Kansas Cancer Prevention and Control Plan

2017-2021

Kansas Cancer Partnership

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Kansas

Department of Health and Environment

Dear Fellow Kansans:

As the Chair and Co-Chair of the Kansas Cancer Partnership (KCP), we are pleased to provide you with the 2017-2021 Kansas Cancer Prevention and Control Plan. This plan is the result of the collaboration among cancer stakeholders throughout Kansas. Achievement of the goals and objectives presented here will reduce the burden and suffering from cancer and enhance the lives of cancer survivors and their families.

Significant accomplishments were made through the work of individuals and agencies since the release of the previous Kansas cancer plan in 2012, yet more work remains. To echo the 2016 National Cancer Moonshot Initiative, we look forward to working with Kansans toward unprecedented improvements in prevention, diagnosis, and treatment of cancer.

The 2017-2021 plan outlines goals and objectives along a cancer continuum. Goals include:

Cross-Cutting: Build overall capacity for cancer prevention and control in Kansas

Prevention: Prevent cancer from occurring or recurring

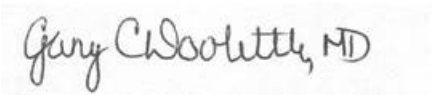
Early Detection and Diagnosis: Detect cancer in its earliest stage through early detection and a timely, definitive diagnosis

Post-Diagnosis and Quality of Life: Assure the highest quality of life during and after treatment for Kansans who have been diagnosed with cancer

Cancer touches many Kansans every day. We have both personally been diagnosed with cancer, and were fortunate to have excellent support systems of family and friends, access to quality cancer care and health insurance. These are all factors that reduce the burden of a cancer diagnosis on the individual, their family and on Kansas. All Kansans should have the same opportunities.

The Kansas Cancer Partnership fosters the development, coordination and implementation of cancer prevention and control in Kansas. We encourage new members to take an active role in working with us on the goals, objectives and strategies in this plan. Please visit www.KSCancerPartnership.org for information on becoming a member and join us to address the burden of cancer in Kansas.

Sincerely,



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Capitol Federal Masonic Professor,
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Introduction

Purpose

The Kansas Cancer Prevention and Control Plan is a road map for addressing cancer in the following ways:

- Addresses issues common across all cancers and highlights cancers with the highest incidence and mortality in Kansas.
- Presents methods that have worked in similar communities to prevent, diagnose and treat cancers, and improve survivor quality of life.
- Promotes activities that increase healthy choices, cancer screening, access to care and health equity.

Kansas Cancer Partnership (KCP)

Comprehensive Cancer Prevention and Control is an approach supported by the Centers for Disease Control and Prevention (CDC) that brings together key partners and organizations to form coalitions dedicated to preventing and controlling cancer. State and regional coalitions include diverse partners from all areas of the community who commit time and resources to address cancer in their state. Coalitions are charged with developing a plan to reduce the number of community members who get or die from cancer.

The Kansas Cancer Partnership (KCP) coordinates partners to identify and prioritize goals and objectives to prevent cancer from occurring, detect cancer at its earliest stages, assure access to high quality cancer treatment and improve the quality of life of cancer patients and survivors as they live with and beyond the disease. The state cancer plan and its companion document, Burden of Cancer in Kansas, January 2017, inform work of KCP, its workgroups and regional coalitions. KCP recognizes the contributions of the many individuals, advocates and agencies working on cancer initiatives that are and are not represented in this plan.

State Cancer Plan Implementation

The key to a successful plan lies in implementation. KCP workgroups and regional coalitions select priority objectives annually, using criteria such as need, potential impact and likelihood for success. Ultimately, state plan implementation will increase use of evidence-based approaches, data for planning and evaluation, clinical-community linkages, health systems change and quality clinical preventive services. Baseline data and five year targets will be used for evaluation of strategies in the plan.

> *The Kansas public health system is committed to continual improvement and working together to prevent disease and injury, help people manage existing health conditions and promote healthy behaviors. In keeping with this commitment, the KDHE Cancer Prevention and Control Program supports Kansas Cancer Partnership efforts to implement this state plan by providing staff support, training and technical assistance, assessment of epidemiologic data, and evaluation of intervention effectiveness to accomplish the goal of reducing the incidence and burden of cancer in Kansas.*
>
> *Susan Mosier, MD, MBA, FACS*
> *KDHE Secretary and State Health Officer*

KCP Membership

KCP is an inclusive coalition that welcomes new members who want to take an active role in working on the goals, objectives and strategies in the state cancer plan. KCP meets in-person twice a year, with workgroups meeting more often by video conferencing or conference call. Information about KCP membership may be found at www.KSCancerPartnership.org.

Regional Coalitions

Regional coalitions conduct strategic planning to select locally relevant priorities from the state cancer plan and design interventions specific to the unique characteristics of their regions. Regional coalitions meet approximately monthly by phone or in person. In 2017 there were regional coalitions in the south central, south east and north central areas of the state, with a fourth planned in south west Kansas.

Goals and Objectives (Overview)

Cross-Cutting Issues:

Build overall capacity for cancer prevention and control in Kansas

1. **Health Equity** - Increase health equity related to race, ethnicity, income or population density by including at least one strategy for each state plan objective that will improve health equity.
2. **Financial Burden** - Decrease the number of Kansans who report financial problems as a barrier to accessing cancer care.
3. **Clinical Trials** - Increase the percentage of Kansas adults 18 years old and older who have been diagnosed with cancer and participated in a cancer-related clinical trial.
4. **Genetics** - Increase the number of adult Kansans who know their family history of cancer back through second-degree relatives (parents, siblings, children, grandparents, aunts, uncles).
5. **Patient Navigation** - Increase the number of cancer patient navigators who participate in the state navigation network to promote high-quality cancer care from early detection through treatment and survivorship.

Prevention:

Prevent cancer from occurring or recurring

1. **Fruits & Vegetables** - Increase consumption of fruits and vegetables among adults and adolescents.
2. **Human Papilloma Virus (HPV)** - Increase HPV immunization rates to prevent HPV-related cancers.
3. **Physical Activity** - Increase the percentage of adults and adolescents who participate in physical activity.
4. **Radon** - Increase the percent of Kansas homes tested and mitigated for radon during purchase or construction.
5. **Tobacco Use:**
   a. **Adults** - Reduce the percentage of adults who use cigarettes, e-cigarettes and any tobacco products.
   b. **High School Students** - Reduce the percentage of high school students who use cigarettes, e-cigarettes and any tobacco products.
6. **Ultraviolet (UV) Radiation**
   a. **Sunburn** - Reduce the percentage of Kansans that report sunburn.
   b. **Indoor Tanning** - Reduce the percentage of Kansans that use indoor tanning devices.

Early Detection and Diagnosis:

Detect cancer in its earliest stage through early detection and a timely, definitive diagnosis

1. **Breast Biopsies** - Increase the percentage of breast biopsies by percutaneous biopsy vs. excisional surgery for breast cancer diagnosis.
2. **Breast Cancer** - Increase the percentage of age-appropriate women who had a discussion with their health care provider about breast cancer screening.
3. **Cervical Cancer** - Increase the percentage of Kansas women who receive cervical cancer screening (i.e., Pap test) based on nationally recognized guidelines.
4. **Colorectal Cancer** - Increase the percentage of Kansas adults (50-75) using one of the screening options recommended for colorectal cancer based on nationally recognized guidelines.
5. **Lung Cancer** - Increase the percentage of high risk population (current and former smokers aged 55 to 74 year olds) who had a discussion with their provider about lung cancer screening.
6. **Prostate Cancer** - Increase the percentage of men aged 50 to 69 who had a discussion with their provider about prostate cancer screening.

Post-Diagnosis and Quality of Life throughout the Cancer Journey:

Assure the highest quality of life for Kansans who have been diagnosed with cancer during and after treatment

1. **Quality of Life** - Improve the physical and mental health of people who have had a cancer diagnosis, as well as that of their care providers.
2. **Treatment Summary** - Increase the number of cancer patients with curative intent (i.e., seeking cancer-specific treatment) and who have completed therapy (other than hormonal) who report receiving treatment summaries and survivorship care plans.
3. **Palliative and Hospice Care** - Improve Kansas scorecard for access to Palliative Care services, as measured by Center to Advance Palliative Care (CAPC).
4. **Transportable Physician Orders for Patient Preferences (TPOPP)** - Increase the number of health systems in Kansas that have an infrastructure for increasing understanding of and honoring treatment preferences for seriously ill patients as they move across the continuum of care.

