

# 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, advancing public policy, workforce diversity, 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. Individuals with low socioeconomic status have higher cancer death rather than people with higher socioeconomic status, and the gap is widening.<sup>1</sup> This status is, “measured in terms of income, education and/or health insurance status.”<sup>8</sup> Individuals of lower status have limited access to quality care and nutrients, as well as a higher risk of exposure to cancer-causing infections and harmful exposures like air pollutants based on where they live. These factors cause a higher likelihood of developing cancer, a delayed detection resulting in late-stage cancer, and they are less likely to receive the standard of care.<sup>8</sup>

The table 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 north central (Salina) south central (Wichita), and southeast (Pittsburg) areas, with a fourth on hold for southwest Kansas due to COVID 19.

**Disparities in Cancer Screening, Incidence and Mortality by Selected Sociodemographic Characteristics among Kansas Population**

	Annual Household Income	Education level	Health Insurance Status	Population Density		Race	Ethnicity		Gender	
	<\$15,000 <sup>1</sup>	≤ high school <sup>2</sup>	Uninsured <sup>3</sup>	Frontier/Rural	Urban/Semi-Urban	African American <sup>4</sup>	Hispanic	Non-Hispanic	Male	Female
<b>Screening</b>										
Colorectal	✓	✓	✓	✓						
Breast	✓	✓	✓	✓						
Cervical	✓	✓	✓							
Lung	✓									
<b>Incidence (overall)</b>										
Overall					✓			✓	✓	
Colorectal				✓				✓	✓	
Breast					✓			✓		
Cervical										
Prostate						✓		✓		
Lung						✓		✓	✓	
Melanoma					✓			✓	✓	
<b>Incidence (late stage)</b>										
Colorectal								✓	✓	
Breast						✓		✓		
Cervical										
Prostate						✓				
Lung				✓				✓	✓	
Melanoma									✓	
<b>Mortality</b>										
Overall						✓		✓	✓	
Colorectal				✓					✓	
Breast						✓				
Cervical						✓				
Prostate						✓				
Lung									✓	
Melanoma									✓	

1: compared to \$50,000 or more; 2: Compared to college graduate; 3: Compared to insured; 4: Compared to White  
 Note: - cells shaded in grey indicate comparison is 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/Alaskan 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: 2020 Kansas BRFSS

Colorectal-Percentage of adults ages 50-75 years old who met the USPSTF recommendation for colorectal cancer screening

Breast-Percentage of women ages 40 years & older who have received a mammogram during the past two years

Cervical-Percentage of women ages 21-65 years old who met the USPSTF recommendation for cervical cancer screening

Incidence data: 2014-2018 Kansas Cancer Registry

Mortality data: 2015-2019 Kansas Vital Statistics

In Table1, 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 in cancer control.**

### Performance Measures (Disparities in Cancer Screening, Incidence and Mortality by Selected Sociodemographic Characteristics among Kansas Population)

1. Percentage of data points with disparities in cancer screening, incidence, and mortality from the disparity table.

Baseline:

32.9%

Target:

25.0%

### Strategies

1. Promote the use of Community Health Workers to improve access to and coordination of health care.
2. Strategically enhance collaborations between KDHE, community/health care organizations and academic institutions to improve health equity.
3. Increase provider and community awareness and knowledge of social determinants of health and their influence on cancer rates.
4. Use culturally and linguistically appropriate health education materials that match health literacy levels.
5. Increase equitable and affordable access to financial, transportation, and lodging resources for vulnerable populations.
6. Promote and support telemedicine through training of providers and community members and advocate for policies that support expansion.
7. Implement evidence-based interventions to decrease the proportion of adults who report poor communication with their health care provider.
8. Increase availability of telemedicine services and infrastructure.
9. Increase and standardize data sources and methodologies used to establish baselines and five-year targets for monitoring improvement in health equity.
10. Implement best practices and evidence-based approaches to assess and address social determinants of health.
11. Prioritize implementation of state plan strategies that will increase health equity.
12. Increase KCP capacity to evaluate interventions designed to improve health equity.

### Jennifer Lane Lehr

To the stakeholders at the Kansas Department of Health and Environment— Thank you very much for allowing me to share my story. And thank you for the work you are doing to serve Kansans affected by cancer.

I have had the opportunity to see cancer from many vantage points. From the vantage point of a goal oriented allied healthcare provider. From the vantage point of a compassionate care partner to a parent. From the vantage point of an overwhelmed patient. From the vantage point of a determined survivor. From the vantage point of a focused leader to bring oncology services to others in need.

