A Comprehensive Cancer Action Plan for Missouri - 2004

The REALITY of CANCER in MISSOURI

by the Missouri Cancer Consortium and the
Missouri Department of Health and Senior Services

A message from the Director of The Missouri Department of Health and Senior Services

Dear Colleagues:

The word "cancer" evokes fear in many and can affect the quality of life and cause additional burdens to the patient and his/her circle of family, friends, and supporters. These other burdens may include financial hardship as families adjust to increasing medical bills and insurance premiums, lost time at work and wages as well as an economic impact on employers.

However, the good news is that healthy behaviors increase the chance of being cancer free. Studies prove that people can greatly reduce the risk of cancer by choosing a healthier lifestyle, which not only reduces cancer risks but also increases chances of survivability if diagnosed.

More than 40 professionals working in the cancer field from all areas of the state have volunteered their expertise and leadership to form the Missouri Cancer Consortium. Together with this Consortium, the Missouri Department of Health and Senior Services is dedicated to addressing the burden of cancer and reducing the number of new cancer cases and deaths through development and implementation of a comprehensive cancer control plan.

This action plan describes the comprehensive approach to reduce the number of new cases of cancer and lives lost to cancer. The Department's unique collaboration with the statewide Consortium, along with many other professionals and Regional Comprehensive Cancer Control Coalitions, will deliver a positive cancer message to our communities. It's a tremendous job, one that will take bravery and boldness, to tackle this epidemic. The reality will then become Missourians replacing the fear of cancer with better health enjoyment. Together with your support we can achieve this goal.

Sincerely,
Richard C. Dunn
Director,
Missouri Department of
Health and Senior Services

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Acknowledgements

This report is made possible through the partnership of the Missouri Department of Health and Senior Services (DHSS) and the Missouri Cancer Consortium. The Consortium is a statewide group of health-care professionals concerned about cancer who worked together over the past two years to develop a strategic plan to lower the incidence and mortality of cancer. Special acknowledgement is given to the six Consortium committees for their contribution to this plan and for future leadership as the plan is deployed throughout the state. The DHSS Cancer Control Unit, DHSS Center for Health Information Management and Evaluation, DHSS Office of Surveillance, Epidemiology and Public Health Information, and the University of Missouri - Columbia that supports the Missouri Cancer Registry also provided special assistance and data support.

Missouri's Comprehensive Cancer Plan reflects the reality of cancer in Missouri and the strategic interventions to address this burden in the next few years. These interventions include increased public education and awareness, early detection, and screening, which ultimately will increase survivorship. All Missourians benefit when people live longer, healthier, cancer-free lives. The burden is great, but the hope is greater.

Sincerely,
Michael Bukstein, M.D.
Chair, Missouri Cancer Consortium

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The Reality of Cancer - Executive Summary

For some, cancer statistics are just numbers. For others, the word "cancer" evokes fear and the inability to cope. Most people do not contemplate the impact of the disease – until it confronts them or their own family or friends. Maybe the disease is too frightening to think about – even though many people recover, survive, and live long lives.

The Goal

The Missouri Department of Health and Senior Services (DHSS) and the Missouri Cancer Consortium are committed to decreasing the number of new cases of cancer, increasing the survivorship of cancer patients once diagnosed, and informing all citizens about the reality of cancer.

The Choice

DHSS recognizes that certain groups of people in the city and countryside, especially those underserved by virtue of their income, race, ethnicity, disability, or sexual orientation, suffer the greatest consequences. These citizens are at increased risk of dying of cancer due to smoking, eating a poor diet, lacking exercise, and having limited options for primary and secondary prevention services.

The Change

Addressing cancer needs in Missouri requires the collaboration of many individuals, agencies and organizations. In 2000, DHSS took the administrative initiative to form the Missouri Cancer Consortium. The Consortium is a collective group of more than 40 professionals and agencies dedicated to tackling the burden of cancer in Missouri. The results of their focused, intensive process to establish a plan to enhance the infrastructure for comprehensive cancer control activities is summarized in this booklet.

It is also essential that relationships with public and private health-care providers and regional cancer coalitions be enhanced. This focused and strengthened position of partnerships will provide the maximum benefits to people in their communities.

The Challenge

Decreasing cancer-related morbidity and mortality requires continued focus on the cancer continuum including prevention, screening, diagnosis, treatment, and cancer care services. Increased opportunities for education and awareness about high-risk behaviors and their impact on new cancer cases are needed to reach populations. The challenge is for everyone to be bold and daring by taking a proactive approach to assure the greatest number of Missourians will be offered appropriate, timely, and much-needed information across the cancer continuum. Cancer is a condition that brings not only challenges but also hope. The following pages will outline Missouri's plan to meet those challenges.

More and more people are benefiting from the early detection of cancer and its successful treatment.

Healthy People 2010

The U.S. Department of Health and Human Services Healthy People 2010 Initiative, a broad-based collaborative effort among government, private, public, and nonprofit organizations, has set national disease prevention and health promotion objectives to be achieved by the end of this decade. The effort has two overarching goals: to increase the quality and length of healthy life and to eliminate health disparities.

Healthy People 2010 challenges individuals, communities, and professionals – indeed, all of us – to take specific steps to ensure that good health, as well as long life, are enjoyed by all.

The Missouri Department of Health and Senior Services and Missouri Cancer Consortium use these objectives as a guide for developing strategies and will measure actual progress within a specified time period. The objectives focus on the determinants of health, which encompass the combined effects of individual and community physical and social environments. They also focus on the policies and interventions used to promote health, prevent disease, and ensure access to quality health-care. The ultimate measure of success in any health improvement effort is the health status of the target population.

Healthy People 2010 Objective*	Healthy People 2010 Target	Change needed in Missouri to meet Healthy People 2010 Objective
Reduce the overall cancer death rate.	159.9 deaths per 100,000.	24.8% reduction in Missouri mortality rate.
Reduce the lung cancer death rate.	44.9 deaths per 100,000.	30.6% reduction in Missouri mortality rate.
Reduce the female breast cancer death rate.	22.3 deaths per 100,000 females.	22.8% reduction in Missouri mortality rate.
Reduce the colorectal cancer death rate.	13.9 deaths per 100,000.	39.3% reduction in Missouri mortality.
Reduce the prostate cancer death rate.	28.8 per 100,000 males.	10.3% reduction in Missouri mortality.
Reduce the rate of melanoma cancer deaths.	2.5 deaths per 100,000.	13.8% reduction in Missouri mortality.
Increase the proportion of women who receive a Pap test. Women age 18 years and older who have ever received a Pap test: 1998 baseline 91%.	97%	2.5% increase in Missouri.
Increase the proportion of adults who receive a colorectal cancer screening examination (sigmoidoscopy or colonoscopy).	50%	70% increase in Missouri.
Increase the proportion of health-care professionals who counsel their at-risk patients about tobacco use cessation, physical activity and cancer screening.	85%	No current Missouri data.

*Death rates are age-adjusted to the 2000 standard.

Progress of Cancer Control

The nation is making some progress toward major cancer-related Healthy People 2010 targets. However, more work remains to reduce the burden of cancer.

- Death rates from the four most common cancers continue to decline although the rates for all cancers combined have begun to stabilize.
- The rate of cancer incidence began to stabilize in the mid 1990s with evidence of a recent rise.
- Some preventive behaviors have shown improvement. Adult smoking is down dramatically since the 1960s, although rates fell only slightly in the 1990s.
- The use of screening tests for breast, cervical, and colorectal cancers is increasing. However, screening for colorectal cancer remains low despite its proven effectiveness.
- Youth smoking was on the rise during much of the 1990s but has shown declines since 1997.
- People are doing slightly more to protect themselves from the sun. However the nation is losing ground in other important areas that demand attention, such as early detection and treatment for melanoma.
- The incidence of cancers of the breast and lung in women, as well as non-Hodgkin's lymphoma, melanoma of skin, and liver cancer in men and women, is rising.
- More people are overweight and obese, and physical activity is increasing only slightly.
- Cancer treatment spending continues to rise along with total health-care spending.
- Unexplained cancer-related health disparities remain among population subgroups. For example, African Americans and people with low socioeconomic status have the highest rates of both new cancers and cancer deaths.

Prevention and Behavioral Factors

Choosing the right behaviors and preventing exposure to certain chemicals may help prevent cancers before they can start. Scientists estimate that as many as 50% - 75% of cancer deaths in the United States are caused by human behaviors such as smoking, physical inactivity, and poor dietary choices. Modifying behaviors can help prevent cancer. Smoking causes about 30% of all U.S. deaths from cancer. Avoiding tobacco use is the single most important step Americans can take to reduce the cancer burden in this country.

Additional important steps include maintaining a healthy weight, being physically active, eating a low-fat diet and increasing fruits and vegetables, balancing calories with physical activity, avoiding too much alcohol, and protecting skin from sunlight.

Certain chemicals in the environment are known to cause cancer. The most common are secondhand smoke and radon. Secondhand smoke contains over 60 carcinogens and other irritants, toxicants, and mutagens.

In addition to lung cancer, investigation continues to link tobacco smoke to nasal sinus, cervical, breast, and bladder cancers. Studies continue in children to link secondhand smoke to other cancers such as brain cancer, leukemia, and lymphoma.

Early Detection

The use of screening tests to detect cancers early often leads to more effective treatment with fewer side effects. Patients whose cancers are found early also are more likely to survive these cancers than are those whose cancers are not found until symptoms appear. The following screening tests have been found to detect cancers accurately and to decrease the chances of dying from cancer:

- Mammography / Clinical breast examination (for breast cancer)
- Pap smear (for cervical cancer)
- Fecal occult blood test (for colorectal cancer)
- Colorectal endoscopy (sigmoidoscopy or colonoscopy for colorectal cancer)
- PSA / Digital rectal examinations (for prostate)

Diagnosis

The rates of newly diagnosed cancer cases (incidence) are one way to measure progress against cancer. Another important measure is the proportion of cancers diagnosed at a late stage. The stage of a cancer shows how far the disease has progressed. The earlier the stage at diagnosis, the better the chances for cure. Downward trends in the proportion of late cancer diagnoses are a sign that screening is working for the cancers for which effective early detection methods are available.

Treatment

Cancer treatment is improving – saving lives and extending survival for people with cancers at many sites, including the breast and colon, and for people with leukemias, lymphomas, and pediatric cancers. Clinical trials are the major avenue for discovering, developing, and evaluating new therapies. However, only about 3% of all adult cancer patients participated in clinical trials sponsored by the National Cancer Institute in 1999. It is important to increase physician and patient awareness and participation in clinical trials to test new treatments more rapidly, find more effective treatments, and broaden the options available to patients. Studies also show that older individuals and members of racial-ethnic minority groups are less likely to receive treatments or participate in clinical trials.

The ultimate measure of success against cancer is how far the death rate from this group of diseases can be lowered. After years of increase, Missouri and national age-adjusted cancer death rates began to fall during the 1990's. This trend must be maintained and accelerated.

Why Comprehensive Cancer Control in Missouri?

Missouri has joined many states and U.S. territories in developing a coordinated approach in cancer prevention and control. This comprehensive approach will not only help limit duplication of effort, but will also help identify missed opportunities in the cancer and disease prevention realm. Strategies have been developed to best address the economic and financial burden of cancer with the limited resources available.

Many improvements in the delivery of public health and education have been achieved with the comprehensive approach, including increased professional expertise, improved understanding of the complexities of delivering community-based screening services, additional research and clinical trials as well as greater availability of program results through evaluation. Such improvements have reinforced the value of coordinated cancer prevention and control programs at the national, state, and community levels. These improvements are shared through the many partnerships formed with agencies and other health-care partners interested in reducing the burden of cancer in Missouri. Along with the significant growth of cancer prevention and control programs, Missouri has also addressed the need for improved coordination of cancer control activities to maximize resources and achieve desired cancer control outcomes. This coordinated approach will lead to increased efficiency for delivering public health messages and services to the public.

The Centers for Disease Control and Prevention (CDC) helped to develop and clarify the concept of a comprehensive approach to cancer prevention and control. Through this process, Missouri has joined more than 50 other states and U.S. territories in developing a plan to address the whole cancer care continuum. The CDC's National Comprehensive Cancer Control Program serves as a national resource for supporting Missouri's efforts.

Comprehensive cancer control is based on the following principles:

- Scientific data and research are used systematically to identify priorities and inform decision making.
- The full scope of cancer care is addressed, ranging from primary prevention to early detection and treatment to survivorship and end of life issues.
- Many stakeholders are engaged in cancer prevention and control, including not only the medical and public health communities but also volunteer agencies, insurers, businesses, survivors, government, academia, and advocates.
- All cancer-related programs and activities are coordinated, thereby creating integrated activities and fostering leadership.
- The activities of many disciplines are integrated. Appropriate disciplines include administration, basic and applied research, evaluation, health education, program development, public policy, surveillance, clinical services, and health communications.

The more we learn about cancer, the more likely we are to find ways to prevent it.