Cross Cutting Issues

Goal: Build overall capacity for cancer prevention and control in Kansas

The Kansas Cancer Partnership (KCP) identified cross-cutting issues (e.g., health equity, financial burden of cancer, clinical trials, genetics and patient navigation) that have an impact across the cancer continuum of cancer prevention, early detection, diagnosis, treatment and post-treatment quality of life.

Health Equity

Achieving health equity is important for ensuring progress on objectives related to prevention, early detection, diagnosis, treatment and post-treatment quality of life. Socioeconomic factors are associated with cancer through health risk behaviors such as tobacco use and poor nutrition. Income, education and health insurance coverage influence access to appropriate early detection, treatment and palliative care. Low-income men, women and members of minority groups who have little or no health insurance coverage are more likely to be diagnosed with cancer at later stages, when survival times are shorter and treatment is more costly.[1] The current expectation for cancer survivorship is five years following diagnosis for about two out of every three people diagnosed, but health disparities influence these survival rates.[2]

The table on the next page summarizes characteristics of populations experiencing health disparities. This can serve as a guide for focusing work to achieve health equity. Throughout this state cancer plan, strategies listed under each objective include recommendations for evidence-based activities designed to increase health equity. KCP health equity and other workgroups will ensure current disparity data are used to develop or adapt culturally specific and linguistically appropriate interventions. Regional Cancer Coalitions will use local data as available to design interventions specific to unique characteristics of populations in their regions. Current Regional Cancer Coalitions are located in South Central (Wichita), South East (Pittsburg) and North Central (Salina) areas, with a fourth planned for South West Kansas.

[1] American Cancer Society. *Cancer Facts & Figures 2016*. Atlanta: American Cancer Society; 2016. Accessed through https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2016/cancer-facts-and-figures-2016.pdf.

[2] Centers for Disease Control and Prevention. *Cancer Survivorship: Basic Information for Cancer Survivors*. Accessed through https://www.cdc.gov/cancer/survivorship/basic_info/index.htm

Disparities in Cancer Screening, Incidence and Mortality by Selected Sociodemographic Characteristics

	Annual Household Income		Education Level		Health Insurance Status	Population Density		Race / Ethinicity			Gender	
	< $15,000	< $50,000	< high school	≤ high school	Uninsured	Frontier/ Rural	Urban/ Semi-urban	African American	Hispanic	Non-Hispanic	Male	Female
Screening												
Colorectal	✓		✓	✓	✓	✓			✓			
Breast	✓		✓		✓	✓						
Cervical	✓		✓		✓							
Incidence (overall)												
Overall							✓	✓		✓	✓	
Colorectal						✓		✓		✓	✓	
Breast							✓			✓		
Cervical						✓			✓			
Prostate							✓	✓		✓		
Lung							✓	✓		✓	✓	
Melanoma							✓			✓	✓	
Incidence (late stage)												
Colorectal						✓		✓			✓	
Breast								✓		✓		
Cervical												
Prostate							✓	✓				
Lung							✓	✓		✓	✓	
Melanoma											✓	
Mortality												
Overall								✓		✓	✓	
Colorectal						✓		✓			✓	
Breast								✓		✓		
Cervical												
Prostate								✓		✓		
Lung								✓		✓		
Melanoma											✓	

Note - cells shaded in grey indicate data are not available, or sufficient counts are not available to calculate reliable rates.
- disparities for late stage incidence are only presented by cancer-specific site and not overall.
- Kansas-specific data for the American Indian/Alaska Native (AI/AN) population are insufficient to include in the table. However, national data indicate that the AI/AN population experiences health disparities.

Screening data – Kansas BRFSS (USPSTF guideline)
Incidence data – Kansas Cancer Registry
Mortality data – Kansas Vital Statistics

In the table above, a checkmark points to a population that experiences a significant disparity in the form of lower cancer screening rates, higher cancer incidence or higher cancer mortality for that specific sociodemographic characteristic. For example, checkmarks in the <$50,000 annual household income, ≤ high school education, uninsured, frontier/rural, Hispanic and male columns tell us that each of these distinct populations would benefit from evidence-based interventions to increase colorectal screening rates among that subgroup.

Health Equity

Objective 1. Health Equity – Increase health equity related to race, ethnicity, income or population density by including at least one strategy for each state plan objective that will improve health equity.

Performance Measure (KCP minutes)

Number of implemented and evaluated state plan strategies that were specifically designed to reduce health disparities (income, education level, insurance status, population density, race/ethnicity, gender)

Baseline	5 Year Target
6	8

Strategies

1. Increase data sources and methodologies used to establish baselines and five-year targets for monitoring improvement in health equity.
2. Increase state capacity to evaluate interventions designed to reduce health disparities.
3. Prioritize implementation of state plan strategies that will increase health equity.
4. Support primary care clinic implementation of the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) to identify social determinants of health, establish partnerships to target community-based regional and/or state level resources to improve health outcomes, increase health equity and contribute to standardized datasets at the organization and state levels.
5. Increase KCP membership to better reflect communities that experience health disparities.

Financial Burden

The financial costs of cancer care are a burden to people diagnosed with cancer, their families, and society as a whole. National expenditures associated with cancer have been steadily increasing in the United States with care for cancer survivors estimated at $125 billion in 2010 and increasing to at least $158 billion in 2020.[3] In Kansas, annual expenditures related to cancer are estimated to be $1,213,000,000 annually.[4]

As the population ages, cancer prevalence and the number of people treated for cancer will increase even if cancer incidence rates remain constant or decrease. Costs are also likely to increase as new, more advanced, and more expensive treatments are adopted as standards of care. Financial distress can lead to poor health outcomes, in part because patients may discontinue or fail to adhere to treatment. Patients experiencing financial distress rate their physical and mental health, social

[3] Mariotto, A. B., Yabroff, K. R., Shao, Y., Feuer, E. J., & Brown, M. L. (2011). *Projections of the Cost of Cancer Care in the United States: 2010-2020.* JNCI: 103(2), 117-128.

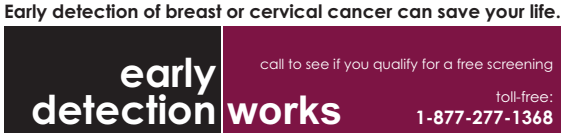
[4] Center for Disease Control and Prevention. *Chronic Disease Prevention and Health Promotion: Chronic Disease Cost Calculator Version 2.* Accessed through https://www.cdc.gov/chronicdisease/calculator/.

activities, and relationships poorly. The American Society of Clinical Oncology recommends that physicians and patients discuss the costs of care "openly and routinely." While most patients want to discuss costs with their physicians, few report having such discussions.

Steps to reduce financial hardship include health care team guidelines for talking with patients about treatment costs (beginning at the time of diagnosis), and patient and family education about financial resources and easily accessible financial counseling during and after treatment.[5]

> Out-of-pocket expenses might have such an impact on the cancer experience as to warrant a new term: "financial toxicity." Out-of-pocket expenses related to treatment are akin to physical toxicity, in that costs can diminish quality of life.
>
> *Zafar SY, Abernethy AP. Financial toxicity, Part I: a new name for a growing problem. Oncology (Williston Park). 2013 Feb;27(2):80-1, 149.*

Early Detection Works!



Staff members from a rural Federally Qualified Health Center (FQHC) referred a 45-year-old Hispanic woman to the Early Detection Works* (EDW) breast and cervical cancer screening and diagnostic program to enroll for a free breast exam and mammogram. EDW, its related partners and providers help decrease financial barriers to breast cancer screening, diagnosis and treatment for women across Kansas. The woman had never had a mammogram and had no complaints. The clinical breast exam was normal and a screening mammogram ordered. The radiologist recommended a diagnostic left mammogram after identifying a group of microcalcifications. A diagnostic mammogram was done a few days later and surgical consult followed within 10 days. Five days later the patient had a breast biopsy that revealed ductal carcinoma in situ (DCIS).

The patient received a lumpectomy three weeks later and no longer has evidence of disease. Because staff members at the FQHC were proactive and encouraged this young woman to enroll in EDW, she received her diagnosis at an earlier, lest costly and easier to treat stage.

* Early Detection Works (EDW) pays for breast and cervical cancer screening and diagnostics for Kansas women who are 45 to 64 years old (or younger with symptoms), low income, and who do not have health insurance. These services are supported by a combination of state, federal, Susan G. Komen for the Cure and American Cancer Society funding sources. Women who are Kansas residents and diagnosed with cancer through EDW are referred to KanCare (Kansas Medicaid) for treatment.

[5] Financial Distress among Cancer Survivors, RTI & LIVESTRONG®, 8th Biennial Cancer Survivorship Research Conference, Washington DC, June 16-18, 2016 (poster presentation).

Objective 2. Financial Burden – Decrease the number of Kansans who report financial problems as a barrier to accessing cancer care.

