanic population, as well as several non-traditional faith communities. Culturally-tailored education and outreach services are needed so that individuals may learn and accept available screening and diagnostic tests and treatments.

There are two other significant barriers: language and literacy.[32] Language is a frequent problem, with many patients and physicians having learned English as a second language. Many patients are recent immigrants who have yet to learn the language. Likewise, many Kentucky physicians, especially in under-served areas, are foreign-born and speak English with accents that are difficult for patients to understand. Low literacy is also a key barrier. A majority of patients find cancer education materials to be an important source of information. However, due to low literacy, others are unable to read and comprehend available written materials. Also, many physicians have difficulty communicating medical information about a patient's diagnosis and prognosis in terms that are understandable to the patient. Many rural physicians in Kentucky speak English as their second language, which often limits patient's comprehension as well. Individuals in all of these situations should be empowered to take responsibility for their health. This empowerment is dependent on having information presented in a manner that is culturally appropriate and easily understood.

**Recommendation 12:** Improve communication among cultural and limited literacy groups in the understanding of physician advice and cancer information.

***Priority 12.1:*** Increase demand for cancer screening and treatment in culturally unique and low literacy populations.

Strategies:

- Identify special populations, i.e. African Americans, Hispanics, members of faith communities, and work with opinion leaders in these cultures to develop treatment messages that are appropriate;
- Work with special populations to increase access to screening and treatment services.

***Priority 12.2:*** Increase availability of patient information and advice for non-English speaking and low literacy patients

Strategies:

- Identify cancer information for special populations and low literacy groups and find distribution channels in communities that reach these populations;
- Promote use of the Spanish-language services of the Cancer Information Service.

***Priority 12.3:*** Improve provider communication with culturally diverse and limited literacy patients.

Strategies:

- Integrate patient-provider communication training into healthcare training programs.

## ***End-of-Life Care***

Recent debates over assisted suicide have highlighted some uncomfortable facts about dying in America. Too many people with terminal illnesses die in the sterile settings of hospitals or nursing homes, often in prolonged, uncontrolled pain. Moreover, physicians frequently fail to manage their patients symptoms, adding to their suffering. Further, the wishes of patients are often ignored as they are subjected to intrusive, often futile, medical interventions; and aggressive end-of-life care often upsets families that are already in crisis.

In response to these circumstances, a growing emphasis has been put on palliative care. One of the first principles of palliative medicine is that patients should not die in pain. According to a definition published by the World Health Organization in 1990, palliative care has to address not only pain, but also psychological, social and spiritual problems to achieve "the best possible quality of life for patients and their families.[33] Once it is clear that a patient's condition is unlikely to improve, the focus should be on enabling them to continue an alert, pain-free life and to manage other symptoms so that their last days may be spent with dignity and quality, surrounded by their loved ones. The objective of pain and symptom control is to help patients to be comfortable while allowing them to remain in control of their lives. This means that side effects are managed to ensure that patients are as free of pain and symptoms as possible yet still alert enough to make decisions that they feel are important. In addition to pain control, attention must be paid to the spiritual needs of the patient and family members, and to whether end-of-life care will be provided in the hospital or in the home.

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| **Recommendation 13:** | Ensure quality care at the end-of-life. In particular, the management of cancer-related pain and timely referral to palliative and hospice care. |

***Priority 13.1:*** Increase capacity of patients and caregivers for handling of end-of-life issues.

Strategies:

- Encourage medical schools to incorporate the palliative-care philosophy into their curricula;

- Provide physicians with resource information that list support services, including hospice care, counseling services, caregiver respite programs, and others;
- Increase referrals to hospice in a timely manner;
- Facilitate environment to improve culture and practice of pain management and to advance care planning in long term care facilities.

***Priority 13.2:*** Increase resources available to help patients and their families deal with end-of-life issues.

Strategies:

- Ensure that home care and hospice services for cancer patients are locally available;
- Expand availability of support groups, information and counseling services to assist cancer patients and their families.

## ***Quality of Life and Survivorship***

From the time of discovery and for the balance of life, an individual diagnosed with cancer is a survivor, according to the National Coalition for Cancer Survivorship.[34] The coalition has how expanded that definition to include families, friends, and care givers as well. For all cancers combined, the 5-year survival rate is nearly 60 percent. The National Cancer Institute estimates that about 8.4 million Americans alive today have a history of cancer. That number includes everyone who has had a cancer diagnosis, those recently diagnosed, as well as long-term survivors.

With successful treatment, the number of cancer survivors will increase. The needs of increasing numbers of cancer survivors must be considered in long-range planning and provision of services. With increased numbers of survivors, there will be more demand for long-term follow-up services. Policymakers must work to ensure that services, both treatment and psychosocial, are available and accessible, especially in underserved areas.