National Cancer Institute

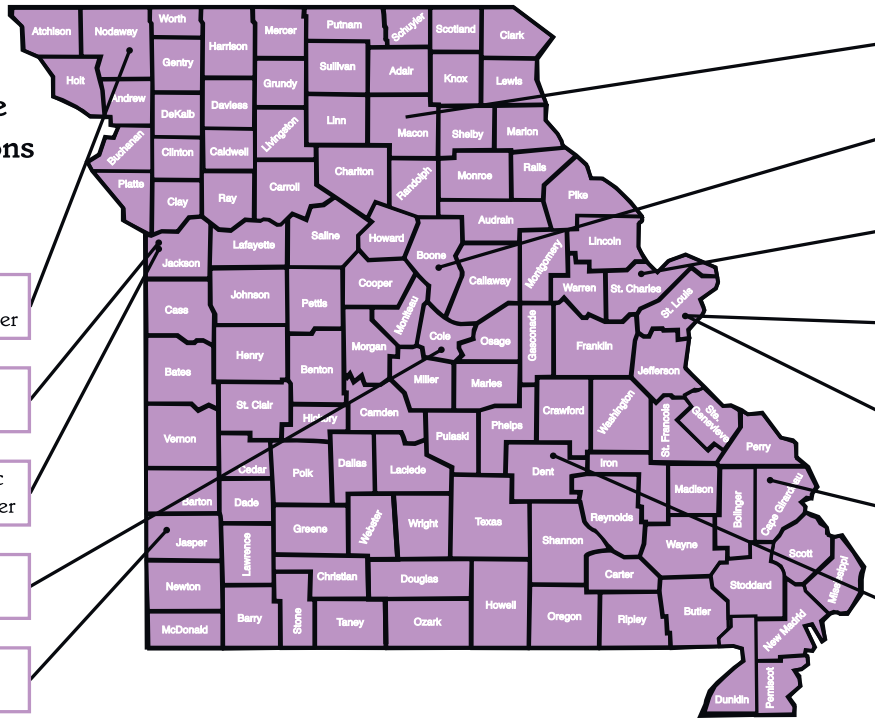
Regional Comprehensive Cancer Coalitions

Regional Comprehensive Cancer Control Coalitions in Missouri are defined as "a broad-based, multi-organizational, community partnerships that may bring together the public, private, and nonprofit sectors in an effort to reduce morbidity and mortality and improve quality of life." Coalitions work to develop goals and objectives that meet the needs of their own communities. These Coalitions were charged with the delivery of education and a limited number of cancer services through small awards at the local level. Coalition members represent community organizations such as public health departments; voluntary organizations; community-based agencies; professional associations; cancer patients, survivors, and their support systems; community and private hospitals and clinics; managed care organizations; health-care providers; social services; public and private schools; religious organizations; recreational organizations; local businesses; pharmaceutical companies; local media; and elected officials.

In addition, the Missouri Breast and Cervical Cancer Control Program has supported a number of regional coalitions since 1992 in an effort to recruit eligible clients for early detection and screening services to reduce breast and cervical cancer morbidity and mortality. The goal is to keep every woman healthy as well as support those women who have developed breast and/or cervical cancers.

In 2004, the Cancer Control Coalitions and the Breast and Cervical Cancer Control Coalitions were merged into a system known as Missouri Regional Comprehensive Cancer Control Coalitions. The strength and energy from this merger has revitalized the important work of comprehensive cancer control from early detection to survivorship and end of life issues. The work of all these coalitions continues to be essential and indispensable in their communities, and the Missouri Cancer Consortium recognizes the invaluable service these coalitions provide.

Missouri's Regional Comprehensive Cancer Coalitions



Nodaway County Crusade Against Cancer

Kansas City Cancer Coalition

Coalition of Hispanic Women Against Cancer

Central Region Cancer Coalition

Tri-State Cancer Coalition

Northeast Cancer Control Coalition

Mid-Missouri Partnership Coalition

St. Charles County Cancer Coalition

STL Partnership Cancer Coalition

Lane Cancer Coalition

Southeast Cancer Control Coalition

South Central Cancer Control Coalition

Coalition list as of July 2004.

The COMMITTEES of the Missouri CANCER Consortium.

Advocacy and Legislative

Cancer is a political, as well as a medical, social, psychological, and economic issue. Advocacy for cancer-related issues is needed to promote beneficial policies, laws, and regulations to reduce cancer incidence rates and mortality rates, especially among the medically underserved. Advocacy is needed to increase access to quality health-care, provide early detection and treatment options, encourage clinical trials, and work with managed care organizations, insurers and health maintenance organizations to improve the type and quality of services for their clients.

It is the goal of the Advocacy and Legislative Committee to develop a strategic link between agencies interested in advocating for improvements in the cancer health delivery system and provide education and work with state and local policy makers to achieve the goals and strategies of the state cancer control plan. The committee encourages a strong volunteer structure via Regional Comprehensive Cancer Control Coalitions to educate and promote cancer control legislative efforts.

Strategy

1. Link advocacy and legislative groups toward common objectives of assuring the enactment of quality cancer control legislation.

Activities

- Create a comprehensive cancer control legislative communication network with Consortium member agencies to educate groups involved in cancer control.
- Regularly monitor legislation that impacts quality cancer control and share with Consortium member agencies.
- Communicate a comprehensive cancer control legislative agenda to all groups involved with cancer control activities.

Strategy

2. Propose cancer control legislation as appropriate.

Activities

- Research/evaluate the need for legislation and identify priorities.
- Identify and meet with legislative leaders.
- Assist in drafting legislation.
- Provide testimony, expert witnesses, fact sheets, data, and coordination of grassroots activities.

Strategy

3. Assist state, regional, and local volunteer groups and coalitions to develop ordinances and policies.

Activities

- Provide technical assistance in drafting model ordinances and support statewide cancer initiatives.
- Link with local, regional, and state policy and ordinance activities.
- Identify and engage additional Consortium members at local and regional levels.

Strategy

4. Monitor federal and other states' legislation that may impact quality cancer control in Missouri.

Activities

- Connect with national cancer advocacy groups to coordinate an alert system on legislative issues for Consortium member agencies.
- Disseminate federal legislative updates and alerts to Consortium member agencies.

Committee Members

Maryann Coletti,
Chair
Alvin J. Siteman
Cancer Center

Barry Freedman,
American Lung
Association of
Missouri

William (Bill) Gurley,
St. Louis Prostate
Cancer Connection

Ileane Fagin,
St. Louis Breast
Cancer Coalition

Sharon Burnett,
Missouri Hospital
Association

Vicky Barshis,
LCSW, OSW,
Leukemia &
Lymphoma
Society

"Having cancer is bad enough! Not knowing what to do about it is even worse." ***R.A. Bloch Foundation***

Cancer Data and Planning

The Missouri Cancer Consortium defines "cancer data" as data relevant to the disease in terms of its risk factors, incidence, stage at diagnosis, mortality, and survival rates; insurance coverage for cancer-related services; cost and economic consequences of cancer services; availability of cancer resources; and demographics of the population affected. Having cancer data that is complete, comprehensive, timely, and of high quality is essential in charting progress to reduce the burden of cancer in Missouri. These data allow health-care professionals to monitor, plan, design, and evaluate interventions for implementation at the state, regional, and local levels. Data are used to inform legislators, the general public, and national partners about the human and financial impact that cancer has on Missourians.

It is the goal of the Data and Planning Committee to assure the availability of cancer-related data across the cancer care continuum for planning, implementation, and evaluation of evidence-based interventions to reduce the cancer burden in Missouri.

Strategy

1. Collaborate with Consortium members on research projects aimed at reducing incidence, mortality, and/or adverse risk behavior.

Activities

- Develop a procedure (readiness checklist) for requests by the Consortium to collaborate on studies, assuring required conditions for collaboration on studies are met.
- Increase awareness of clinical trials, especially for underserved populations, and collaborate with Consortium.

Having cancer data that are complete, comprehensive, timely, and of high quality is essential in charting progress to reduce the burden of cancer in Missouri. These data allow health-care professionals to monitor, plan, design, and evaluate interventions for implementation.

Strategy

2. Assure availability of data to the Consortium to promote integration of data resources and to inform planning and evaluation efforts.

Activities

- Assess the level of participation in committee activities.
- Develop a survey to determine member data needs.
- Survey all Missouri Cancer Consortium members.
- Identify gaps in the availability of data sources and provide summary to Consortium.
- Develop resource/data listing for sharing among Consortium members. (e.g., website development)
- Develop plan of action to address gaps in needs assessment.
- Implement a plan to provide quality, user-friendly data to the Consortium to guide strategic planning, monitoring, and evaluation efforts.

Committee Members

Mary Jane King,
Chair
Missouri Department of Health and Senior Services

Amy Gaier,
National Cancer Institute's Cancer Information Services

Mario Schootman, Ph.D.,
Alvin J. Siteman Cancer Center
Washington University School of Medicine and Barnes-Jewish Hospital

The DHSS Center for Health Information Management and Evaluation, in collaboration with the Missouri Cancer Registry, developed a unique cancer data resource for citizens, health professionals, researchers, and policy makers: Missouri Information for Community Assessment (MICA). The cancer MICA allows users to create tables showing cancer incidence by year, age, sex, race, cancer site, cancer stage, cancer grade, and the geographic location of cancer patients at the county level.

Thirty percent of all cancer deaths, including 90% of lung cancer deaths, can be attributed to tobacco.

Cancer Services

The word "cancer" evokes disturbing images and feelings of alarm to patients and their families and friends. Quality of life may be diminished and additional burdens may include anxiety and other emotional stress; financial hardship caused by increased medical costs and insurance premiums; lost productivity to employers and their respective local economies.

The goal of the Cancer Services Committee is to be the leader in assuring that adequate, appropriate, and legitimate programs, services, and information are available to patients as well as their caregivers, significant others, and the community in which they live and work. No one – people with cancer and those who love them – should fight cancer alone. The Cancer Services Committee will seek to coordinate counseling, support groups, and techniques for pain management to improve the quality of life for all Missourians touched by cancer.

Colorectal cancers can almost always be cured if they are detected early.

Strategy

1. Foster effective communication among all agencies/groups involved in cancer services to avoid duplication of services, encourage collaboration, and increase access for patients.

Activities

- Identify Missouri Cancer Consortium organizations involved in cancer services, including pain management, access to treatment, support group meetings, etc.
- Identify organizations to fill gaps in patient services.
- Assist in development of website communication and coordination of all stakeholders.
- Work with Public Education Committee on its collaboration with research grants.

Strategy

2. Identify the strengths and weaknesses in cancer services.

Activities

- Identify characteristics of high quality cancer services.
- Identify barriers to services for rural and racial/ethnic minority populations, the uninsured, and the underinsured.
- Evaluate the results of identified needs and services and develop action plan to overcome the barriers.

Strategy

3. Facilitate public awareness of available cancer programs, services, and information.

Activities

- Develop a quick fact sheet of recognized support service organizations across the cancer care continuum for patients.
- Distribute talking points for patients on how to speak with physicians regarding cancer care.
- Use the Consortium's webpage to link the public to cancer programs, services, and information.

Committee Members

Pam Duitsman, Ph.D.,
Co-Chair
American Cancer Society

Marianne Ronan,
Co-Chair
Missouri Department of Health and Senior Services

Barbara Carr,
NAPNAP (National Association of Pediatric Nurse Practitioners)

Clay Anderson, M.D.,
Ellis Fischel Cancer Center

Peg Heckathorn,
University of Missouri Sinclair School of Nursing

Vicky Barshis,
LCSW, OSW
Leukemia & Lymphoma Society

The committee will seek to coordinate counseling, support groups, and techniques for pain management to improve the quality of life for all Missourians touched by cancer.

Professional Education

Positive interaction between health-care professionals and patients to reduce cancer risk factors is one of the strongest determinants in reducing cancer. Health-care professionals should routinely incorporate national guidelines for the prevention and early detection of cancer into their daily practices, including screenings at appropriate intervals; discussions on reducing tobacco use; and suggestions to improve diet and increase physical exercise. Communication skills with patients are essential since patient anxiety can lead to poor compliance and result in incomplete or inadequate treatment, particularly in conjunction with ethnic or cultural barriers. Efficient office management systems can help overcome barriers to preventive and early detection services. Clinic office managers and hospitals can assist the health-care professional to be apprised of the patients' risk factors and screening needs and reinforce routine counseling and screening practices.

The goal of the Professional Education Committee is to assist Missouri health-care professionals to become knowledgeable about and utilize evidence-based cancer research and practices to improve patient outcomes. Providing easy access to continuing education for health-care providers becomes increasingly important. Such means as the Internet, teleconferencing, and interactive educational software are methods that can be used by health-care professionals who reside in rural communities or who have difficulty taking time away from their solo practices.

Strategy

1. Provide health-care professionals, trainees, and students access to evidence-based knowledge and skills needed to prevent, detect, and treat cancer as well as care for patients with cancer.

Activities

- Identify professional education resources and assure accessibility by health-care-professionals, trainees, students, and the public.
- Identify, assess, and publicize the availability of advanced training in cancer prevention education, screening, and diagnosis for health-care professionals, trainees, and students.
- Assist in placing resource training for health-care professionals on evidence-based practices on the website.
- Assist in the provision of patient services information to health-care professionals, trainees, and students.

Efficient office management systems can help overcome barriers to preventive and early detection services.

Strategy

2. Encourage health-care professionals, trainees, and students to acquire current cancer knowledge, skills, and resources.

Activities

- Promote strategies to encourage primary-care providers, especially those who provide services to low-income and medically underserved families, to obtain special training.
- Promote health-care professional outreach programs and treatment options, including enrollment in clinical trials, to rural and underserved parts of the state.
- Partner with agencies to promote continuing professional education programs.
- Publicize training opportunities for health-care professionals, trainees, and students on effective cancer prevention counseling methods and educational materials for patients.
- Publicize the need to address quality of life issues and options across the continuum of care and increase access and utilization of palliation, pain control techniques, and end of life care.