Performance Measures	Baseline	5 Year Target
Kansans reporting not seeing a doctor because of cost in the past 12 months (2015 KS BRFSS)	11%	6%
Kansans reporting financial barriers to accessing cancer screening services (KS BRFSS)	TBD	TBD
Kansans reporting financial barriers to accessing cancer diagnostic services (KS BRFSS)	TBD	TBD
Kansans reporting financial barriers to beginning, adhering to, or completing cancer treatment (KS BRFSS)	TBD	TBD

Strategies

1. Collaborate with community health workers, promotoras de salud (Spanish term for community health workers) and patient navigators to improve awareness to lessen financial barriers to cancer services (i.e., screening, diagnosis, treatment, follow-up care).
2. Support and enhance effective programs (e.g., Early Detection Works) that increase access to cancer screening, diagnosis, treatment and follow up services.
3. Develop and support a user-friendly web page in English and Spanish for patients and providers with suggestions for conversations about insurance coverage, out of pocket costs and treatment options so patients are able to make informed decisions about their cancer treatment.
4. Identify partners that have contact with the newly unemployed and/or newly uninsured (e.g., Kansas Workforce Centers) to provide information on resources for accessing health services while uninsured.
5. Develop and provide free professional education with CME/CNE's that includes information on cultural competency, financial assistance, financial toxicity and treatment outcomes.
6. Assess the number of facilities that implement strategies to reduce financial burden (e.g., dedicated financial counselor) and document successful models for replication.
7. Educate patients and providers about insurance mandates to ensure patients are not billed for wellness and preventive services.
8. Conduct a policy review to identify a range of effective strategies for increasing access to wellness and prevention services, screening, diagnosis, treatment and follow-up care.

Clinical Trials

Some clinical trials study treatments, while others look at new ways to prevent, detect, diagnose and learn the extent of disease. Other trials focus on how to improve the quality of life of those living with cancer. Many trials are drug trials, and some test other forms of treatment such as new surgery, radiation therapy techniques or complementary/alternative medicines.

The biggest barrier to the completion of clinical trial studies is that not enough people participate. Fewer than 5 percent of adults with cancer take part in a clinical trial. Clinical trials are much more commonly used to treat children with cancer. In fact, 60 percent of children under age 15 participate in clinical trials. This is one reason that survival rates for childhood cancer have increased so dramatically in the last few decades. The main reason people give for not taking part in a clinical trial is that they did not know the studies were an option for them.[6]

> Clinical trials test how new medications or treatments work. Patients who participate have access to these new drugs and treatments. By joining a clinical trial, patients can contribute to the medical knowledge that may improve their cancer care and help future patients battle the disease.
>
> *Midwest Cancer Alliance: Cancer Clinical Trials*

Objective 3. Clinical Trials - Increase the percentage of Kansas adults 18 years old and older who have been diagnosed with cancer and participated in a cancer-related clinical trial.

Performance Measures (2015 KS BRFSS)	Baseline	5 Year Target
Kansans whose health care provider has ever talked to them about participating in a clinical trial	4%	10%
Kansans ever diagnosed with cancer who were enrolled in a cancer clinical trial arranged by their Kansas health care provider	31%	37%

Strategies

1. Map clinical trial participation by cancer treatment center in Kansas, determine areas of need and tailor provider and patient education to increase participation.
2. Develop and provide free professional education with CME/CNE's that includes information on accessing clinical trials.
3. Implement culturally appropriate messaging about cancer clinical trials to influence patient "culture" shift towards acceptance of clinical trials.
4. Work with patient groups at cancer treatment centers to provide culturally competent patient education about clinical trials.

[6] American Cancer Society, 2016. *Clinical Trials: What You Need to Know.* Accessed through https://www.cancer.org/treatment/treatments-and-side-effects/clinical-trials/what-you-need-to-know.html

Access to Clinical Trials

Vicky McDowell - Lucas, KS

More than four years ago my primary physician discovered cancer in my liver, and I started on conventional chemotherapy. Several months later, we found out it was actually breast cancer metastasized to the liver. We changed to a combination of several different types of chemotherapy for the next three years. The cancer didn't get worse, but it didn't get much better either.

Before this journey with cancer, I have to admit some ignorance of clinical trials – I thought one group was a test group, and the second group was a placebo group. Then I researched new therapies and saw that by participating in a clinical trial, patients have access to new treatments not available elsewhere. Becoming educated about the true nature of clinical trials and having access to new treatment was reassuring.

Last spring, my tumor marker numbers started rising, indicating possible cancer spread. We decided the current strategy was becoming ineffective and we needed to do something different. I was very pleased when a clinical trial for dosage determination of an already approved drug was offered.

Before I started the clinical trial, I travelled nearly 250 miles to Kansas City to receive treatment at the University of Kansas Cancer Center (KUCC). But it turns out, through the Midwest Cancer Alliance, KUCC partners with cancer centers across the state and so I was able to continue my treatment at Heartland Cancer Center in Great Bend, only about 60 miles from home!

Clinical trials are so important for the collection of data for research because you never know when an exciting breakthrough occurs or leads to further innovations or explorations of treatments. And those treatments could be the answer for you and others.

Genetics

According to the National Cancer Institute, cancer genetics are related to all aspects of cancer management including prevention, screening and treatment. Cancer can be caused by many factors including genetic, environmental, medical and lifestyle factors. Knowledge of cancer genetics is rapidly improving understanding of cancer biology, identification of at-risk individuals, and establishment of treatment tailored to specific patient needs.

About 5 to 10 percent of all cancers result from an abnormal gene that is passed from generation to generation. Having a genetic risk does not mean that a person will develop cancer, and not having a known genetic risk doesn't mean that a person won't develop cancer. Cancer is such a common disease that most families have at least a few members who have had cancer. Sometimes this is not genetic, but is because family members have risk factors in common, such as tobacco use or obesity, which can increase cancer risk.[7]

[7] American Cancer Society, 2016. *Family Cancer Syndromes*. Accessed through https://www.cancer.org/cancer/cancer-causes/genetics/family-cancer-syndromes.html.

A woman's lifetime risk of developing breast and/or ovarian cancer is greatly increased if she inherits a harmful mutation in BRCA1 or BRCA2.

Breast cancer: About 12 percent of women in the general population will develop breast cancer sometime during their lives. By contrast, 55 to 65 percent of women who inherit a harmful BRCA1 mutation and around 45 percent of women who inherit a harmful BRCA2 mutation will develop breast cancer by age 70.

Ovarian cancer: About 1.3 percent of women in the general population will develop ovarian cancer sometime during their lives. By contrast, 39 percent of women who inherit a harmful BRCA1 mutation and 11 to 17 percent of women who inherit a harmful BRCA2 mutation will develop ovarian cancer by age 70.

National Cancer Institute; reviewed April 1, 2015

Objective 4. Genetics - Increase the number of adult Kansans who know their family history of cancer back through second-degree relatives (parents, siblings, children, grandparents, aunts, uncles).

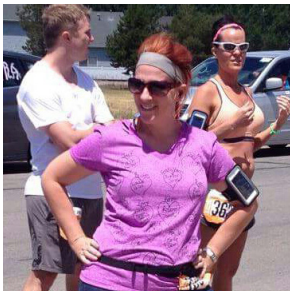
Performance Measures (2015 KS BRFSS)	Baseline	5 Year Target
Kansas adults who have collected specific health history information from their family members to share with their health providers	TBD	TBD
Kansans with family history of cancer who report that they have received genetic counseling (breast, ovarian or colorectal cancer)	24%	30%

Strategies

1. Educate the public about the role of genetic testing and genetic counseling in cancer detection, diagnosis and treatment.
2. Identify partners (e.g., Kansas Hispanic & Latino American Affairs Commission) willing to disseminate user-friendly tools for documenting family medical history.
3. Develop and provide free professional education with CMEs/CNEs that includes recommended guidelines for genetic testing and counseling, and deliver through educational settings used by primary care clinicians and oncology specialists.
4. Use consistent messaging to increase awareness about the importance of understanding family history related to cancer, tailoring strategies to populations without health insurance and those living in frontier counties.
5. Develop culturally appropriate and user-friendly resources on genetic testing and counseling for patients who have been identified at high risk.