Kentucky's cancer survivors will also continue to face challenges regarding employment and health insurance. The Americans with Disabilities Act of 1990 (ADA) provides important legal rights for individuals with cancer. The ADA, which applies to employers with 15 or more employees, protects qualified individuals with disabilities from discrimination in employment. The definition of disability is broad, encompassing the individual with a physical or mental impairment which substantially limits one or more major life activities — activities that the average person can perform with little difficulty, such as walking, seeing, breathing, and working. A cancer survivor who is no longer disabled, but is discriminated against by an employer because of a history of cancer, also would be protected by the ADA.[35]

In order to assert a claim of discrimination, an individual must be able to perform the essential functions of the job with or without reasonable accommodation. The ADA requires the employer to make reasonable accommodation(s) to enable an individual with a disability to do the job, unless the accommodation would cause the employer undue hardship. Reasonable accommodation might include time off for treatment, rest breaks, restructuring a job so that another employee handles marginal functions that an individual is unable to perform, or reassignment to a vacant position.[35]

Physicians can assist patients in receiving accommodations since employers are entitled to medical documentation of the need for accommodation. Medical documentation should establish that the individual meets the statutory definition of disability.[35]

The ADA's prohibition on discrimination also applies to discrimination in insurance. The employer cannot refuse to hire an applicant or discharge an employee because of a disability which is not covered by the employer's insurance, or because the employer's insurance premiums would increase because of the person's disability. The statute does, however, legitimize certain insurance practices. It appears that traditional practices such as limits on pre-existing conditions, caps on benefits, and other practices based on risk classification can be continued under the ADA, although there will likely be litigation challenging such practices.[35]

**Recommendation 14:** Ensure adequate availability of services and equitable quality of life for cancer survivors.

***Priority 14.1:*** Increase number of patients who are referred to support services.

Strategies:

- Work at the community level to increase availability of cancer support services;
- Refer all patients to existing community support services and the Cancer Information Service;
- Optimize the use of cancer funds raised within a community to fund durable equipment not otherwise covered.

***Priority 14.2:*** Enforce laws relating to discrimination against patients.

Strategies:

- Inform physicians and nurses about the provisions of the ADA so that they may be able to assist cancer patients in obtaining entitlements under the statute;
- Increase Human Resources/Workplace education regarding patient rights.

# *Legislation*

Legislative Action will be required to achieve many of the goals presented in this plan. Kentucky was one of the first states to provide insurance coverage and allocate state funding for breast cancer screening. Most recently funding has been allocated for tobacco prevention use and control, as well as lung cancer research, and continuance of the Breast Cancer Action Plan. Fortunately, Kentucky governmental leaders have historically supported progressive legislation in cancer control.

## ***Prevention***

- Provide and maintain adequate funding for tobacco use prevention and cessation.
- Incorporate cancer prevention education into all public school curricula.
- Allocate tobacco settlement funds for tobacco-related costs, including prevention and cessation programs.
- Require reimbursement under health insurance for coverage of tobacco-use cessation costs.

## ***Early Detection***

- Expand health insurance coverage for cancer screening.

## ***Cancer Care***

- Insure employability and insurability.
- Increase capacity for supportive cancer services, such as patient navigators and lay health workers.
- Expand health insurance coverage of clinical trials.
- Legislate for patients waiver of sales tax on chemotherapeutic medications administered in outpatient settings.

# *Evaluation*

This plan will be evaluated based on measurable objectives outlined in the cancer related *Healthy People 2010* goals. Outcome evaluation will be measured by improvements in incidence and stage of disease through cancer incidence data. Other quantitative data sources will also be used for monitoring progress in achieving these recommendations through annual reviews of the following:

**Behavioral Risk Factor Surveillance System (BRFSS).** The BRFSS is an ongoing system of surveys conducted by state health departments in cooperation with the Centers for Disease Control and Prevention.

**Kentucky Cancer Registry (KCR).** The KCR records the incidence of cancer for the Commonwealth of Kentucky. Since 1991 the registry has collected and maintained a population-based registry of all cancer cases diagnosed or treated in Kentucky

**Health Plan Employer Data and Information Set (HEDIS).** HEDIS measures performance of more than 90 percent of the nation's managed care organizations. It contains data based on a set of standardized performance. It monitors the following categories: effectiveness of care; access/availability of care; satisfaction with the experience of care; health plan stability; use of services; cost of care; informed health care choices; and health plan descriptive information. HEDIS is sponsored by the non-profit National Committee for Quality Assurance (NCQA),

**PULSE Survey.** The PULSE Database is a proprietary database of INFORUM. It is the result of the largest annual survey of healthcare utilization in the United States. Since 1988, Inforum has surveyed annually, via national market research firms, 100,000 households. The PULSE Database now includes ten years of results from 1,000,000 respondents. The survey covers more than 60 categories of healthcare utilization, as well as types of insurance coverage.

**Surveillance, Epidemiology, and End Results Program (SEER).** In the SEER Program, the National Cancer Institute contracts with 11 population-based registries throughout the United States to provide data on all residents diagnosed with cancer during the year and to provide current follow-up information on all previously diagnosed patients.

**Youth Risk Behavior Surveys (YRBS).** YRBS consists of biennial, national, state, and local school-based surveys of representative samples of 9th- through 12th- grade high school students.

The ultimate measure of the plan's success will be reduced cancer mortality rates in the Commonwealth. However, a noticeable change will take years to materialize. In the interim, progress must be measured against the recommendations and priorities proposed in this plan. It is anticipated that organizations and individuals designated in the prevention, early detection, and cancer care grids will assume responsibility for monitoring progress.

It is acknowledged that limitations in setting and evaluating measurable objectives exist. These might include shifts in science, reimbursement, the economy or political climate. As additional and expanded data sources become available, every effort will be made to utilize them in proposed annual reviews.

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