Strategy

3. Encourage health-care professionals and students to routinely offer cancer prevention, early detection, and follow-up services to patients and families during health-care visits.

Activities

- Encourage the use of office management systems to remind health-care professionals and patients of need for routine risk assessment, counseling, and screening.
- Encourage the use of American Cancer Society guidelines for clinical preventative services.
- Encourage physicians to publicize the availability of clinical trials, especially among underserved populations.
- Identify data sources and methodologies to determine differences in cancer treatment and care across demographic variables such as age, gender, race, and socioeconomic status.
- Prepare talking points for physicians on how to talk with patients and their loved ones.

Committee Members

Joe Corrado, M.D.,
Chair
American College of Surgeons

Bonnie Bowles,
Missouri Association of Osteopathic Physicians & Surgeons

Lori Ladd,
Purdue Pharma

Cathy Davis,
UAW / Ford Community Health Care Initiatives

Sue Hilton,
Missouri Family Health Council

Lizabeth Fleenor,
Missouri State Medical Association

Dot Guccione,
Missouri Cancer Coalition

Sharon Burnett,
Missouri Hospital Association

Peg Heckathorn,
MU - Sinclair School of Nursing

Public Education

The public is bombarded with cancer messages in a variety of forms – media alerts, press stories, radio spots, on-line stories, among others. The cancer control community needs to coordinate educational messages to Missourians as well as stay connected to the media and advise policy makers of important cancer issues. People fear what they are not aware of, and many people do not understand their cancer risk factors; cancer screening, diagnostic, and treatment options; or policy and environmental issues that impact cancer.

The goal of the Consortium's Public Education Committee is to provide effective public education on best practices in comprehensive cancer control (prevention, early detection, screening, diagnosis, treatment and care) to reduce the incidence and risk of death from cancer. In addition, public education must be designed to reach the diversity of Missouri's citizens. These messages and programs need to be accurate and tailored to people according to age, cultural backgrounds and beliefs, educational levels, literacy levels, and economic status.

Scientists estimate that as many as 50% to 75% of cancer deaths in the United States are caused by human behaviors such as smoking, physical inactivity, and poor dietary choices. To help prevent cancer:

- **Do not use cigarettes or other tobacco products**
- **Do not drink too much alcohol**
- **Eat five or more daily servings of fruits and vegetables**
- **Eat a low-fat diet**
- **Eat a diet in which total calories taken in are balanced with calories expended by physical activity**
- **Maintain or reach a healthy weight**
- **Be physically active**
- **Protect skin from sunlight**

A message from the National Cancer Institute

Strategy

1. Encourage all Missourians to adopt evidence-based cancer prevention strategies.

Activities

- Research existing information and education messages (prevention and early detection) and methods of distribution from Consortium members.
- Research tailored cancer information and education messages and methods for distribution specifically to minorities, rural citizens, and ethnic communities.
- Identify gaps in information research sources via recognized agencies, and seek permission to use information.
- Consult with universities regarding Center of Excellence in Cancer Communication Research grants for strategies to improve communication and dissemination of materials.
- Utilize the Consortium's webpage to coordinate distribution of information and education messages.
- Collaborate with external partners in educational systems to promote healthy lifestyles in nutrition and exercise.

Strategy

2. Encourage all Missourians to receive appropriate screenings for early detection at recommended intervals.

Activities

- Work with the Consortium to identify and publicize the importance of appropriate screening intervals, early detection, and diagnostic tests, especially for underserved populations.
- Identify a state spokesperson to publicize the need for appropriate cancer screenings.

Committee Members

Katherine Jahnige-Mathews, M.D., Chair
Washington University School of Medicine and Barnes-Jewish Hospital

Dalen Duitsman, Ph.D.,
Department of Health, Physical, Education, and Recreational, SMSU

Glenda Meachum-Cain,
Missouri Department of Health and Senior Services

Pat Lindsey,
St. Louis University School of Public Health

Ed Johnson,
American Cancer Society

The early detection of certain cancers can save lives, reduce the extent of treatment, and improve quality of life. Currently, screening is available for cancers of the breast, colon, rectum, cervix, prostate, testes, oral cavity, and skin. Self-examinations of the skin and female breast may also result in earlier cancer detection.

Resources

Educators, parents, health-care professionals, insurance companies, media, government agencies, volunteer organizations, and employers, to name a few, all have important roles in disseminating information about cancer resources. Networks need to be established to ensure distribution of consistent and up-to-date information. The Internet provides new avenues for disseminating and tailoring information to the public, but information must be presented in a variety of formats and settings to accommodate particular populations. Furthermore, barriers such as lack of transportation or the inability to pay for cancer services must be addressed.

The goal of the Resource Committee is to become a clearinghouse to identify and disseminate resources to include financial, scientific and evidence-based information across the cancer continuum. The committee will identify and discern validity of information; locate sources for specialized services and for material, financial, and technical resources; and publicize the availability of these services and resources to facilitate improved cancer control.

Strategy

1. Provide the Consortium and Regional Comprehensive Cancer Control Coalitions a portal of entry to evidence-based cancer information.

Activities

- Establish a communication network of evidence-based interventions as issued by credible sources.
- Encourage the Consortium and coalitions to disseminate these interventions to constituents through an information network.
- Guide coalitions to adopt proven systems of intervention at regional and local levels.

Evidence-based cancer control is the process of methodically identifying, assessing, and applying existing discoveries as the basis for making decisions and promoting interventions.

Strategy

2. Identify third-party coverage for cancer-related services.

Activities

- Review and collate relevant state statutes.
- Review and collate existing cancer-related coverage by insurers.
- Make available position papers from advocacy groups about standards for coverage.
- Establish partnerships among health insurers to ensure managed care plans cover and publicize information about screening, diagnostic, and treatment services.
- Collaborate with other Consortium Committees.

Strategy

3. Disseminate information regarding emerging trends, news articles, and studies to the Consortium members and coalitions.

Activities

- Develop database and distribute information from relevant sources on programs, services, and activities to the Consortium members and coalitions.
- Distribute peer-reviewed research articles on alternative and complementary therapies used during treatment and publicize to the Consortium and coalitions.
- Provide reports, rebuttals, and critiques from credible sources regarding controversial reports, articles, or studies.

Strategy

4. Link technical support services to all Consortium members.

Activities

- Develop a webpage as a portal of entry for cancer information and resources.
- Familiarize committee members with broadcast media resources, research capabilities, publication and printing, technology support, staffing capabilities, and physical facilities.

Committee Members

Jutta Nenninger,
Co-Chair
Saint Louis University

Stan Cowan,
Co-Chair
Missouri Department of Health and Senior Services

Lorna Wilson,
Missouri Association of Local Public Health Agencies

Mimi Casteel,
Missouri Consolidated health-care Plan

Michelle Koeppen,
The Cancer Institute

Sharon Turner,
Cancer Information Services

William (Bill) Gurley,
St. Louis Prostate Cancer Connection

Vangie Rich,
R.A. Bloch Cancer Foundation

Surviving Cancer

Overview

The Centers for Disease Control and Prevention is working diligently with all states to address comprehensive cancer control planning and the vital component of increasing the chances of surviving cancer. Missouri has also adopted the national objective from Healthy People 2010 to "increase the proportion of cancer survivors who are living five years or longer after diagnosis."

The National Cancer Institute states, "An individual is considered a cancer survivor from the time of diagnosis, through the balance of his/her life." Family members, friends and caregivers are also impacted by the survivorship experience.

Currently, there are more than 9.6 million cancer survivors nationally (about 4% of the population). By 2015, there will be an estimated 11.3 million cancer survivors nationally. However, the circle of survivor relationships (family, friends, caregivers, employers) will total approximately 50 million to 100 million.

Key to addressing needs of survivors is gaining understanding of unique needs and concerns through the diagnosis/screening, treatment, and recovery phases of the cancer experience. These needs and concerns span the physical, psychological, social, emotional, and spiritual domains. Examples of survival issues include concern regarding late-term and long-term effects of cancer treatment, re-employability, insurability, and fear of recurrence.

The Missouri Cancer Consortium will address the needs of the growing survivor population through activities that span the priority areas of primary prevention; early detection; treatment and care; palliation and quality of life; research and clinical trials; and data and surveillance. It will take a coordinated effort to obtain better and more accurate data to describe the needs of survivors and to develop the means to appropriately and adequately address those needs.

The National Cancer Institute states, "An individual is considered a cancer survivor from the time of diagnosis, through the balance of his/her life." Family members, friends and caregivers are also impacted by the survivorship experience.

Statistics in Missouri

Cancer is the second leading cause of death in Missouri, representing almost 22% of all deaths in 2002.

Although Missouri's age-adjusted cancer death rate fell during the past decade, it remains slightly higher than the national rate (207.9 versus 199.8 per 100,000 people respectively, for 1997-2000, according to the National Cancer Institute's cancer profiles).

Lung cancer is the leading cause of cancer death for both men and women in Missouri, with an overall age-adjusted rate of 62.9 per 100,000 people in 2002. Cigarette smoking is the strongest risk factor for lung cancer, and studies regarding secondhand smoke also indicate increased risk of developing cancers.

Because 4,000 children begin smoking each year, outreach programs targeting parents and pregnant women should be priority. "There is no redeeming value to tobacco products, and we have to eliminate tobacco products from society," said Dr. Richard Carmona, Surgeon General of the United States. Dr. Carmona emphasized that America cannot afford the disease burden imposed by the use of tobacco, and that a "paradigm shift" from a focus on treatment to a focus on prevention is needed.

Breast cancer is the second leading cause of cancer death in Missouri women while prostate cancer is the second leading cause of cancer death in Missouri men. Colorectal cancers are the third leading cause of cancer deaths in both men and women and may be the most amenable to nutritional interventions.

A cancer registry is a system for collection, storage, analysis and interpretation of data on cancer patients. Cancer registries may be hospital-based or centralized. Hospital-based registries use information abstracted from medical records to assess the number of diagnoses per year and frequencies by sites. Central cancer registries depend on the information obtained from hospital-based registries and from other sources (e.g., pathology laboratories, free-standing cancer clinics and treatment centers, physician offices, and other state central registries). Data submitted by hospitals and other reporting facilities are edited for quality and consolidated to remove duplicate cases. The ultimate goal is a true population-based cancer registry, and Missouri has achieved that goal.

Cancer Overview

What is Cancer?

Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it may result in death. Most types of cancer cells form a lump or mass called a tumor and are named after the part of the body where the tumor originates. Cancer is caused by both external factors (for example, tobacco, chemicals, radiation, and infectious organisms) and/or internal factors (for example, hormones, immune conditions, and genetic mutations).

How Many Missourians Today Will Get Cancer?

In the years to come, cancer will affect approximately three of every four Missouri families; about two in five Missourians now living will eventually develop cancer. Nationally, men have a little less than a one in two lifetime risk of developing cancer; for women, the lifetime risk of developing cancer is a little more than one in three.

How Many New Cases of Cancer Will Occur This Year in Missouri?

In 2004, approximately 30,290 Missourians are expected to be diagnosed with cancer, and about 12,480 are expected to die of the disease, according to the American Cancer Society. This amounts to three new cases of cancer diagnosed every hour of every day. These estimates do not include non-melanoma skin cancer and carcinoma in situ (for sites other than the urinary bladder).

Who is at Risk of Developing Cancer?

Anyone in Missouri is at risk of developing cancer. Although cancer may strike at any age, it is mostly a disease of middle and old age. About 78% of all cancers in Missourians are diagnosed at age 55 or older.

What are the Recent Data Regarding Cancer Genetics?

The area of cancer genetics is advancing rapidly. Research regarding this topic is increasing on a daily basis, and interest is evidently growing among the population with the advent of new methods of genetic studies to determine future diseases.

In order to understand genetics, one needs to know that there are 46 chromosomes in the human body: 22 pairs of autosomes and 1 pair of sex chromosomes. Offspring inherit half of their chromosomes from each parent, and this is the basis for inheritance of diseases. With this in mind, researchers have found gene locations that may be related to certain cancers. For example, there are at least 82 different genetic locations that are related to breast cancer, at least 47 locations for lung cancers, and at least 53 locations related to colorectal cancers. These different locations code for different relations to the particular cancer, including predisposition to diseases that are found to increase predisposition to cancer.

On the basis of genetics, population and family studies are being done. Research groups have been conducting family studies for more than three decades. Some families

have been participating since the 1960s, and many have enrolled in recent years. These researchers are focused on patterns of inheritance and aim at trying to predict the predisposition of individuals to get certain types of cancer based on studies of family members and their diseases.

Can Cancer Be Cured?

Yes. In general, if a person's cancer has been in remission for five years (all signs and symptoms of the disease are absent), the cancer is considered cured. However, cancer may still recur after this time period. The length of remission at which a person is considered cured differs for various kinds of cancer. Certain types of skin cancer are considered cured as soon as the lesion is removed. With other cancers, eight to ten years must pass before the person is considered cured.

What is the Economic Burden of Cancer in Missouri?

While the most important cost of cancer is the loss of lives, the huge economic burden of cancer cannot be ignored. The Centers for Disease Control and Prevention estimates that the direct and indirect cost of cancer in the United States was $170 billion in 2002. This estimate includes about $60 billion in medical costs and $110 billion for lost productivity. This means that with a population of 5.7 million, the economic cost for cancer in Missouri was $3.3 billion, or approximately $585 for each person.