Being a PREvivor

Julie Sanders



I am not a SURvivor – I am a PREvivor, meaning I never had cancer. I had genetic testing done in 2010 when I was 35 years old due to an extensive family history of breast and ovarian cancer. In four generations, it didn't skip one single female on my mother's side, and each generation, the cancer came at earlier ages. My test came back positive for the BRCA-2 gene, meaning I was 90 percent likely to develop cancer due to both genetic and familial risk. At the time I was only two years younger than my mother was when she developed cancer. In the next few months after I received my result, as I struggled with the decision of whether to undergo prophylactic surgeries, I developed a tumor. Luckily, it was benign, but it served as a big wake-up call that I had no time to lose. I had my double mastectomy and reconstructive surgeries as soon as I could, plus I underwent a total abdominal hysterectomy and oophorectomy. All of these surgeries occurred within nine months of each other. While this option was a lot to handle physically and emotionally, the thought that gave me strength is that if I had waited for cancer to come and get me, I'd be doing all of this plus chemotherapy, all the while wondering how long I would live. This way, I only had to deal with the pain, and eliminated much of the risk to my survival. Now, my risk of 90 percent is less than 2 percent. Those are some odds I'm willing to take.

My advice for anyone considering genetic testing is this: Know your options. A positive genetic test does not mean you have to have prophylactic surgeries; it only opens up a multitude of choices for prevention or early detection measures that allow peace of mind in choosing the best option for yourself. A negative test can also give peace of mind – not only in knowing your own personal risk is decreased, but in knowing that the gene cannot be passed on to your children. For a person already diagnosed with cancer, a genetic test will help the oncology team guide treatment and determine follow-up needs, and it helps the patient's family members decide if genetic testing is something they should consider as well.

I believe that getting the genetic test gave me the option to decide what quality of life I wanted to have, and I truly believe that prophylactic treatment SAVED my life. Mostly, I thank my mother - if she had not pioneered the testing of her own accord, I might not have been here today to write this piece. Her courage set the example for me to follow.

To read more about Julie's journey, visit www.KSCancerPartnership.org.

Patient Navigation

Some Kansans face significant barriers to accessing and completing cancer screening, diagnostics and treatment. Patient navigation is a strategy to reduce disparities by helping people overcome those barriers. The National Breast and Cervical Cancer Early Detection Program defines patient navigation as, “Individualized assistance offered to clients to help overcome healthcare system barriers and facilitate timely access to quality screening and diagnostics as well as initiation of treatment services for persons diagnosed with cancer.”

The Midwest Cancer Alliance (MCA) describes Patient Navigators as health care professionals who foster connections between cancer patients, their families and the resources necessary to address the educational, emotional and financial needs that come with a diagnosis. Navigators work to erase structural barriers to care and enhance knowledge by coaching patients and families through the community healthcare system.

Objective 5. Patient Navigation - Increase the number of cancer patient navigators who participate in a state navigation network to promote high-quality cancer care from early detection through treatment and survivorship.

Performance Measures	Baseline	5 Year Target
Number of members in the Midwest Cancer Alliance state navigation network (2017, MCA)	35	58
Number of certified Academy of Oncology Nurse & Patient Navigators in Kansas (2016, AONN)	2	25
Late stage cancer diagnosis (regional+distant) (2013 KCR cases per 100,000 persons)	202	197

Strategies

1. Collaborate with the state navigation network to promote use of the George Washington (GW) Cancer Institute’s free Barriers Assessment Tool to track and address patient barriers.
2. Distribute a statewide directory of cancer survivorship resources electronically to patient navigators and promote use of the directory to address patient needs.
3. Assess professional learning needs of patient navigators using the GW Cancer Institute Navigation Competency Self-Assessment Tool.
4. Provide professional development opportunities for patient navigators and community health workers to enhance core competencies for practice.
5. Promote training and certification for patient navigators (e.g., Academy of Oncology Nurse & Patient Navigators, GW Cancer Institute).

Team Spirit

Rhonda Hicks - 47, Wichita, KS

Rhonda is a mother of two, who helps at-risk high school and first-generation college students navigate the education system. You might say she actively cheers them on. When Rhonda was diagnosed with a very aggressive type of breast cancer (triple negative) in 2013, she was referred to a breast care specialist right away. One of the staff members was Terri Leschuk, nurse navigator, who helps guide patients through their cancer journey. Rhonda and Terri made an immediate connection as they realized they had been cheer squad members together in high school! Both the breast care specialist and Terri provided Rhonda with the information she needed to map out her course of treatment.

"They were knowledgeable and caring and delivered the information I needed in a way that spoke to my learning style," Rhonda shared. Rhonda chose aggressive treatment that included chemotherapy, surgery to remove both breasts, radiation and reconstruction. As challenging as this course of treatment was, she never lost confidence in the treatment plan that Terri helped her navigate.

Rhonda highlights three key tenets that helped her through her cancer journey:

1. *Find a scripture you can stand on – "I will not relax my hold on you." Hebrews 13:5*
2. *Seek, rather than avoid, information so you can make the best decisions possible.*
3. *Look for the treasure in your pain – reconnecting with Terri and developing new friendships with her care team.*

Rhonda appreciates the patient navigation services that she received, saying "I don't want anyone to go down this road, but the phenomenal care I received from start to finish brings tears to my eyes."

To read more about Rhonda's journey, visit www.KSCancerPartnership.org.

Prevention

Goal: Prevent cancer from occurring or recurring

Some risk factors for cancer cannot be avoided, such as genetics, age and gender. However, a person's risk of cancer can be reduced with healthy choices like avoiding tobacco exposure, limiting alcohol use, protecting skin from the sun, avoiding indoor tanning, eating a diet rich in fruits and vegetables and being physically active. The human papillomavirus (HPV) vaccine helps prevent most cervical cancers and other HPV-related cancers in both women and men, and the hepatitis B vaccine can lower liver cancer risk.

Fruits & Vegetables

The National Center for Health Statistics estimates that more than 70 percent of adults are overweight or obese in the U.S., resulting in increased risk of heart disease, stroke, type 2 diabetes and cancer – leading causes of preventable death. The known links between being overweight or obese and specific cancers are outlined below:

[8] Being overweight or obese is clearly linked with an increased risk of many cancers, including:

- Breast (in women past menopause)
- Colon and rectum
- Endometrium (lining of the uterus)
- Esophagus
- Kidney
- Pancreas

Being overweight or obese might also raise the risk of other cancers, such as:

- Gallbladder
- Liver
- Non-Hodgkin lymphoma
- Multiple myeloma
- Cervix
- Ovary
- Aggressive forms of prostate cancer

Objective 6. Fruits & Vegetables - Increase consumption of fruits and vegetables among adults and adolescents.

Performance Measures	Baseline	5 Year Target
Adults (2015 KS BRFSS):		
Consumed at least one fruit serving per day	56%	75%
Consumed at least one vegetable serving per day	78%	85%
High School Students (2013 KS YRBS):		
Consumed fruit in the past seven days	94%	100%
Consumed vegetables during the past seven days	95%	100%

Strategies

1. Collaborate with food policy councils in low income communities to promote policies to increase availability of healthy food and drink in worksites, schools, and childcare and public facilities.
2. Promote community garden initiatives in areas frequented by low income and senior populations.
3. Expand summer nutrition programs for low income school aged children.
4. Work with partners to identify and eliminate food deserts[9] (areas that lack access to affordable fruits, vegetables, whole grains, low-fat milk and other foods that make up the full range of a healthy diet) in communities with large low income and senior populations.
5. Increase the number of farmers' markets that include implementation of Supplemental Nutrition Assistance Program/Electronic Benefit Transfer, and Senior Farmers Market Nutrition Programs.

[8] National Cancer Institute, 2015. *Obesity and Cancer Fact sheet.* Accessed through https://www.cancer.gov/about-cancer/causes-prevention/risk/obesity/obesity-fact-sheet

[9] Centers for Disease Control and Prevention 2016. *A Look Inside Food Deserts.* Accessed through https://www.cdc.gov/features/FoodDeserts/index.html

Human Papilloma Virus (HPV)

In both women and men, HPV infection can cause anal cancer, mouth/throat cancer, and genital warts or warts in the throat. HPV infection can cause cervical, vaginal and vulvar cancers in women, and penile cancer in men. HPV vaccines are recommended for all 11- and 12-year-olds to protect against infection with the types of HPV that most commonly cause health problems. Women should get regular Pap tests in addition to receiving HPV vaccine.[10]

Objective 7. Human Papilloma Virus (HPV) - Increase HPV immunization rates to prevent HPV-related cancers.

Performance Measures (2015 NIS-Teen)	Baseline	5 Year Target
Adolescents who have recieved ≥ 1 HPV vaccine	52%	66%
Adolescents who are up to date on HPV vaccinations	36%	45%

Strategies

1. Increase the number of Kansas providers who complete provider assessment and feedback activities to increase clinic-level HPV vaccine rates.
2. Increase the number of providers and payer sources using reminder recall systems.
3. Develop and provide free professional education with CMEs/CNEs that includes the prevention value of HPV vaccination at appropriate ages, safety information and guidance on communication and messaging to parents.
4. Promote use of the Vaccines for Children Program to provide free vaccinations for uninsured adolescents from low income families.
5. Expand data sources for monitoring HPV and other vaccination rates through enhanced KS BRFSS questions.
6. Collaborate with Immunize Kansas Coalition and other partners to coordinate use of consistent messaging to increase public, parent and adolescent awareness about the value of HPV vaccines.

