

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 / Ethnicity			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

6

5 Year Target

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, less 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.

Early detection of breast or cervical cancer can save your life.



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)

Kansans whose health care provider has ever talked to them about participating in a clinical trial

Kansans ever diagnosed with cancer who were enrolled in a cancer clinical trial arranged by their Kansas health care provider

Baseline

4%

31%

5 Year Target

10%

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)

Kansas adults who have collected specific health history information from their family members to share with their health providers

Kansans with family history of cancer who report that they have received genetic counseling (breast, ovarian or colorectal cancer)

Baseline	5 Year Target
TBD	TBD
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

Number of members in the Midwest Cancer Alliance state navigation network (2017, MCA)

Baseline

35

5 Year Target

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.