According to a recent study published in the Annual Review of Public Health, medical costs for cancer steadily increased from 1963 to 1995, amounting to billions of additional dollars. This is partly due to the emergence of more expensive treatment modalities for each type of cancer. With the continuing development of new therapies and the increasing elderly population in Missouri, the cost is expected to increase substantially during the next decade.

Could More People Be Saved?

Yes. More than half of cancers are preventable by taking advantage of current knowledge. According to the American Cancer Society, one-third of cancer deaths can be prevented through lifestyle changes such as eliminating tobacco use, improving dietary habits, exercising regularly, maintaining a healthy weight, avoiding exposure to the sun's rays, and obtaining cancer-screening tests. Certain cancers that are related to infectious exposures such as Hepatitis B, human papillomavirus (HPV), human immunodeficiency virus (HIV), heliobacter, and others, could be prevented with behavioral changes, vaccines, and antibiotics.

Smoking causes about 30% of all U.S. cancer deaths. Avoiding tobacco use is the single most important step Americans can take to reduce the cancer burden in this country. Key aspects of improving nutrition include modifying diets to lower consumption of animal fat; increasing consumption of grains, fiber, fruits, and vegetables; and limiting alcohol use.

Early diagnosis saves lives by identifying cancers when they are most curable. Five-year relative survival rates for common cancers such as breast, prostate, colorectal, cervical and melanoma of the skin are 90% to 100%, if they are discovered and treated before spreading beyond the organ where the cancer began. Screening for several cancers has been shown to be effective but is underutilized.

American Cancer Society Cancer Detection Guidelines

Cancer-Related Checkup

For people having periodic health examinations, a cancer-related checkup should include health counseling, and depending on a person's age, might include examinations for cancers of the thyroid, oral cavity, skin, lymph nodes, testes, and ovaries as well as for some non-malignant diseases.

Special tests for certain cancer sites are recommended by the American Cancer Society.

Site	Type of Screening and Recommended Screening Periods
Breast Cancer	• Yearly mammograms starting at age 40 and continuing for as long as a woman is in good health. • Clinical breast exams (CBE) should be part of a periodic health exam, about every three years for women in their 20s and 30s and every year for women 40 and over. • Women should report any breast change promptly to their health-care providers. Breast self-exam (BSE) is an option for women starting in their 20s. • Women at increased risk (e.g., family history, genetic tendency, past breast cancer) should talk with their doctors about the benefits and limitations of starting mammography screening earlier, having additional tests (e.g., breast ultrasound or MRI), or having more frequent exams.
Colon and Rectum Cancer	Beginning at age 50, both men and women should follow one of these five testing schedules: • Yearly fecal occult blood test (FOBT)* • Flexible sigmoidoscopy every 5 years • Yearly fecal occult blood test* plus flexible sigmoidoscopy every 5 years.** • Double-contrast barium enema every 5 years • Colonoscopy every 10 years *For FOBT, the take-home multiple sample method should be used. **The combination of FOBT and flexible sigmoidoscopy is preferred over either of these two tests alone. All positive tests should be followed up with colonoscopy. People should begin colorectal cancer screening earlier and/or undergo screening more often if they have any of the following colorectal cancer risk factors: • A personal history of colorectal cancer or adenomatous polyps. • A strong family history of colorectal cancer or polyps (cancer or polyps in a first-degree relative younger than 60 or in two first-degree relatives of any age) Note: a first degree relative is defined as a parent, sibling, or child. • A personal history of chronic inflammatory bowel disease. • A family history of an hereditary colorectal cancer syndrome (familial adenomatous polyposis or hereditary non-polyposis colon cancer).

Site	Type of Screening and Recommended Screening Periods
Cervical Cancer	The American Cancer Society recommends: • All women should begin cervical cancer screening about 3 years after they begin having vaginal intercourse, but no later than 21 years old. Screening should be done every year with the regular Pap test or every 2 years using the newer liquid-based Pap test. • Beginning at age 30, women who have had 3 normal Pap test results in a row may get screened every 2 to 3 years with either the conventional (regular) or liquid-based Pap test. Women who have certain risk factors such as diethylstilbestrol (DES) exposure before birth, HIV infection, or a weakened immune system due to organ transplant, chemotherapy, or chronic steroid use should continue to be screened annually. • Another reasonable option for women over 30 is to get screened every 3 years (but not more frequently) with either the conventional or liquid-based Pap test, plus the HPV DNA test. • Women 70 years of age or older who have had 3 or more normal Pap tests in a row and no abnormal Pap test results in the last 10 years may choose to stop having cervical cancer screening. Women with a history of cervical cancer, DES exposure before birth, HIV infection, or a weakened immune system should continue to have screening as long as they are in good health. • Women who have had a total hysterectomy (removal of the uterus and cervix) may also choose to stop having cervical cancer screening, unless the surgery was done as a treatment for cervical cancer or precancer. Women who have had a hysterectomy without removal of the cervix should continue to follow the guidelines above.
Endometrial (Uterine) Cancer	The American Cancer Society recommends that all women should be informed about the risks and symptoms of endometrial cancer and strongly encouraged to report any unexpected bleeding or spotting to their doctors. For women with or at high risk for hereditary nonpolyposis colon cancer (HNPCC), annual screening should be offered for endometrial cancer with endometrial biopsy beginning at age 35.
Prostate Cancer	Both the prostate-specific antigen (PSA) blood test and digital rectal examination (DRE) should be offered annually, beginning at age 50, to men who have at least a 10-year life expectancy. Men at high risk (African-American men and men with a strong family history of one or more first-degree relatives [father, brothers] diagnosed at an early age) should begin testing at age 45. Men at even higher risk, due to multiple first-degree relatives affected at an early age, could begin testing at age 40. Depending on the results of this initial test, no further testing might be needed until age 45. Information should be provided to all men about what is known and what is uncertain about the benefits and limitations of early detection and treatment of prostate cancer so they can make an informed decision about testing. Men who ask their doctor to make the decision on their behalf should be tested. Discouraging testing is not appropriate. Also, not offering testing is not appropriate.
References	American Cancer Society. Cancer Facts and Figures 2004. Atlanta, GA: American Cancer Society; 2004. Smith RA, Saslow D, Sawyer KA, et al. American Cancer Society Guidelines for Breast Cancer Screening: Update 2003. CA Cancer J Clin. 2003;53:141-169. Revised 1-6-04

*American Cancer Society

Cancer of the Lung and Bronchus

Bottom Line

Lung cancer is the most common cancer in Missouri. Between 1996 and 2000, an average of 4,653 new cases of lung cancer was diagnosed each year in Missouri. It is the number one cause of cancer death in the United States, killing more than 160,000 Americans every year, including nearly 3,700 Missourians. Lung cancer causes more deaths every year than do colorectal, breast, cervical, and prostate cancers combined. The lung cancer mortality rate in Missouri (62.7 per 100,000 from 1999-2000) was 13% higher than the national mortality rate (55.7 per 100,000). Tobacco use is the leading cause of lung cancer. Despite the fact that lung cancer most frequently affects older people, the population most at risk for eventually developing lung cancer is current smokers. However, people of all ages, even children of middle school age, become tobacco users.

Nationally, approximately 23% of adults reported smoking (a decrease from 42.4% in 1965). Despite this encouraging national trend, 26.5% of Missouri adults reported that they smoked at least some days in 2002. Other causes include exposure to secondhand smoke, exposure to asbestos, and prolonged exposure to environmental radon.

Prevention and Early Detection

Presently, there are no effective methods to detect lung cancer in an early, more treatable stage, but studies are currently underway. Prevention is the most important aspect in eliminating lung cancer. More than 90% of lung cancers could be avoided by not smoking. Preventing the start or stopping the use of tobacco could nearly eliminate lung cancer. Although lung cancer has been reduced among some groups in recent years, a significant percentage of Americans – including adults, adolescents, and children – continue to smoke or use tobacco in some other form.

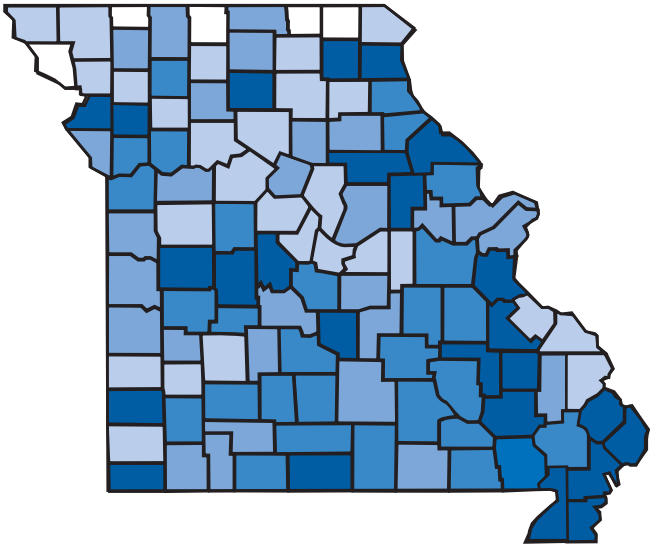
Secondhand smoke – also known as environmental tobacco smoke – is what comes from a burning cigarette, pipe, or cigar, plus what the smoker exhales. Tobacco is known to contain at least 60 cancer-causing agents. People who are exposed to secondhand smoke inhale these chemicals, just as smokers do, although at a lower level. According to the U.S. Environmental Protection Agency, secondhand smoke causes about 3,000 lung cancer deaths in the United States each year among nonsmokers.

Radon – an invisible, odorless, tasteless gas that is released from rocks and soil – enters homes through cracks and holes in the foundation. Radon is second only to tobacco as

the leading cause of lung cancer. Radon may contribute to as many as 20,000 lung cancer deaths in the United States each year. Researchers estimate that lowering indoor radon exposure could prevent about 30% of lung cancer deaths from radon. Only 18% of Americans who were aware of radon lived in homes actually tested for radon.

Routine exams to detect lung cancer have not been shown to reduce mortality. Chest x-ray, analysis of cells contained in sputum, and fiber optic examination of the bronchial passages have all shown only limited effectiveness in early detection of lung cancer. Newer tests, such as low-dose spiral computed tomography (CT) scans and molecular markers in sputum, are currently being evaluated in scientific studies. The Missouri Department of Health and Senior Services and the Missouri Cancer Consortium will continue to work closely with all agencies whose focus is on preventing the use of tobacco products (or stopping its use). Members will also work closely with selected communities who are addressing the need for clean indoor air.

Lung & Bronchus Cancer Incidence Rates by County 1996-2000



Colors indicate age-adjusted rate of cancer of the lung & bronchus in that county, per 100,000 residents.

- 40.4 to 68.0
- 68.1 to 79.6
- 79.7 to 87.3
- 87.4 to 120.0
- Numerator too small for rate calculation

*1996-2000 data from the Missouri Cancer Registry.

Colon and Rectum Cancer

Bottom Line

Screening tests offer a powerful opportunity for the prevention and early detection of colorectal cancers. Although people cannot change their genetic makeup, most can reduce their risk of colorectal cancer by following screening guidelines; eating a low-fat, high-fiber diet; and participating in physical activity. Colorectal cancers can be cured if they are detected early. Screening tests, such as colonoscopy, sigmoidoscopy, and fecal occult blood testing, can detect colon polyps (tissue growths) even before they become cancerous, as well as early-stage colorectal cancers.

Cancer Burden

Colorectal cancer is the third most common cancer in both men and women, nationally and in Missouri. An average of 3,399 Missourians developed colorectal cancer annually during 1996 to 2000, and an average of

1,271 Missourians died of the disease each year during 1999-2000.

Increased use of sigmoidoscopy or colonoscopy, which in turn has increased polyp removal, has been suggested as one possible reason for the decline in incidence and mortality rates. Unfortunately, risk factors for colorectal cancer, such as a sedentary lifestyle, obesity, and an unhealthy diet, have also increased over time and may adversely affect incidence and mortality rates.

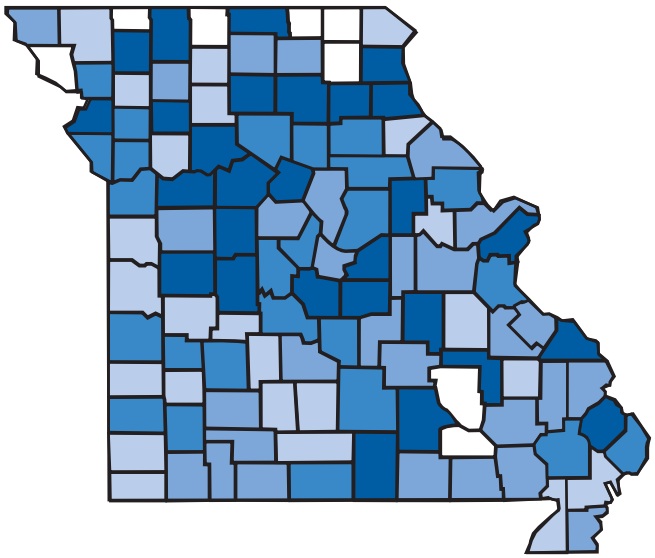
Prevention and Early Detection

Obtaining appropriate screening for polyps as well as modifying behavioral risk factors greatly reduces the chances for colorectal cancer. Research suggests that aspirin-like drugs, postmenopausal hormones, folic acid, calcium supplements, selenium, and vitamin E may help prevent colorectal cancer. At least 70% of colon cancers could be prevented by healthy behaviors that include: 1) maintaining a healthy body weight; 2) participating in moderate daily physical activity; 3) limiting red meat intake; 4) not smoking; 5) taking a multiple vitamin; and 6) avoiding high alcohol intake.