[10] HHS Vaccines.gov 2016. *HPV Vaccine*. Accessed through https://www.vaccines.gov/diseases/hpv/index.html

"I promised him that I would be his voice, for him."

Dana Montgomery - Hutchinson

On February 20, 2014, Dana lost her husband Kurtis to oropharyngeal cancer. In her personal story she states, "I promised him that I would be his voice, for him. Oral/head and neck cancer caused by the HPV is rapidly becoming more and more common. This is serious. Look it up, learn about it, learn what causes it, and learn what can make it worse. Here is what we have learned: HPV is prevalent in most of us at one point in time or another. Don't let this happen to your kids. This can be prevented, get vaccinated. Kurtis was adamant that not only girls be vaccinated but boys too. Educate yourself, educate others. Cancer sucks but cancer sucks worse when it can be prevented."

To read more about Dana and Kurtis's journey, visit www.KSCancerPartnership.org.

Physical Activity

Researchers at the National Cancer Institute and the American Cancer Society confirm the benefit of physical activity on cancer risk, and support physical activity's critical role in population-wide cancer prevention and control. Greater levels of leisure-time physical activity are associated with a lower risk of developing at least 13 different types of cancer.[11]

Environmental and policy approaches to increasing physical activity provide opportunities and support to help people be more active. These approaches may involve:

- Physical environment
- Social networks
- Organizational norms and policies
- Laws

Potential partners for increasing physical activity may include: public health professionals; community organizations; legislators; departments of parks, recreation, transportation and planning; the media; and coalitions such as Chronic Disease Alliance of Kansas, Kansas State Department of Education, Let's Move Active Kansas Schools, Wellness Policy and the Governor's Council on Fitness.[12]

Objective 8. Physical Activity - Increase the percentage of adults and adolescents who participate in physical activity.

Performance Measures	Baseline	5 Year Target
Adults who participated in physical activities other than their regular job in the past 30 days (2015 BRFSS)	73%	85%
High school students who participated in physical activity at least 60 minutes per day in the past 5 or more days (2013 KS YRBS)	48%	60%

[11] National Institute of Health 2016. *Increased physical activity associated with lower risk of 13 types of cancer*. Accessed through https://www.nih.gov/news-events/news-releases/increased-physical-activity-associated-lower-risk-13-types-cancer

[12] The Community Guide. *Chapter 2: Physical Activity.* Accessed through https://www.thecommunityguide.org/sites/default/files/assets/Physical-Activity.pdf

Strategies

1. Increase the number of communities implementing master bike/pedestrian plans intended to increase biking and walking.
2. Conduct built environment assessments.*
3. Promote daily physical activity in schools and childcare settings.
4. Collaborate with Healthy Kansas Schools (grantees based on percent of children who qualify for free/reduced lunch) to coordinate activities to increase physical activity.

* Built environment includes homes, schools, businesses, streets/sidewalks, open spaces, and transportation options. The built environment can influence community health and individual behaviors such as physical activity and healthy eating. Assessments measure qualities that affect health (i.e., walking, biking and other types of physical activity).

Radon

Radon is a naturally-occurring, odorless, colorless, invisible radioactive gas that can be a health hazard indoors. Radon is the second-leading cause of lung cancer in the U.S., and the first leading cause of lung cancer in people who have never smoked. More than 40 percent of Kansas homes have elevated radon levels and more than 200 lung cancer deaths per year in Kansas may be linked to indoor radon.

Objective 9. Radon - Increase the percent of Kansas homes tested and mitigated for radon during purchase or construction.

Performance Measures	Baseline	5 Year Target
Homes tested for radon during purchase	30%	40%
Kansas cities that have adopted building codes requiring radon-resistant building techniques	5	15

Strategies

1. Provide radon technical information to building code jurisdictions that are considering adopting radon resistant new construction.
2. Increase the number of real estate professionals trained in radon issues.
3. Coordinate consistent messaging with radon stakeholders about radon in homes, schools and childcare centers.

Tobacco

Smoking also increases the risk of dying from cancer and other diseases in cancer patients and survivors.[13] If nobody smoked, one of every three cancer deaths in the United States would not happen.[14] Cigarette smoking accounts for about one-third of all cancers, including 90 percent of lung cancer cases.[15]

Smoking can cause cancer almost anywhere in your body:

- Bladder
- Blood (acute myeloid leukemia)
- Cervix
- Colon and rectum (colorectal)
- Esophagus
- Kidney and ureter
- Larynx
- Liver
- Mouth and throat
- Pancreas
- Stomach
- Trachea, bronchus and lung

KanQuit!
KANSAS TOBACCO QUITLINE
1-800-QUIT-NOW (784-8669)
KSquit.org

Kansas Tobacco Quitline services are evidence-based and include client telephone support to increase a person's success at tobacco use cessation.

"Everybody was very helpful, very informative. They knew exactly what they were talking about, so I was going to an expert, not just anyone off the street. Anytime I needed assistance they were there… just being informative and knowledgeable and being understanding and caring."

Objective 10. a. Adults – Reduce the percentage of adults who use cigarettes, e-cigarettes and any tobacco products.

Performance Measures	Baseline	5 Year Target
Kansas adults who currently smoke (2015 KS BRFSS)	18%	13%
Kansas adults who currently use e-cigarettes (2016 KS BRFSS)	TBD	TBD
Kansas adults who smoke cigarettes or use any smokeless tobacco product (2015 KS BRFSS)	21%	17%

Strategies

1. Incorporate restrictions on the use of electronic nicotine delivery systems (e.g., e-cigarettes) in all state and local smoke-free and tobacco-free initiatives.
2. Support efforts to adopt and implement evidence-based pricing strategies that discourage tobacco use.

[13] U.S. Department of Health and Human Services. The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, 2014.

[14] U.S. Department of Health and Human Services. How Tobacco Smoke Causes Disease: What It Means to You. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, 2010.

[15] National Institute on Drug Abuse 2016. *Cigarettes and Other Tobacco Products*. Accessed through https://www.drugabuse.gov/publications/drugfacts/cigarettes-other-tobacco-products

3. Work with partners to place advertisements to encourage lung cancer screening and promote Kansas Tobacco Quitline at locations where tobacco is sold.
4. Collaborate with Tobacco Free Kansas Coalition to develop and implement a large scale counter-marketing communication campaign to promote tobacco use prevention and control.
5. Develop and disseminate model tobacco-free policies that prohibit the use of nicotine delivery systems (e.g., e-cigarettes) and electronic smoking devices in educational campuses, health care facilities, worksites or other places where 18- to 24-year-olds are exposed to tobacco use.
6. Promote adoption of the Kansas Tobacco Guidelines for Behavioral Health Care.
7. Collaborate with Early Detection Works and other entities that work with low income populations to increase referrals to Kansas Tobacco Quitline services to encourage cessation of tobacco use.
8. Partner with Kansas Tobacco Quitline, Federally Qualified Health Centers and KanCare (Kansas' managed care program) to encourage tobacco use assessment and provide free professional education with CME/CNE's such as the Brief Tobacco Intervention online training.

Objective 10. b. High School Students - Reduce the percentage of high school students who use cigarettes, e-cigarettes and any tobacco products.

Performance Measures	Baseline	5 Year Target
Kansas high school students who currently smoke (2013 KS YRBS)	10%	5%
Kansas high school students who used e-cigarettes in the past 30 days (KS YRBS)	TBD	TBD
Kansas high school students who smoke cigarettes or use some type of other tobacco product every day or some days (2013 KS YRBS)	19%	14%

Strategies

1. Support zoning and licensing initiatives to restrict youth access to tobacco products in the retail environment.
2. Develop and disseminate model tobacco-free policies that prohibit electronic nicotine delivery system devices (e.g., e-cigarettes) on K-12 school properties and worksites where youth may be exposed to tobacco use.
3. Support the adoption and implementation of Tobacco 21 policies that prohibit sale of tobacco products to individuals less than 21 years old.

Ultraviolet (UV) Radiation Exposure

Most skin cancers are a direct result of exposure to UV rays in sunlight and/or exposure to artificial sources of UV rays, such as indoor tanning.

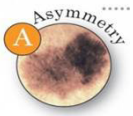
Objective 11a. Sunburn – Reduce the percentage of Kansans who report sunburn.