Scientific research and development continue in an effort to identify earlier detection of colorectal cancer through minimized screening methods. One such method is by examination of computer-generated images from an abdominal computer tomographic (CT) examination. These images simulate the effect of a conventional colonoscopy, and if polyps are found, it then becomes necessary to perform a follow-up conventional colonoscopy. These methods are promising, but more research is needed before they are used in routine medical practice. While persons at average risk of colorectal cancer should be screened starting at age 50, individuals with a family history of colorectal cancer or adenomatous polyps in a first-degree relative (in a parent or sibling before age 60 or in two first-degree relatives of any age); a personal history of colorectal cancer, polyps, or chronic inflammatory bowel disease; or a family history of hereditary colorectal cancer syndrome should consider screening prior to age 50. However, most colorectal cancers occur in people over age 50 with no predisposing factors.

In 2002, only 44.2% of Missourians age 50 and over reported having had a sigmoidoscopy or colonoscopy exam.

Colon & Rectum Cancer Incidence Rates by County 1996-2000



Colors indicate age-adjusted rate of cancer of the colon & rectum in that county, per 100,000 residents.

- 37.9 to 52.2
- 52.3 to 56.7
- 56.8 to 63.5
- 63.6 to 88.7
- Numerator too small for rate calculation

*1996-2000 data from the Missouri Cancer Registry.

Breast Cancer

Bottom Line

Nearly all breast cancers can be treated successfully if detected early. Obtaining an annual mammogram and clinical breast examination starting at age 40 is the most effective way to detect breast cancer at an early, treatable stage. A number of risk factors for breast cancer have been identified, but most women do not have any known risk factors at the time of their diagnosis. Some risk factors for breast cancer, such as family history and age, cannot be changed. Other factors are modifiable; women may reduce their risk of developing breast cancer by: 1) staying physically active; 2) avoiding midlife weight gain; 3) avoiding prolonged use of hormone replacement therapy; and 4) avoiding daily alcohol consumption. Even so, the proportion of breast cancer attributable to these individual risk factors has been typically less than 10%.

Cancer Burden

Excluding all cancers of the skin, breast cancer is the most common cancer among women in Missouri and accounts for nearly one-third of all cancers diagnosed in women.

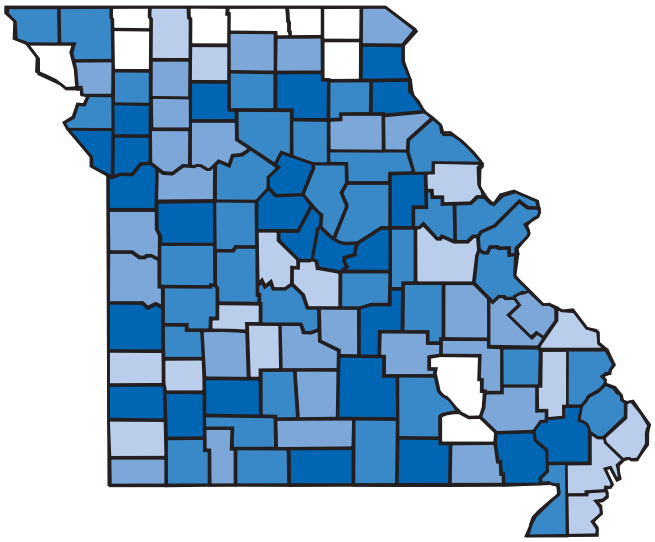
Prevention and Early Detection

Maintaining a healthy weight through lifestyle factors such as regular physical activity and a low-fat diet may reduce the risk of breast cancer. Postmenopausal hormone therapy may increase the risk of breast cancer, although there is little known risk associated with the use of oral contraceptives. The risk of developing breast cancer increases with age.

Women with a family history of breast cancer, especially a first-degree relative (mother, sister, or daughter), have an increased risk of developing breast cancer themselves.

At this time, there is no guaranteed way to prevent breast cancer for women who are at average risk, which is why screening via mammography and clinical breast examination is so important. Mammography can detect breast cancer about two years before physical symptoms develop. Studies have shown that early detection, followed by prompt, appropriate treatment, saves lives and increases treatment options.

Female Breast Cancer Incidence Rates by County 1996-2000



Colors indicate age-adjusted rate of cancer of the female breast in that county, per 100,000 women.

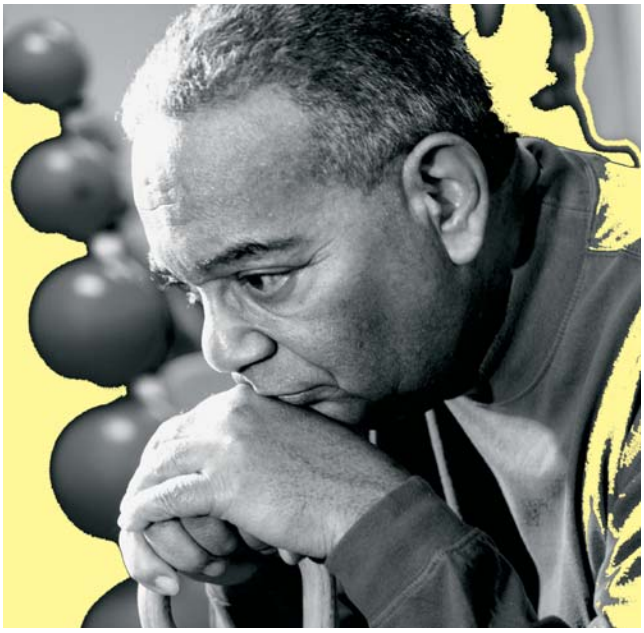
- 72.3 to 103.5
- 103.6 to 116.1
- 116.2 to 128.2
- 128.3 to 164.8
- Numerator too small for rate calculation

*1996-2000 data from the Missouri Cancer Registry.

Prostate Cancer

Bottom Line

Prostate cancer is the most common type of cancer for men nationally and in Missouri, other than skin cancer, and the second leading cause of cancer death after lung cancer. Age is the main risk factor for prostate cancer. At present, several national organizations recommend informed decision making about testing for prostate cancer rather than recommending that all men be screened for the disease. Men 50 years and older should talk to their doctors about their risk for prostate cancer and the importance of digital rectal exams (DRE) and prostate-specific antigen (PSA) tests to detect prostate cancer early. The American Cancer Society recommends that men at high risk (African-American men and men who have a first-degree relative diagnosed with prostate cancer) should begin testing at age 45. Men should discuss an abnormal DRE or PSA with their doctors, especially since it is currently not clear if all men need to be treated immediately for prostate cancer or if watchful waiting is the appropriate course of action.



Prevention and Early Detection

According to the 2002 Missouri Behavioral Risk Factor Surveillance System, 56.8% of Missouri men age 50 and older had a PSA test within the past year. Fifty-six percent of Missouri men 50 years of age and older reported having a digital rectal exam in the past year.

The only well-established risk factors for prostate cancer are age, race/ethnicity, and genetic factors. Studies indicate that dietary fat may also be a risk factor, suggesting that 20% to 25% of the incidence of prostate cancer among white and African-American men may be due to high levels of saturated fat intake.

Because the exact cause of prostate cancer is not known, use of the PSA test offers men of higher risk some opportunity to detect the disease early. Risk factors such as age, race, and family history, should be discussed with a physician since these factors impact a man's decision to be screened and to seek follow-up and treatment as needed.

The prostate cancer incidence rate among African-American men in Missouri was nearly 70% higher than the rate for white men in Missouri (223.3 per 100,000 versus 132.6 per 100,000 respectively, from 1996-2000).

Melanoma of the Skin

Bottom Line

Nearly all skin cancers are preventable by limiting unprotected exposure to the sun. When they do occur, most skin cancers can be treated successfully if detected early – even melanoma, the most serious type of skin cancer. Ultraviolet (UV) exposure is associated with a small percentage of all cancer deaths.

Cancer Burden

Since it is not a requirement to report non-melanoma skin cancers, the full extent of these skin cancers is unknown. Nationally, approximately 55,100 new cases of melanoma are expected to be diagnosed in 2004 in the United States. An average of 554 Missourians was diagnosed with malignant melanoma every year during 1996-2000. The melanoma incidence rate in Missouri from 1996-2000 was 9.8 per 100,000. One hundred sixty-five Missourians died annually from malignant melanoma during 1999 and 2000. Missouri's annual mortality rate during 1999-2000 (2.9 per 100,000) was very similar to the national rate of 2.7 per 100,000.

Sunburn during childhood and intense intermittent sun exposure increase the risk of melanoma and other skin cancers. According to the 1999 Behavioral Risk Factor Surveillance System, 34.5% of adults age 18 or older in the United States reported that they had at least one sunburn during the past year (39.7% for men and 28.8% for women).

Prevention and Early Detection

Risk factors for melanoma include: light skin color; a personal or family history of melanoma; presence of moles and freckles; and a history of excessive sun exposure, including severe sunburn occurring early in life. Risk factors for basal and squamous cell cancers include: chronic exposure to the sun, a personal or family history of skin cancer, and light-skin color.

Sunburn during childhood and intense intermittent sun exposure increase the risk of melanoma and other skin cancers. According to the 1999 Behavioral Risk Factor Surveillance System, 34.5% of adults age 18 or older in the United States reported that they had at least one sunburn during the past year (39.7% for men and 28.8% for women).

Cancer of the Oral Cavity and Pharynx

Bottom Line

Cancers of the oral cavity (lip, salivary gland, mouth, and throat) are estimated at 28,260 new cases and 7,230 U.S. deaths in 2004. Two known causes of oral cancer are tobacco and alcohol use.

- Tobacco use – smoking cigarettes, cigars, or pipes; chewing tobacco; or dipping snuff – accounts for 80 to 90 percent of oral cancers.

- Chronic and/or heavy use of alcohol also increases the risk of oral cancer, even for people who do not use tobacco. However, people who use both alcohol and tobacco have an especially high risk of oral cancer. Scientists believe that these substances increase each other's harmful effects.

Two known causes of oral cancer are tobacco and alcohol use.

Cancer Burden

In Missouri, an average of 586 new cases of oral cancer was diagnosed every year during 1996-2000 (10.4 per 100,000). This is very similar to the National Cancer Institutes Surveillance, Epidemiology, and End Results (SEER) program incidence rate for oral cancer.

An average of 141 Missourians died every year during 1999-2000 from oral and pharyngeal cancer (2.4 per 100,000). This is the same as the national mortality rate for oral and pharyngeal cancer.

Prevention and Early Detection

Oral and pharyngeal cancers are largely preventable. Oral cancer deaths could be reduced significantly by eliminating smoking and smokeless tobacco and by reducing heavy alcohol consumption.

Although there is insufficient evidence to recommend for or against routine screening of asymptomatic persons for oral cancer by primary care physicians, clinicians should remain alert to signs and symptoms of oral cancer and premalignancy in persons who use tobacco or regularly use alcohol.

Often lip and oral cavity cancers are found by dentists when examining the teeth. The prognosis depends on where the cancer is located and whether it has spread to other tissues.

Cervical Cancer

Bottom Line

Screening by means of the Pap test offers a powerful method for the prevention and early detection of cervical cancer. The use of the Pap test on a regular basis reduces the risk of death from cervical cancer by 90%, mainly through the detection and treatment of preinvasive lesions. Cervical cancer incidence and mortality rates have decreased markedly in the past several decades, with most of the reduction attributed to the introduction of the Pap test.

Cancer Burden

In an average year, 304 Missouri women will develop invasive cervical cancer, and 89 women will die of the disease. The incidence rate of cervical cancer in Missouri from 1996-2000 was 10.4 per 100,000. The mortality rate from cervical cancer among Missouri women from 1999-2000 was 2.8 per 100,000, the same as the national rate.

Prevention and Early Detection

Cervical cancer risk is closely linked to sexual behavior and to sexually transmitted infections with certain types of human papilloma virus (HPV), a virus that can promote the development of cancer. These types of HPV are known as "High Risk", and are found in 99.7% of cervical cancers. An HPV Profile test may be done to determine if a woman has the high risk type. Women should consult with their health-care provider to determine if a HPV Profile test is needed. Women who have sex at an early age (before age 18), have many sexual partners, or have partners who have had many sexual partners are at increased risk of developing the disease. Condoms may provide some protection from HPV. Cigarette smoking increases cervical cancer risk, especially in conjunction with the use of oral contraceptives. A concern is the increase of smoking among younger women during the 1980s, which may translate into more cervical cancers among this population in the future.

Pap tests can detect precancerous cells, allowing these problems to be treated before cervical cancer develops. Invasive cervical cancer and related mortality have decreased significantly over the past 25 years because of increased screening with Pap tests and prompt treatment once diagnosed. In Missouri in 2002, 84% of women reported having a Pap smear in the past three years.

The Show Me Healthy Women program provides free breast and cervical cancer screenings and diagnostic tests to underserved Missouri women residents ages 35-64. Treatment, if needed, is provided through the Medicaid Breast and Cervical Treatment Act.

Blood Related Cancers

Blood-related cancers include malignancies of the lymphatics (Hodgkin and non-Hodgkin Lymphomas) and malignancies of the blood cell line (leukemia and myeloma).

Hodgkin and non-Hodgkin Lymphomas

Hodgkin and non-Hodgkin lymphomas are cancers that start in lymphoid tissue. Non-Hodgkin can often be distinguished from Hodgkin lymphoma by examining the cancerous tissue under a microscope. In some cases, more tests to identify specific chemical components of the lymphoma cells or tests of the cells' DNA may be needed.

Cancer Burden

The American Cancer Society estimates that about 7,800 new cases of Hodgkin disease will be diagnosed in 2004 in the United States. It is most common in two age groups: ages 15-39 and age 75 and older. About 13% of cases are diagnosed in children and adolescents 19 years of age and younger.

In Missouri, there was an average of 154 new cases per year during 1996-2000, producing an incidence rate of 2.8 per 100,000. Mortality from Hodgkin disease is low. In Missouri, the average was 27 deaths per year from 1999-2000. The Missouri mortality rate was the same as the national mortality rate during 1999-2000 (0.5 per 100,000).

Non-Hodgkin lymphoma is the sixth most common cancer in this country, excluding nonmelanoma skin cancers. In Missouri from 1996-2000, there was an average of 1,057 new cases per year of non-Hodgkin lymphoma for an incidence rate of 18.5 per 100,000. Males had a higher incidence rate than females (15.5 per 100,000). Missouri mortality rate was slightly higher than the national rate for 1999-2000 (8.7 per 100,000 vs. 8.0 per 100,000 respectively).

Prevention and Early Detection

Risk factors for the lymphomas are largely unknown but in part involve reduced immune function, exposure to infectious agents, and age. Other possible risk factors include occupational exposure to herbicides. There is currently no method for early detection of the lymphomas. Non-Hodgkin lymphoma was more common in men than in women in Missouri during 1996-2000. Whites (18.8 per 100,000) are affected more often than African Americans (13.0 per 100,000) in Missouri.

Leukemias

Leukemia constitutes less than 5% of cancers in the United States but includes a wide range of biologically and clinically distinct subtypes. Despite extensive epidemiologic study, the prospect for prevention of leukemia is limited because its causes are largely unknown.

Cancer Burden

Overall, about 33,440 new cases of leukemia are expected in the United States during 2004 according to the American Cancer Society. Approximately half will be acute leukemia and half will be chronic leukemia. An estimated 23,300 adults and children in the United States will die of leukemia during 2004.

Prevention and Early Detection

There currently are no tests to detect leukemia in an early, more treatable stage. Early symptoms often are not defined enough to generate a diagnosis of leukemia. These symptoms frequently resemble those of other, less serious conditions, which makes leukemia difficult to detect and treat early. Patients should consult their physician if undiagnosed chronic symptoms linger, especially if there is a history of leukemia in the family.

Multiple Myeloma

Plasma cells, produced by B-cells in response to infections, grow out of control in myeloma tumors. These tumors can grow in several sites, particularly in the soft middle part of bone called the bone marrow. When these tumors grow in multiple sites they are called multiple myeloma.

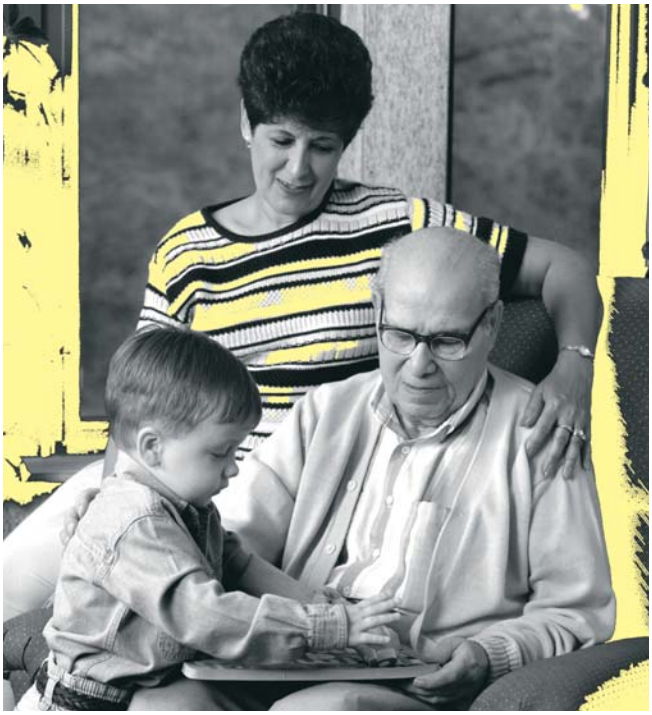
Cancer Burden

It is estimated that about 15,270 new cases of multiple myeloma will be diagnosed nationally during 2004, according to the American Cancer Society. About 11,070 Americans are expected to die of multiple myeloma in 2004.

An annual average of 283 new cases of multiple myeloma was diagnosed among Missourians during 1996-2000. The rate among men (5.9 per 100,000) was higher than among women (4.2 per 100,000). During 1999-2000, an average of 206 Missourians died from multiple myeloma for an average mortality rate of 3.6 per 100,000, which was similar to the national rate for the same time period (3.9 per 100,000).

Prevention and Early Detection

The average age at diagnosis is 70. People with other plasma cell diseases may also be at higher risk. Exposure to radioactivity has been suggested as a risk factor but accounts for a very small number of cases. The disease seems to be more common in some families, suggesting genetic or common environmental influences. There currently are no methods available to detect multiple myeloma in an early, more treatable stage. Multiple myeloma is twice as common in African Americans as among whites. The reason for this is not known.



Cancer Disparities

The burden of cancer is not borne equally by all population groups in Missouri. That is exemplified by differences in cancer incidence and mortality as a function of race, ethnicity, gender and socioeconomic status. Eliminating health disparities is a key goal of the Missouri cancer control plan as well as national organizations and agencies, including the American Cancer Society and the U.S. Department of Health and Human Services Healthy People 2010 Initiative. Despite research demonstrating the existence of health disparities, there is strikingly little known about the causes of these disparities and how to prevent them. Poor and medically underserved populations have higher risks of developing cancer and poorer chances of early diagnosis, optimal treatment, and survival. Moreover, these populations have not benefited equally from recent improvements in cancer prevention, early detection, and treatment.

Interventions

Addressing disparities requires a multifaceted approach because the underlying factors producing disparities are complex. Disparate health outcomes are not primarily due only to one microbe or genetic factor. Instead, a broad range of social, economic, and community conditions interplay with such individual factors to intensify susceptibility, provide less protection, and affect healthy behaviors. These conditions, such as deteriorated housing, poor education, limited employment opportunities, limited household resources, readily available cheap high-fat foods, and limited access to parks and recreational facilities, are particularly exacerbated in neighborhoods where people of low income live.

Research has now shown that after adjusting for individual risk factors, there are neighborhood differences in cancer screening, incidence, treatment, and survival. It is the relationship between place, race, and poverty that can lead to the greatest disparities. Reducing such disparities requires action at several levels to maximize impact.

Individuals need to be equipped with the knowledge, skills, and motivation to make changes. Community institutions such as health-care facilities, work places, schools and faith-based organizations are ideal venues for reaching individuals. They also offer systems of social support that increase the likelihood of maintaining healthier behaviors. Although education plays a valuable role in shaping behavioral choices, addressing the social and physical environment that influences behavioral choices is an essential strategy in changing behavioral patterns throughout a population. Focusing only on individual responsibility for lifestyle changes ignores larger environmental and policy factors that can work against the educational message.

In addition to shaping behavior, the environment also has a direct influence on cancer development. The physical environment tends to be worse in areas in which the population is low-income. There may be toxic sites and other hazards concentrated in areas where low-income and minority populations reside.

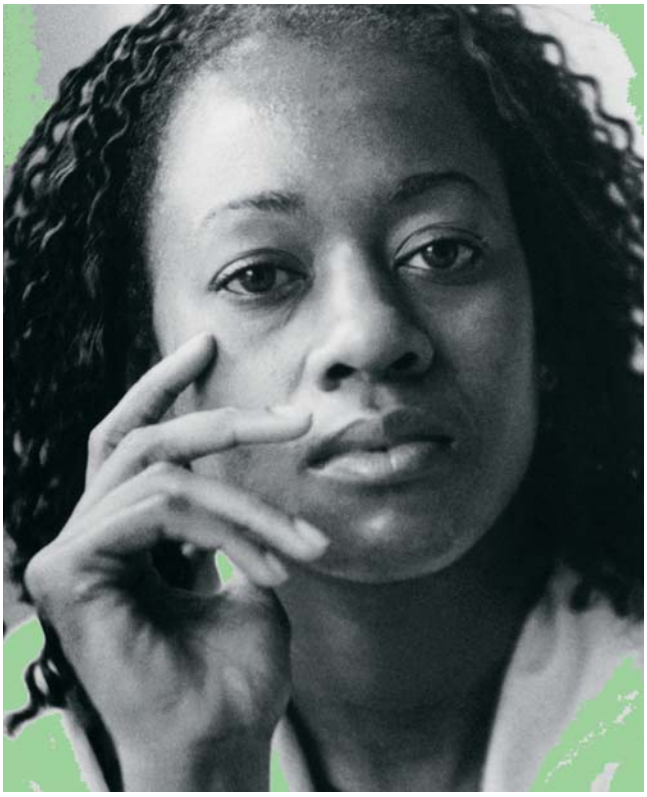
Strengthening community environments and improving access and quality of health-care are not only necessary elements in the strategy to reduce health disparities but are mutually supportive. Providing timely and effective diagnosis and treatment for cancer not only reduces demands on the medical system, but also better enables people to contribute to the community environment through activities such as work and civic participation.

Eliminating health disparities and improving health outcomes requires participation from key public and private institutions working in partnership within their communities.

Evidence suggests that multistrategy interventions are more effective than any one intervention alone. Examples include programs that integrate case management by culturally sensitive community health educators and the print or other media to communicate the benefits of mammography, general education of the community regarding screening, and the handling of logistic barriers by arranging appointments and transportation to those appointments.

Multiple interventions directed at patients, physicians, the health-care system, and the community may provide the best approach to improving rates of screening for cancer. In one review, 33% of studies using single interventions and 85% of multicomponent trials were associated with increased rates of screening. Elimination of financial and access barriers to screening improves screening rates. For example, through the use of health insurance coverage, reduced cost sharing, and the availability of free screening at public clinics, screening rates increase. In addition, certain organizational innovations are tied to improved screening rates, such as the implementation of office systems to prompt health-care providers to recommend screening, facilitate referrals, and remind patients and providers of the need for rescreening. Other opportunities to improve screening rates, particularly among underserved populations, include the use of nurses to provide outreach and education, and case management.

The Missouri Cancer Consortium is committed to working with researchers, health-care professionals, community organizations, and others to better determine the causes of health disparities, to determine the needs of our aging population, and to develop interventions to address these issues across the cancer care continuum ranging from prevention, early detection, diagnosis, treatment, survival, quality of life, and end of life care.



Missouri Insurance Mandates:

Missouri state regulations mandate that private insurance companies, Medicaid, and public employee health plans provide coverage and reimbursement for specific health services and procedures when it comes to cancer prevention, early detection, and treatment services (Missouri Revised Statutes, Chapter 376, Life, Health and Accident Insurance).

Covered Cancer Screenings

Health carriers are required to notify enrollees of covered cancer screenings at regular intervals, consistent with American Cancer Society guidelines, and specifies the method of notification.

Mammography

Mammography. Health insurers and similar entities shall provide benefits or coverage for low-dose mammography screening for any nonsymptomatic woman covered under such policy or contract which meets the minimum requirements; such benefits or coverage shall include at least the following:

- A baseline mammogram for women age thirty-five to thirty-nine, inclusive;
- A mammogram for women age forty to forty-nine, inclusive, every two years or more frequently based on the recommendation of the patient's physician;
- A mammogram every year for women age fifty and over;
- A mammogram for any woman, upon the recommendation of a physician, where such woman, her mother, or her sister has a prior history of breast cancer.

Pelvic, Prostate, Colorectal Exams, and Pap Smears

Health insurers and similar entities are required to provide coverage for pelvic exams and pap smears for nonsymptomatic women in accordance with American Cancer Society guidelines. Prostate exams and laboratory tests will be covered for nonsymptomatic men and colorectal cancer exams and laboratory tests will be covered for nonsymptomatic persons in accordance with American Cancer Society guidelines. Coverage and benefits related to the examinations and tests are subject to dollar limits, deductibles, and copayments similar to those of other covered benefits or services. Accident-only, hospital indemnity, Medicare supplement, long-term care, limited benefit health insurance policies, and short-term major medical policies of six months or less are exempted from these requirements.

Phase III and IV Clinical Trials

Mandated coverage for routine care costs for Phase III and IV Clinical Trials. This mandate requires health insurance companies to provide coverage for routine patient care costs incurred as the result of phase III or IV of clinical trials undertaken to treat cancer. Entities providing clinical trial treatment must have sufficient expertise and training to treat a sufficient number of patients. There must be identical or superior non-investigational treatment alternatives available before providing clinical trial treatment. Clinical trial coverage shall include coverage for drugs and devices approved by the FDA, whether or not the FDA has approved the drug or device for the patient's particular condition. The clinical trials

will be covered only if they are approved or funded by certain entities. Providers participating in clinical trials shall obtain the patient's informed consent for participating in the clinical trial. This provision is similar to RSMo Section 376.429.

Second Opinions

Mandated coverage for second opinions upon a new cancer diagnosis. This mandate allows a physician to refer a patient who has been newly diagnosed with cancer to a specialist for a second opinion regarding the patient's treatment. Insurance companies must provide coverage for the second opinion rendered by the specialist. A referral must be given to an out-of-network specialist if a specialist is not available within the provider's network. This provision does not apply to certain insurance policies.