Performance Measure (2015 KS BRFSS)	Baseline	5 Year Target
Kansans reporting sunburn	40%	35%

Strategies

1. Implement Pool Cool program statewide to increase awareness and promote sun protective behaviors for children, their parents and outdoor pool staff.
2. Promote community-wide consistent messaging related to sun protective behaviors.
3. Promote policies and sun/UV safety messages for teachers/caregivers in childcare centers and school-related facilities.
4. Encourage sun-protective policies at daytime outdoor settings, with particular focus on non-Hispanic populations and people living in urban areas.
5. Increase access to sun-protective products at summer outdoor venues.

The "ABCDE" rule describes the features of early melanoma.

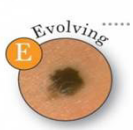


Asymmetry - The shape of one half does not match the other half.

Border that is irregular - The edges are often ragged, notched, or blurred in outline. The pigment may spread into the surrounding skin.

Color that is uneven - Shades of black, brown, and tan may be present. Areas of white, gray, red, pink, or blue may also be seen.

Diameter - There is a change in size, usually an increase. Melanomas can be tiny, but most are larger than 6 millimeters wide (about 1/4 inch wide).



Evolving - The mole has changed over the past few weeks or months.

National Cancer Institute

Objective 11b. Indoor Tanning - Reduce the percentage of Kansans who use indoor tanning devices.

Performance Measures (KS BRFSS)	Baseline	5 Year Target
Kansas adults who use indoor tanning devices	TBD	TBD
Kansas minors who use indoor tanning devices	TBD	TBD

Strategies

1. Use consistent messaging to educate the public about legislation restricting minors' access to indoor tanning devices.
2. Promote community-wide consistent messaging related to dangers of UV exposure related to tanning bed use.

Chasing a Tan

Billie Blenden

At age 22, I chased a pretty tan in a tanning bed for a good six months. On New Year's Eve, I noticed what I thought was a pimple on my shoulder, but over the next few months, it grew, cracked and bled, and became a painful, convoluted crusty growth. My doctor took one look and said it looked like skin cancer. *What?! I am 22 years old - how can I have skin cancer?* Having it removed left me with a seven inch scar across my shoulder. It was a squamous cell carcinoma and no further treatment was needed. I knew I needed to stop tanning and keep my skin protected. I didn't know I would worry about every new freckle.

A dozen years later, my dermatologist noticed two large freckles where my first excision had been. One of them turned out to be melanoma, which I also had surgically removed. My mother asked the doctor what would have happened if we hadn't caught it early. He said flatly, "It would kill her."

My new rules included seeing the dermatologist every three months, having my husband help perform monthly skin checks, and telling my hairstylist, gynecologist and dentist that I had melanoma and to watch for any new moles, freckles or changes in my skin.

I am now a young widow raising three children, so ensuring I stay healthy has taken on even more importance. Protect your children's skin in the sun; protect your skin and don't use tanning beds.

Chasing that pretty tan just isn't worth the risk.

To read more about Billie's journey, visit www.KSCancerPartnership.org.

Early Detection and Diagnosis

Goal: Detect cancer in its earliest stage through early detection and a timely, definitive diagnosis

Research shows that screening for cervical and colorectal cancer at recommended intervals can prevent these diseases by finding lesions/polyps that can be treated before they become cancerous. Screening also helps find cervical, colorectal and breast cancers at an early, most treatable stage. Lung cancer screening is recommended for some people who are at high risk, and men should make an informed decision with their health care provider about prostate cancer screening.

Breast Biopsies

Biopsy options to diagnose breast cancer include surgery and percutaneous (needle) biopsy. The Commission on Cancer recommends surgery not be performed as the initial pathologic evaluation of most breast abnormalities. Percutaneous biopsy is less invasive, less expensive and associated with decreased post-procedural complications and fewer overall surgeries.

Objective 12. Breast Biopsies – Increase the percentage of breast biopsy by percutaneous techniques versus excisional surgery for breast cancer diagnosis.

Performance Measure (TBD)	Baseline	5 Year Target
Breast biopsies by percutaneous biopsy versus excisional surgery for breast cancer diagnosis	TBD	TBD

Strategies

1. Develop and provide free professional education with CMEs/CNEs that includes recommended breast biopsy guidelines.
2. Increase the number of clinicians (e.g., surgeons, radiologists) who are trained to perform percutaneous biopsies.

Breast Cancer

Objective 13. Breast Cancer - Increase the percentage of age-appropriate women who had a discussion with their health care provider about breast cancer screening.

Performance Measures	Baseline	5 Year Target
Age-appropriate women who had a discussion with their health care provider about breast cancer screening (KS BRFSS)	TBD	TBD
Kansas women ages 50 to 74 who report having a mammogram within the past two years (2014 KS BRFSS)	76%	85%
Late stage breast cancer diagnosis (regional+distant) (2013 KCR cases per 100,000 persons)	39	34

Strategies

1. Develop and provide free professional education with CMEs/CNEs to clinicians that includes assessment of patient risk, use of current screening guidelines and quality improvement activities to increase clinical level screening rates (i.e., provider assessment & feedback, provider reminder & recall systems, client reminders, reducing structural barriers).
2. Develop and implement a social media campaign to promote mammography.
3. Work with Kansas managed care providers to increase screening among newly insured or uninsured women.
4. Coordinate and collaborate with the Kansas Early Detection Works program to increase screening among low income and uninsured women, particularly those who are Hispanic or African American, or who have less than a high school education.
5. Work with employers on adopting comprehensive employee wellness programs and increasing screening rates through health education and flex time/paid leave for preventive and screening services.
6. Collaborate with free standing clinics (urgent care) to encourage screening.
7. Implement programs that use community health workers to navigate low income women into cancer screening.

Cervical Cancer

Objective 14. Cervical Cancer - Increase the percentage of Kansas women who receive cervical cancer screening (i.e., Pap test) based on nationally recognized guidelines.

Performance Measures	Baseline	5 Year Target
Kansas women aged 21 to 65 years who report having a Pap test within the past three years (2014 KS BRFSS)	82%	87%
Late stage cervical cancer diagnosis (regional+distant) (2013 KCR cases per 100,000 persons)	2	1

Strategies

1. Develop and implement a social media campaign to promote cancer screening.
2. Work with employers on adopting comprehensive employee wellness programs and increasing screening rates through health education and flex time/paid leave for preventive and screening services.

3. Collaborate with free standing clinics (e.g., urgent care) to encourage cervical cancer screening including HPV testing, as recommended by American Society for Colposcopy and Cervical Pathology.
4. Develop and provide free professional education with CMEs/CNEs that includes quality improvement activities to increase clinic level cervical cancer screening rates (i.e., provider assessment & feedback, provider reminder & recall systems, client reminders, reducing structural barriers).
5. Partner with the Kansas Early Detection Works Program to increase cervical cancer screening among low income and uninsured women, particularly Hispanic women or those who have less than high school education, or who live in rural/frontier areas.

Colorectal Cancer

Objective 15. Colorectal Cancer - Increase the percentage of Kansas adults aged 50 to 75 years using one of the screening options recommended for colorectal cancer based on nationally recognized guidelines.

Performance Measures	Baseline	5 Year Target
Adults aged 50 to 75 years who are up-to-date with USPSTF colorectal cancer screening guidelines (2014 KS BRFSS)	65%	85%
Late stage colorectal cancer diagnosis (regional+distant) (2013 KCR cases per 100,000 persons)	21	16

Strategies

1. Provide technical assistance to help providers use their clinic EHR systems to document clinic level screening rates.
2. Develop and provide free professional education with CMEs/CNEs that includes dissemination of the American Cancer Society Colorectal Cancer (CRC) Screening Toolkit and strategies for increasing clinic screening rates as part of quality improvement activities (i.e., provider assessment & feedback, provider reminder & recall systems, client reminders, reducing structural barriers).
3. Conduct a needs assessment to identify Kansas provider preferences for health systems change strategies that would be most effective for increasing cancer screening rates in their practices.
4. Expand FluFit (providing CRC screening kits at time of flu shots for age-appropriate patients) in rural areas or areas with larger populations of people who are Hispanic, or who have lower income or educational levels.

5. Develop and implement a social media campaign to promote CRC screening.
6. Work with state managed care providers to increase CRC screening among newly insured or uninsured patients.
7. Implement programs that use community health workers to navigate low income men and women into cancer screening.

Don't put off screening!

Kirk Breen - Assaria, Kansas

I'm like a lot of guys. I usually wait until I am sick before going to see the doctor. But that changed after a friend was diagnosed with colon cancer after a colonoscopy. That and a special incentive through my employer to get a colonoscopy made me decide to be screened. My colonoscopy revealed that I had stage III colon cancer. At age 52 I couldn't believe it. My cancer was found in the nick of time. After surgery and chemotherapy I am happy to say that today I no longer have evidence of disease! I'm extremely fortunate I got the colonoscopy when I did. The truth is, colon cancer can strike any one of us.