Bone Marrow Testing

Mandated coverage for bone marrow testing. This mandate requires certain health carriers and benefit plans to cover human leukocyte antigen testing for use in bone marrow transplantation. Testing must be performed in an appropriate facility. A form indicating informed consent must be completed, which will authorize use of the results in the National Marrow Donor Program. Health plans may limit enrollees to one testing per lifetime to be reimbursed at a cost of no more than $75, but may not charge extra fees for the test.

In 1999, Missouri led the nation in passing comprehensive cancer screening mandates.

Mastectomy

Mandated coverage for reconstruction and prosthetics after mastectomy. This mandate requires health insurance carriers to provide coverage for mastectomies, prosthetic devices, or reconstructive surgery. The bill prohibits a time limit from being imposed on an individual for the receipt of a prosthetic device or reconstructive surgery. The bill also requires that if an individual changes insurer, the new policy will be subject to and provide coverage consistent with the federal Women's Health and Cancer Rights Act.

Breast / Cervical Cancer Program

The Breast and Cervical Cancer Mortality Prevention Act of 1990 addresses six specific areas:

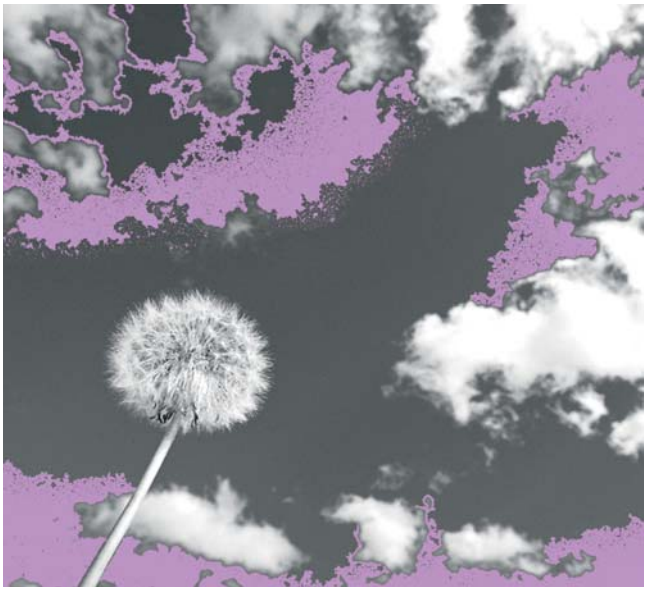
- Screen medically underserved women for breast and cervical cancer.
- Provide appropriate and timely referrals of abnormal tests and assure follow-up services.
- Develop and disseminate information to promote the early detection of cancers.
- Provide training to enhance the skills of health professionals in detection and control.
- Assure quality for screening procedures and interpretation.
- Conduct a program evaluation through surveillance systems.

The Federal Medicaid Breast and Cervical Cancer Treatment Act of 2000 provided temporary Medicaid coverage for women diagnosed with cancer through the Show-Me Healthy Women Project funded by the Center for Disease Control and Prevention. The Missouri Breast and Cervical Cancer Treatment Act was signed into legislation and went into effect August 28, 2001. The Show-Me Healthy Women program is administered by the Department of Health and Senior Services.

Palliative Care

How is Palliative Care Defined?

Palliative care is defined as "care that goes beyond the traditional definition of providing comfort to the dying." The Hospice movement, which offers palliative care services, formed because its members recognized the need to consider the psychological issues of patients and their families. In 2001, the Institute of Medicine issued a report called "Improving Palliative Care for Cancer" that defined palliative care as beginning at the diagnosis of cancer or any other chronic or potentially life-threatening disease. The World Health Organization expanded that definition the following year to include "improving the quality of life of patients and their families during the entire course of an illness." In expanding the definition, the Institute of Medicine recommended more attention be given to the emotional, spiritual, and practical needs of patients and their families. Nobody with cancer does it alone and does it well. It takes a medical team to treat patients medically and a secondary team of family and friends to help patients get through.



Why is There a Need for Palliative Care?

The field of palliative care, once largely confined to providing comfort to the dying, has broadened to include the physical, social, psychological, and spiritual aspects of coping with cancer over the entire continuum of cancer care. Very few current cancer treatments and therapies are benign and without side effects. In addition, some elderly cancer patients have other co-morbid illnesses that must be considered when deciding upon treatment regimens. As such, it's important to apply the lessons that have been learned across other chronic diseases to cancer as well.

The Changing Role of Palliative Care

The medical community, public health agencies, and voluntary organizations have expanded the definition of chronic disease – a disease that a patient may live with for many years – to include cancer. Just as people have learned to live with heart disease or diabetes, people are also experiencing and surviving cancer. Yet many still suffer some residual pain or disability as a result of their cancer and their cancer treatment.

The majority of hospice patients are cared for in their own homes or the homes of a loved one. Home is broadly construed to mean nursing homes, hospitals, and prisons as well as residences.

The medical community has researched the negative consequences of cancer treatments and therapies in order to improve the quality of care and quality of life for cancer patients and their families. Palliative care has evolved beyond end of life issues to provide symptom management much earlier in the course of disease as well as other aspects of palliative care that continue across the entire disease trajectory. This change in perspective is due in part to medical advances that have resulted in more people experiencing cancer as a chronic disease. Palliative care can help because it plays a critical role from the moment of diagnosis through treatment and survival.

Palliation and Treatment Should Occur Simultaneously

Treatment should not be undertaken without the benefits of palliative care at the same time. Such care is an excellent way to improve the quality of life for the patient at all stages and should be an integral part of the cancer continuum. Dealing with fatigue and pain while continuing to function as needed; concerns over insurance and medical treatments; and worry about the needs of the family or support system can overwhelm the patient. A person trained in palliative care can assist the patient as well as the patient's family or support system in discussing the disease accurately and completely. The person can identify decisions that need to be made to cope with the cancer and its consequences and work with the medical community to assure the patient can cope with any medical problems such as nausea or lymphedema.

Improved coordination of care and emphasis on palliating rather than curing requires health-care providers to shift their focus from fighting and curing disease to alleviating a person's pain. Indeed, a health-care practitioner employing good palliation pays attention to all of the patient's needs including emotional, spiritual, and social, which affect the decision-making process. Aspects of a quality palliative care program include effectively communicating with patients and their families to determine appropriate goals of treatment in light of the patient's changing condition; sufficient control of pain and other symptoms; and a collaborative, multidisciplinary approach to meeting the patient's and family's physical, emotional, psychosocial, and spiritual needs.

Causes of Cancer Pain

The two most common causes of cancer pain are the cancer itself and the treatments for cancer.

1. The cancer itself. When cancer causes pain, some probable causes include the pressure of a tumor on one of the body's organs or on bone or nerves. Sometimes cancer can cause pain when blood vessels become obstructed by the tumor.

2. Cancer treatments. It is also very important to remember that many treatment-related side effects can be successfully prevented in some cases and treated if they occur. More information about managing side effects is explained where each treatment type is discussed.

Examples of treatment-related pain include:

1. Chemotherapy can cause numerous side effects, including mouth sores (mucositis), peripheral neuropathy (numb and sometimes painful sensations in the feet, legs, fingers, hands, and arms), constipation, diarrhea, nausea, vomiting, and abdominal cramps. Some people also experience bone and joint pain from chemotherapy medications and from some medications used to offset the impact of the chemotherapy on blood counts and on the risk of infection.

2. Surgical treatments will, in some instances, produce pain after they are completed. Medical professionals will assist with medications and techniques to help patients manage surgery-related pain.

3. Procedures related to cancer, such as biopsies, blood draws, lumbar punctures, and laser treatments, can cause pain.

No matter what the cause, most types of cancer pain can be managed with drug and non-drug therapies. It's important to understand, too, that pain can undermine a patient's ability to fight cancer. A patient's appetite may diminish; therefore, the patient may not receive sufficient nutrition to retain energy. This leads to exhaustion and feelings of sadness and depression. As this cycle continues, a person is worn down gradually and may become more vulnerable to infection, and the ability to withstand necessary cancer treatments may diminish.

Missouri health-care professionals have coordinated efforts to address pain by forming the Missouri Pain Initiative. This is a statewide, interdisciplinary, nonprofit organization whose mission is to enhance quality of life through improvement in the quality of care provided to persons in pain through advocacy and education of people involved in pain treatment: patients, families, health-care professionals, the public, and policy makers.

Source: http://www.cancer-pain.org/

End of Life Care

Cancer control includes helping improve the quality of life of those living with cancer, including those who will not ultimately be cured. Impairment of quality of life may be due to cancer itself, or due to either the side effects or complications of treatment or the psychological impact of the presence of cancer in the body. Minimizing this impairment and maximizing quality of life are the focus of two branches of oncology called supportive oncology and palliative care (including end of life care). Supportive oncology focuses on minimizing side effects and toxicity during and immediately after cancer treatments, while palliative and end of life care focus on treating symptoms in those living with cancer or treatment related problems after treatment is completed. Either approach must include a multidisciplinary team and must encompass both pharmacologic and non-pharmacologic interventions. Examples of targeted symptoms in supportive oncology and palliative/end of life care include pain, nausea, vomiting, constipation, diarrhea, shortness of breath, weakness, anxiety, and depression, and all the symptoms are quite treatable in most cases. The care in this setting must be patient-centered, reflecting the person's values, wishes, and goals in the context of compassionate truth-telling by the care team. This patient-centered approach may include desired limits to care such as advanced directives and "Do Not Resuscitate" orders. For most persons who are not cured, hospice care will be incorporated as the best plan of care for the remaining time once anti-cancer treatment is no longer beneficial or medically indicated. In Missouri, all these services and types of care are available, but much progress is needed to inform the public and assure access and information for all Missourians.

"FACT: You have a right to ask for pain relief. In fact, telling the doctor or nurse about pain is what all patients SHOULD do. The sooner you speak up, the better. It's often easier to control pain in its early stages, before it becomes severe."

Patients often worry about having pain from cancer.
-Most pain can be controlled.
-Communication is important.
-Pain can be measured.
-You and your health-care providers can work together to control pain.

National Cancer Institute

What You Can Do To Fight Cancer In Missouri?

The Missouri Cancer Plan identifies broad goals to reduce the burden of cancer. To accomplish these goals, **everyone** needs to be involved. **What can you do?** Listed below are examples that each of us can begin to do right now toward the mission of making cancer history for all Missourians.

What you can do if you are:

...a Hospital

You can:

- Assure that your cancer cases are reported in a timely manner.
- Provide meeting space for cancer support groups.
- Collaborate to sponsor community screening and education programs.
- Maintain American College of Surgeons membership.

...a Local Public Health Department

You can:

- Provide cancer awareness information and data to citizens and groups.
- Collaborate in community-based coalitions.
- Work with physicians to promote screening programs & case reporting.
- Provide space for community survivor support groups.
- Access community needs and implement policy and environmental changes to reduce cancer risks.
- Assure access to care for uninsured and underinsured.

...a Community-Based Organization

You can:

- Provide cancer awareness information to constituents.
- Promote cancer screening among clients.
- Encourage participation in clinical trials.
- Collaborate to provide community prevention programs.

...a Professional Organization

You can:

- Provide continuing education credits on cancer topics.
- Include clinical trials information in meeting agendas.
- Form speakers' bureaus to provide cancer education.
- Train facilitators for survivor support groups.

...an Employer

You can:

- Establish a smokefree work place policy.
- Provide healthy foods in vending machines and cafeterias.
- Encourage employees to increase physical activity.
- Collaborate with hospitals to host screening events.
- Provide health insurance coverage.

...a School or University

You can:

- Include cancer prevention messages in health classes.
- Provide healthy foods in vending machines and cafeterias.
- Increase physical education requirements.
- Make your entire campus a smokefree environment.

...a Faith-based Organization

You can:

- Provide cancer prevention information to members.
- Collaborate with other community-based groups.
- Learn how to provide healthy pot-lucks and meeting meals.
- Open your building for walking clubs in cold weather.
- Encourage members to get cancer screening tests on time.

...a Physician

You can:

- Make sure patients get appropriate cancer screening tests.
- Refer patients to smoking cessation classes and nutrition programs.
- Be sure your cancer cases are reported in a timely manner.
- Find out how to enroll patients in clinical trials.
- Make earlier referrals to hospice for end of life care.

...a Missourian

You can:

- Avoid all tobacco and secondhand smoke.
- Eat a nutritious and balanced diet and maintain a healthy weight.
- Increase your daily physical activity.
- Know when to be screened and obtain screenings on schedule.
- Support smokefree environments.
- If diagnosed, consider enrolling in a clinical trial.
- Show your support and care for those who are diagnosed.
- Volunteer with your hospital, health department, faith community or local groups who support cancer control efforts.