Beginning at age 50, everyone should have a colonoscopy to screen for the disease. Between colonoscopies, experts recommend annual fecal occult blood testing or another type of stool test. Don't put off being screened; it could save your life!

Update: At the time of publication, Kirk had a recurrence and was diagnosed with Stage IV colon cancer. He is undergoing treatment and doing well. To read more about Kirk's journey, visit www.KSCancerPartnership.org.

Lung Cancer

Objective 16. Lung Cancer - Increase the percentage of high risk populations (current and former smokers aged 55 to 74 years) who had a discussion with their provider about lung cancer screening.

Performance Measures	Baseline	5 Year Target
High risk population who had a discussion with their provider about lung cancer screening. (2015 KS BRFSS)	16%	20%
High risk population screened for lung cancer per USPSTF guidelines (KS BRFSS)	TBD	TBD
Late stage lung cancer diagnosis (regional+distant) (2013 KCR cases per 100,000 persons)	44	39

Strategies

1. Develop and provide free professional education with CMEs/CNEs that includes use of low dose CT scans for lung cancer screening and recommended screening guidelines.
2. Partner with Kansas Tobacco Quitline to encourage lung cancer screening and promote Brief Tobacco Intervention Online Training.
3. Develop and implement a comprehensive public media campaign to promote lung cancer screening, particularly for African American males in urban areas.

Prostate Cancer

Objective 17. Prostate Cancer - Increase the percentage of men aged 50 to 69 years who had a discussion with their provider about prostate cancer screening.

Performance Measures	Baseline	5 Year Target
Discussion about advantages of screening (2014 KS BRFSS)	68%	78%
Discussion about disadvantages of screening (2014 KS BRFSS)	30%	50%
Late stage prostate cancer diagnosis (regional+distant) (2013 KCR cases per 100,000 persons)	19	13

Strategies

1. Develop and provide free professional education with CMEs/CNEs that includes discussions of advantages and disadvantages of prostate cancer screening to determine appropriate screening based on patient medical history/preferences.
2. Work with employers on adopting comprehensive employee wellness programs that include health education about informed decision-making and flex time/paid leave for provider visits about prostate cancer screening.
3. Develop and implement a comprehensive media campaign to promote wellness visits that include discussions about prostate cancer screening, particularly for African American men in urban areas.
4. Work with Kansas managed care providers to increase discussions about screening among newly insured or uninsured patients.

Appreciation for Life

Steve Hentzen

During a routine physical, my physician ordered standard tests for a 46-year-old male, including a prostate-specific antigen (PSA) test. I felt fine, but my PSA level was high, which can indicate cancer. After additional tests and consultation with several specialists, I was diagnosed with Stage IIC prostate cancer and had surgery to remove my prostate. My PSA went from 19 to 0.07, but 0.00 is optimal. We decided against more treatment and to monitor my PSA. A year later, my PSA began to rise and I opted for eight weeks of "salvage radiation," targeting where the prostate used to be. My PSA went down again and we continue monitoring every six months.

Before my diagnosis I was overweight, smoked and didn't work out. A friend motivated me to get healthy and now I'm fit and feeling great. Typically, guys don't talk about this disease, but it's not healthy to keep it in. I joined a support group, which eventually led to formation of Prostate Network (www.ProstateNetwork.org), a grassroots organization of survivors and partners to raise awareness and spread hope.

Much research is being conducted around prostate cancer, and it is our fervent hope that national consensus on screening and treatment guidelines will soon be a reality. Without consensus, it is critical to raise public awareness and for healthcare providers to explore screening options with patients. Early detection and targeted treatment is vital to successfully fighting this disease.

My PSA is still not at 0.00 and there is some fear associated with that but I channel my emotions into helping others. Through this journey, I've developed true appreciation for life and I focus on what's important – enjoying every minute of every single day, surrounded by the people who matter most.

To read more about Steve's journey, visit www.KSCancerPartnership.org.

Post-Diagnosis & Quality of Life throughout the Cancer Journey

Goal: Assure the highest quality of life for Kansans who have been diagnosed with cancer during and after treatment.

Cancer survivors are at greater risk for recurrence and developing second cancers due to effects of treatment, lifestyle behaviors, genetics or risk factors that contributed to the first cancer. Cancer survivors can help enhance their quality of life, maintain their health and improve survival. About one in 10 adult cancer survivors in Kansas were diagnosed before age 25. Survivors of childhood cancer have special health care needs and require follow-up care and medical surveillance for the rest of their lives.[16] This specialized care is necessary to monitor late effects that may develop months or years after treatment has ended.[17] The risk of late effects depends on the type of cancer, the type and dosage of treatment received, and the child's age. Late effects of childhood cancer may include: recurrence, second cancers, premature death, disability, impaired development, and learning problems.

While prevention is key to the public health response to cancer among adults, little is known about how to develop evidence-based interventions to prevent cancer among children. Further, there are no nationally-recognized cancer screening guidelines to detect childhood cancers in their early stage.

[16] American Cancer Society 2016. *Cancer in Children*. Accessed through https://old.cancer.org/acs/groups/cid/documents/webcontent/002287-pdf.pdf

[17] National Cancer Institute 2014. *Cancer in Children and Adolescents.* Accessed through https://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet#r2

Annabella's Journey

Told by her mother, Emily

"Our family's faith sees us through this journey. Sometimes we feel helpless, but never hopeless."

Annabella was diagnosed with stage IV alveolar rhabdomyosarcoma when she was 6 years old. The tumor was the most massive of its kind ever seen at Children's Mercy Hospital, and was inoperable. Anna went through six weeks of radiation to shrink the tumor, followed by 52 weeks of chemo.

Anna is now more than five years cancer treatment free, and is a fun-loving, smart, spunky, brave 15-year-old who is always smiling! She enjoys friends, family, church youth group, pets, singing, shopping, swimming and volleyball. She has a big heart for people.

Looking at her, you'd never imagine Anna struggles with potentially life-threatening health problems from the cancer and treatment, including hypothyroidism, chronic pain, arthritis, difficulty swallowing, narrowed airway, chronic sinusitis, enlarged lymph nodes, scar tissue in lungs/head/neck, migraines and compromised immune system. Recurrence or secondary cancer development is possible due to both the initial cancer and treatment. We don't know what the future will hold for Anna's health.

Wishes:

One simple thing I wish is that everyone would get preventable disease vaccines to protect their own health as well as to protect others like Anna who cannot be immunized. Preventable diseases are potentially lethal to people who are not immunized, and even more so for people like Anna with a compromised immune system.

Mostly I wish for more research funding for targeted, effective children's cancer therapies that wouldn't cause so much damage and late effects. Many children with cancer are given the "no known cure" diagnosis. These children have no voice, other than their parents, who are desperately doing everything in their power to save their children's lives.

To read more about Anna's journey, visit www.KSCancerPartnership.org.

Quality of Life

Improving health after diagnosis is important to prevent new or returning cancers early and increase treatment effectiveness. Healthy choices for survivors include:

Being active and maintaining a healthy weight. Being overweight or obese may be related to poorer survival after breast, prostate, colorectal or other cancers. Being physically active may improve quality of life after a cancer diagnosis.

Tobacco cessation. Smoking or being exposed to secondhand smoke is a preventable risk factor for cancer recurrence and additional cancers.

Discussing follow-up care with a health care provider. Important topics to discuss include:

- A personalized survivorship care plan that includes a schedule of recommended follow-up visits, screenings, and medical tests, and names of providers who will be responsible for care.
- Possible delayed effects of treatment.
- The importance of seeking timely care in response to certain signs or symptoms.
- Emotional wellness after cancer and identifying available resources for additional support.
- Lifestyle changes recommended for improving health and well-being.
- Developing an effective support system that meets survivors' medical and emotional needs.[18]

Objective 18. Quality of Life - Improve the physical and mental health of people who have had a cancer diagnosis, as well as that of their care providers.

Performance Measures (2014 KS BRFSS)

Adults aged 18 years and older who have ever been diagnosed with cancer who report that poor physical or mental health kept them from doing usual activities, such as self-care, work, or recreation, on 14 or more of the past 30 days

Baseline	5 Year Target
25%	20%

Strategies

1. Assess current data, determine best practices, identify/develop curriculum and provide free professional education with CMEs/CNEs that includes physical activity and nutritional guidelines.
2. Develop and support a user-friendly web page with resources to inform cancer survivors about physical activity, nutrition and the Kansas Tobacco Quitline for promotion through cancer centers and websites.
3. Promote free CMEs/CNEs through the Brief Tobacco Intervention Online Training for clinicians to improve the availability, accessibility and effectiveness of tobacco cessation services for cancer survivors.