Missouri Cancer Consortium Members

Anderson, Clay, M.D.
Associate Professor of Clinical Medicine, Director of Clinical Services, Ellis Fischel Cancer Center / University of Missouri health-care

Anderson, Tammy
Senior Secretary, DHSS Cancer Control Unit & Missouri Cancer Consortium

Barshis, Vicky, LCSW, OSW-C
Patient Services Manager, Leukemia & Lymphoma Society – Gateway Chapter

Bowles, Bonnie
Executive Director, Missouri Association of Osteopathic Physicians and Surgeons

Bukstein, Michael, M.D.
American College of Surgeons, Hannibal Regional Hospital

Burnett, Sharon, RN, BSN, CCRN
Director, Clinical & Professional Advocacy, Missouri Hospital Association

Carr, Barbara
Project Director, NAPNAP (National Association of Pediatric Nurse Practitioners)

Coletti, Maryann, RN
Government Relations / Patient Advocate, Alvin J. Siteman Cancer Center at Washington University School of Medicine and Barnes-Jewish Hospital

Corrado, Joe, M.D.
American College of Surgeons, State Commission on Cancer

Cowan, Stan
Community Policy Specialist, DHSS Health Promotion Unit

Davis, Cathy, RNC, ANP
UAW – Ford Community health-care Initiatives

Duitsman, Dalen, Ph.D., MPH
Professor, Southwest Missouri State University / Director, Ozark Public Health Institute

Duitsman, Pam
Director of Detection & Treatment, Heartland Division – American Cancer Society

Ewert, Diane
Executive Director, American Academy of Family Physicians

Fagin, Ileane
St. Louis Breast Cancer Coalition

Fleenor, Lizabeth
Director of Communications, Missouri State Medicine Association

Freedman, Barry
Vice President – Community Initiatives, American Lung Association of Missouri

Gaier, Amy
Project Director, National Cancer Institute's Cancer Information Service, Heartland Region

Guccione, Dot, RN, MBA, OCN
Co-Executive Director, Missouri Cancer Coalition

Gurley, William (Bill)
The Prostate Cancer Connection – St. Louis Prostate Cancer Connection

Heckathorn, Peg, RN, M.Ed.
Lymphedema Project Coordinator, MU Sinclair School of Nursing

Heisler, Sue
Program Manager, DHSS Comprehensive Cancer Control Program

Hilton, Sue
Missouri Family Health Council

Jahnige-Mathews, Katherine, M.D.
Community Outreach Coordinator, Barnes-Jewish Hospital – Washington University School of Medicine

Johnson, Ed
Health Initiatives, American Cancer Society

King, Mary Jane
Research Analyst, DHSS Surveillance and Epidemiology

Koeppen, Michelle, RN, MSN, AOCN
Director, Division of Cancer Resources, The Cancer Institute

Ladd, Lori, MSN, APRN, BC
Medical Liaison, Missouri Pain Initiative

Lindsey, Pat, MA
Program Director, Tobacco Prevention Center, St. Louis University, School of Public Health

Meachum-Cain, Glenda, MS
Assistant Chief, DHSS Office of Minority Health

Nenninger, Jutta, MBA
Administrator, St. Louis University – Division of Hematology and Oncology and Co-Executive Director – Missouri Cancer Coalition

Rich, Vangie
R. A. Bloch Cancer Foundation

Ronan, Marianne
Program Director, DHSS Cancer Control Unit

Schootman, Mario, Ph.D.
Alvin J. Siteman Cancer Center Washington, University School of Medicine and Barnes-Jewish Hospital

Turner, Sharon, MSW, MPA
National Cancer Institute's Cancer Information Service, Partnership Program Manager, Heartland Region

Wilson, Lorna
Executive Director, Missouri Association of Local Public Health Agencies

Zachary, Iris, RHIT, CTR
Missouri State Tumor Registrars Association

Websites for Information on Cancer Related Topics

Topic	Listing
Biology of cancer/treatments	www.cancerquest.emory.edu
Cancer (General)	www.cdc.gov/cancer www.cancer.gov www.cancer.org www.dhss.mo.gov www.blochcancer.org www.asco.org www.siteman.wustl.edu www.kccancer.com www.mocancercoalition.org
Cervical Cancer	www.arhp.org http://cme.asccp.org/home/home.cfm
Clinical Trials	www.trialcheck.org/cancertrialshelp/cancertrialshelp.aspx www.cancer.gov www.cancer.org
Colorectal	www.colorectal-cancer.net/twentyfive.htm www.ccalliance.org/march2004/index.html
Community	www.thecommunityguide.org
end of life	http://www.ago.mo.gov/publications/lifechoices.htm
Evidence-based Program Planning	www.cancercontrolplanet.cancer.gov
Lymphoma, Leukemia, Myeloma	www.lls.org/hm_lls
Pain	www.cancer-pain.org www.missouripain.org
Palliative Care	www.acponline.org/public/h_care/contents.htm
Radon	www.dhss.mo.gov/ehcdp/radon_facts.htm
Tobacco & Secondhand Smoke	http://epa.gov/iaq/pubs/etsbro.html www.lungusa.org/tobacco/secondhand_factsheet99.html www.smokingorhealth.org/index.php www.smokelessstates.org www.web.mhanet.com www.ttac.org http://www.dhss.mo.gov/SmokingAndTobacco/index.html
Cancer Statistics	www.cdc.gov/cancer/npcr/uscs/2000/index.htm http://.progressreport.cancer.gov www.dhss.mo.gov http://mcr.umh.edu

Sources of Statistics

Cancer Deaths and Death Rates

Data on the number of deaths nationally were obtained from the National Center for Health Statistics (NCHS) at the Centers for Disease Control and Prevention. The American Cancer Society calculated the numbers of U.S. cancer deaths expected to occur in 2004 by fitting the numbers of cancer deaths for 1969 through 2001 to a statistical model.

The cancer deaths for Missouri were obtained from the Missouri Department of Health and Senior Services (DHSS). Most of the counts were compiled by the Missouri Cancer Registry (MCR) from files provided by the Center for Health Information Management and Evaluation (CHIME). Some counts and rates were obtained from the Missouri Information for Community Assessment (MICA) system maintained by CHIME on the DHSS website (www.dhss.mo.gov) under "Data." MICA is an interactive system that allows users to create custom tables of data on various topics including deaths and new cancer cases. Tables can reflect age, race, sex, and place of residence.

MCR and MICA counts can differ slightly from each other for two reasons: 1) MCR includes deaths which are reported after the cut-off date for the annual file used for MICA, and 2) MCR and MICA use slightly different criteria for some groups of cancers, including lung/bronchus/trachea and colon/rectum/anus. MCR uses criteria from the National Cancer Institute/SEER. MICA's come from NCHS.

The years 1999-2000 were used in order to make comparisons with the most recent national mortality data, while not using data prior to the 1999 revision of the International Classification of Diseases.

Mortality rates (death rates) are defined as the number of people per 100,000 dying of a disease during a time period. Missouri cancer death rates in this publication are based on counts of cancer deaths described above and population data from the U.S. Census Bureau. Mortality rates in this publication are age-adjusted to the 2000 U.S. standard population to allow comparisons across populations with different age distributions. These rates should only be compared to other rates that are age-adjusted to the U.S. 2000 standard population.

New Cancer Cases and Rates

The estimated number of new U.S. cancer cases is calculated by the American Cancer Society by estimating the numbers of cancer cases that occurred each year from 1979 through 2000 and fitting these estimates to a statistical model that forecasts the number of cases expected to occur in 2004. The estimated number of cases for 1979 through 2000 is calculated using cancer incidence rates from states and cities of the United States included in the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program and population data collected by the U.S. Census Bureau. The SEER program is a collection of cancer registries covering about 10% of the U.S. population, including Connecticut, Hawaii, Iowa, Utah, and New Mexico as well as the metropolitan areas of San Francisco, Detroit, Atlanta, and Seattle-Puget Sound.

The numbers of new Missouri cancer cases are obtained from the Missouri Cancer Registry from 1996 through 2000. The Missouri Cancer Registry is a collaboration between the Missouri Department of Health and Senior Services and the University of Missouri – Columbia.

Incidence rates are defined as the number of people per 100,000 who are diagnosed with cancer during a given time period. For this publication, incidence rates were calculated using data on cancer cases collected by the SEER program and the Missouri Cancer Registry with population data collected by the U.S. Census Bureau. Incidence rates in this publication are age-adjusted to the 2000 U.S. standard population to allow comparisons across populations with different age distributions. These rates should only be compared to other rates that are age-adjusted to the U.S. 2000 standard population.

Behavioral Risk Factor Surveillance System (BRFSS)

The Behavioral Risk Factor Surveillance System (BRFSS) is an ongoing telephone survey conducted by all state health departments, the District of Columbia, Puerto Rico, the Virgin Islands, and Guam with assistance from the Centers for Disease Control and Prevention. The BRFSS is the largest continuously conducted telephone health survey in the world. States use BRFSS data to track critical health problems and to develop and evaluate public health programs. The BRFSS is the primary source of information on the health-related behaviors of adults in this country. States use standard procedures to collect data through monthly telephone interviews with non-institutionalized adults 18 years or older. BRFSS interviewers ask questions related to behaviors that are associated with preventable chronic diseases, injuries, and infectious diseases. During 2001-2002, the Missouri BRFSS interviewed 8,908 Missourians regarding their behaviors, including 494 African Americans and 8,005 who were white.

County-level Survey

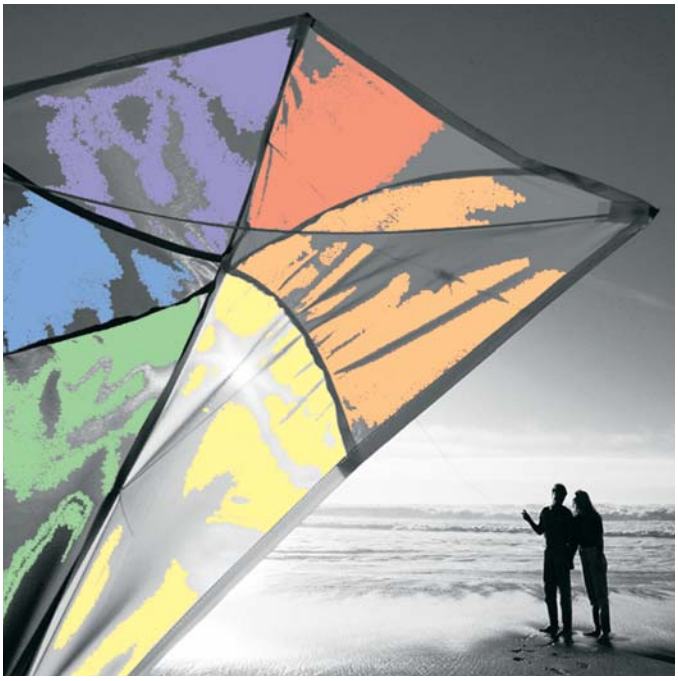
This 2003 survey conducted by the Missouri Department of Health and Senior Services used standard Behavioral Risk Factor Surveillance System methods and techniques to interview via telephone 15,000 Missourians in 114 counties and the City of St. Louis. The questionnaire contained questions from the BRFSS and the Adult Tobacco Survey as well as a few state-added questions.

References

- American Cancer Society. *Cancer prevention & early detection. Facts & figures 2003.* Atlanta, GA, 2002.
- American Cancer Society. *Breast cancer facts & figures 2003-2004.* Atlanta, GA, 2003.
- American Cancer Society. *Cancer facts & figures 2004.* Atlanta, GA, 2004.
- Breen N, Wagener DK, Brown ML, Davis WW, Ballard-Barbash R. Progress in cancer screening over a decade: Results of cancer screening from 1987, 1992, and 1998 National Health Interview Surveys. *J Natl Cancer Inst 93*, 1704-1713, 2001.
- Institute of Medicine. *Fulfilling the potential of cancer prevention and early detection.* National Academies Press, Washington, DC, 2003.
- National Cancer Institute Cancer Information Services. *Cancer progress report, 2001.* National Institutes of Health, US Department of Health and Senior Services. NIH Publication No. 02-5045.
- Schottenfeld D, Fraumeni JF (Eds.). *Cancer epidemiology and prevention.* Oxford University Press; 2nd edition, 1996.
- Swan J, Breen N, Coates RJ, Rimer BK, Lee NC. Progress in cancer screening practices in the United States. Results from the 2000 National Health Interview Survey. *Cancer 97*, 1528-1540, 2003.
- Weir HK, Thun MJ, Henkey BF, Ries LAG, Howe HL, Wingo PA, Jemal A, Ward E, Anderson RN, Edwards BK. Annual report to the nation on the status of cancer, 1975-2000, featuring the uses of surveillance data for cancer prevention and control. *J Natl Cancer Inst 95*, 1276-1299, 2003.
- Wilett W. Cancer prevention and early detection. *Cancer Epidemiol Biomarkers Prev 12*, 252s, 2003 (supplement).

NOTE: Please refer to *The Burden of Cancer in Missouri, Cancer Facts About Missouri Right Now, 2004* for more specific data and information regarding types of cancer in Missouri. A copy can be obtained by contacting the Missouri Department of Health and Senior Services, Cancer Control Unit, 920 Wildwood, Jefferson City, MO 65102, phone (573) 522-2840.

The REALITY of CANCER in MISSOURI



The Missouri Department of Health and Senior Services Comprehensive Cancer Control program, in collaboration with the Missouri Cancer Consortium, is committed to decrease the number of new cases of cancer, to increase the survivorship of cancer patients, and to better inform all citizens about the reality of cancer.

Three out of four Missouri families are affected by cancer. Risks may be reduced and survival increased by the following suggestions:

Avoid tobacco products and second-hand smoke.

Obtain cancer screenings as recommended.

Eat a nutritious and balanced diet.

Comply with recommended treatment or seek help with compliance.

Include about 30 minutes of physical activity daily.

For more information about cancer control, please contact the Missouri Department of Health and Senior Services Comprehensive Cancer Control program at (573) 522-2840.