[18] Centers for Disease Control and Prevention. *Cancer Survivorship: Basic Information for Cancer Survivors*. Accessed through https://www.cdc.gov/cancer/survivorship/basic_info/index.htm

4. Develop and provide free professional education with CMEs/CNEs that includes regionally specific disparate populations and targeted evidence-based practices to improve survivors' quality of life.
5. Provide Senior Farmers Market Nutrition Program voucher applications to eligible, low income cancer survivors and expand partnerships to increase the number of available vouchers.
6. Develop and provide free professional education with CMEs/CNEs that includes information on the treatment, financial, emotional and vocational needs of those living with stage 4 metastatic cancer.

Treatment Summary/Survivor Care Plan

Commission on Cancer standards include comprehensive treatment summaries and survivorship care plans for patients who received treatment aimed at eliminating cancer (i.e., "curative intent," seeking treatment and not solely palliative purposes – see Palliative and Hospice Care below) and who have completed therapy (other than hormonal). Treatment summaries and care plans should contain the required American Society of Clinical Oncology (ASCO) components plus recommendations related to encourage positive mental health, tobacco cessation, physical activity, diet and other healthy lifestyle behaviors to decrease risk of cancer recurrence or other chronic diseases.

Key ASCO **treatment summary** components:

- Contact information
- Diagnosis
- Stage
- Treatments received
- Ongoing toxicity/side effects
- Predisposing conditions/genetic testing, as needed

Key ASCO follow-up **care plan** components:

- Contact information
- Ongoing therapy
- Schedule for visits/testing
- Cancer screening/surveillance tests
- Symptoms of recurrence
- Late/long-term effects
- Psychosocial concerns

Objective 19. Treatment Summary/Survivor Care Plan - Increase the number of cancer patients with curative intent (i.e., seeking cancer-specific treatment) and who have completed therapy (other than hormonal) who report receiving treatment summaries and survivorship care plans.

Performance Measures	Baseline	5 Year Target
Patients who report receiving treatment summaries (KS BRFSS)	TBD	TBD
Patients who report receiving resources for healthy lifestyle behaviors (TBD)	TBD	TBD

Strategies related to adult cancer patients

1. Develop and provide free professional education with CMEs/CNEs on the importance of treatment summaries and ways to improve provider-provider and provider-patient communication.
2. Educate cancer patients to ask for treatment summaries and care plans that include resources to promote positive mental health, tobacco cessation, physical activity, nutrition, and other healthy lifestyle behaviors to decrease the risk of cancer recurrence and other chronic diseases.
3. Provide resources to aid providers in completing a cancer treatment summary and resources for the promotion of healthy lifestyle behaviors (e.g., Kansas Tobacco Quitline).

Strategies related to childhood cancer patients (aged 0 to 19 years)

1. Develop and provide free professional education with CMEs/CNEs that includes use of care plans for childhood cancer survivors, and resources for family and caregiver supports.
2. Establish a data source and collect data to determine the needs of adult survivors of childhood cancers and the extent that the role of coordinated care plans is understood.
3. Develop an education campaign for adult survivors of childhood cancer about the role of care plans and resources for healthy lifestyle behaviors to decrease the risk of cancer recurrence and onset of other chronic diseases.
4. Promote free CMEs/CNEs through the Brief Tobacco Intervention online training for clinicians to improve the availability, accessibility and effectiveness of tobacco cessation services for cancer survivors.

Palliative and Hospice Care

Palliative Care: According to the American Cancer Society, palliative care is “comfort care” that helps people cope with the symptoms of cancer and cancer treatment. Palliative care can be given at any point during a person’s illness to improve quality of life and support that person and his/her family during and after treatment. Palliative care should be available for anyone with a serious illness, regardless of life expectancy. Unlike hospice care, patients may receive palliative care and curative care (cancer-specific treatment) at the same time.

Hospice Care: The National Hospice and Palliative Care Organization describes end of life care as being for someone with a serious illness and a life expectancy measured in months, not years. Treatments are aimed at relieving symptoms, with the goal of comfort rather than a cure.

The End-of-Life Nursing Education Consortium (ELNEC) project was developed by nationally recognized palliative care nursing experts to provide comprehensive information about palliative care and end-of-life (EOL) nursing. A one-day ELNEC course was designed for anyone who wishes to enhance their own knowledge, and a two-day Train-the-Trainer course was designed for those who wish to be “palliative care champions” to disseminate palliative and EOL care information and system

level change in their own practice areas. These courses and a one-day Advance Practice Registered Nurse (APRN) training are offered across Kansas through the Central Plains Geriatric Education Center at the University of Kansas Medical Center.

Objective 20. Palliative and Hospice Care - Improve Kansas scorecard for access to Palliative Care services, as measured by Center to Advance Palliative Care.

Performance Measures (cumulative ELNEC)	Baseline	5 Year Target
Number of one-day ELNEC course attendees	561	976
Number of two-day Train-the-Trainer ELNEC course attendees	112	202
Number of one-day APRN ELNEC course attendees	27	162
Kansas counties providing professional educational opportunities in palliative care	21	26
Performance Measures (Center to Advance Palliative Care)		
Kansas scorecard	C	A
Palliative Care Programs/Hospitals	48.5% (16/33)	80%

Strategies

1. Increase the number and geographic dispersion of attendees at the one-day ELNEC training course on palliative care for health care professionals by offering in-person and internet-based courses.
2. Increase the number of attendees at the two-day ELNEC train-the-trainer course to train palliative care “champions” to drive local system change by recruitment through state and regional coalition partnerships.
3. Implement statewide APRN one-day ELNEC training in primary palliative care techniques/skills by offering in-person and internet-based courses.

Treatment Preferences for Advanced Cancer

The Center for Practical Bioethics (CPB) takes the lead in TPOPP training across Kansas and Missouri. CPB has helped patients and their families, healthcare professionals, policymakers and corporate leaders grapple with difficult issues in healthcare, bioethics, and research for more than 30 years.

Transportable Physician Orders for Patient Preferences (TPOPP) is a program designed to improve the quality of care received at end-of-life by translating patient's treatment preferences for life-sustaining treatment into medical orders. TPOPP is based on the belief that individuals have the right to make their own health care decisions. The TPOPP form is often referred to as the pink form.

Transportable Physician Orders for Patient Preferences (TPOPP)	Advance Directive/ Health Care Proxy
For those with chronic progressive illness or may die within the year	For all adults
Applies to person's current situation. Medical orders for now.	Complete for the future
Not conditional on decision-making capacity	In effect when decision-making capacity is lost
Contains set of medical orders	Contains no medical orders
Accompanies patient across settings	May not be available in all settings

Objective 21. Transportable Physician Orders for Patient Preferences (TPOPP) - Increase the number of health systems across the state that have an infrastructure for increasing understanding of and honoring treatment preferences for seriously ill patients as they move across the continuum of care.

Performance Measures (Center for Practical Bioethics (CPD))	Baseline	5 Year Target
Number of Kansas TPOPP training attendees	104	520
Number of TPOPP Toolkit downloads from CPB website	88	440
Number of Kansas communities active in Kansas-Missouri TPOPP Coalition	10	100

Strategies

1. Increase the geographic dispersion of community coalitions participating in the Kansas-Missouri TPOPP Coalition.
2. Work with the CPB to identify health-related community coalitions, provide information on TPOPP training, and offer technical assistance for implementation.
3. Provide TPOPP information to Cancer Center Quality/Operations Directors in Kansas through mailings, webinars, conference presentations and ads in professional journals.

Information Resources

Acronyms

ASCO: American Society of Clinical Oncology

BRFSS: Behavioral Risk Factor Surveillance System

CoC: Commission on Cancer

EDW: Early Detection Works – Kansas Breast and Cervical Cancer Screening and Diagnostic Program

EHR: Electronic Health Record

HPV: Human Papilloma Virus

KCP: Kansas Cancer Partnership

KCR: Kansas Cancer Registry

KDHE: Kansas Department of Health and Environment

TPOPP: Transportable Physician Orders for Patient Preferences

USPSTF: United States Preventive Services Task Force

YRBS: Youth Risk Behavior Survey

Kansas Cancer Partnership

www.KSCancerPartnership.org

Kansas Cancer Partnership (KCP) Website

To obtain an electronic copy of this document, simplify your search for cancer resources, or for information about the Kansas Cancer Partnership (KCP) please visit the KCP website. This website contains information on KCP, and links to current, scientifically accurate information.

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North Central Regional Cancer Coalition – Salina

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