I first experienced cancer with the deaths of both of my grandmothers as a young adult. My early midlife brought the death of my uncle and my father to cancer. I saw firsthand the challenge care partners face as I assisted my mother in end-of-life decisions for my father. Early midlife also brought my own diagnosis of breast cancer. No one has time or wants to make time for cancer, and I was no exception. Recently divorced, a single



mother to my then 11-year-old, and one year into my solo private practice as an allied health provider, my diagnosis came with the ring of the cell phone. At the age of 42, having just established a stable life for my son and I, cancer had developed during these most stressful of days and months. And it brought with it the same hard decisions, worries and stressors that all patients have in common.

But with these challenges also came lessons and growth within me and help and love around me. These have made me the person I am and continue to shape the person I will be in the years ahead. The years behind me are beginning to stretch from those difficult months of treatment and recovery, but the fear of recurrence remains. So too do the joys of a close relationship with my son born out of those stressful months, the voice I now use to advocate for patients in my work with the KUMC PIVOT program, and the perspective I bring to my job as I build programs to serve patients with cancer throughout rural America.

I cannot share enough how instrumental are the words spoken to patients and the empowerment given to them amidst the myriad of decisions that must be made. These decisions that patients make too often are irreversible and come with long term complications or tradeoffs. What is done for cancer patients at all levels of service comes down to these conversations and subsequent decisions.

For those of you working in research to provide better choices in those decisions, for those of you working in clinic to translate those choices into treatment and outcomes, and for those of you who help us patients understand those choices and make those decisions, I have only one simple thing to say. Thank you.

## Financial Burden

The financial costs of cancer care are a burden to people diagnosed with cancer, their families and society. National expenditures associated with cancer have been steadily increasing in the United States with care for cancer survivors estimated at least being \$208 billion in 2020 to the expected rise of \$240 billion+ by 2030.<sup>3,4</sup> In Kansas, annual expenditures related to cancer are estimated to be \$1,213,000,000 annually.<sup>5</sup>

Patients are receiving more expensive treatments for their cancer such as chemotherapy, immunotherapy and many other new types of treatments. These costs have gone up greatly in the past 10 years. It has been reported that some cancer survivors report spending more than 20% of their annual income on medical care.<sup>6</sup> Financial distress can lead to poor health outcomes. In 2018, 2.5 percent of cancer survivors in Kansas were unable to obtain cancer screening due to cost, while about 11.0 percent were unable to obtain a recommended cancer screening testing due to cost, and about 9.0 percent of cancer survivors went in a financial hardship due to cancer, treatment, or late effects of treatment.<sup>1</sup>

Steps to reduce financial hardship include meeting with a financial navigator for advice on health insurance plans and what cost-saving measures you may qualify for, hospitals posting their prices for transparency when making decisions about which tests and treatments to use, and reforming health insurance.<sup>7</sup>

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

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<sup>3</sup> National Cancer Institute. (2022, April). Financial burden of cancer care. Financial Burden of Cancer Care. Retrieved November 17, 2022, from [https://progressreport.cancer.gov/after/economic\\_burden](https://progressreport.cancer.gov/after/economic_burden)

<sup>4</sup> National Center for Chronic Disease Prevention and Health Promotion. (2022, September 8). Health and economic costs of chronic diseases. Centers for Disease Control and Prevention. Retrieved November 17, 2022, from <https://cdc.gov/chronicdisease/about/costs/index.htm>

<sup>5</sup> Chronic disease cost calculator. Version 2. Atlanta (GA): Centers for Disease Control and Prevention; 2013. <http://www.cdc.gov/chronicdisease/calculator>. Accessed November 17, 2022.

<sup>6</sup> Financial toxicity (financial distress) and cancer treatment (PDQ®)—patient version. National Cancer Institute. (2019, September). Retrieved November 17, 2022, from <https://cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-pdq>

<sup>7</sup> Financial toxicity (financial distress) and cancer treatment (PDQ®)—patient version. National Cancer Institute. (2019, September). Retrieved November 17, 2022, from <https://cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-pdq>

Cancer is one of the most expensive medical conditions to treat in the United States. Cancer survivors usually report higher out-of-pocket spending than people who have not had cancer. Some cancer survivors report spending more than 20% of their annual income on medical care. Studies have shown that patients who have financial toxicity reported having a lower quality of life, more symptoms, and more pain.

*Financial toxicity (financial distress) and cancer treatment (PDQ®)—patient version.* National Cancer Institute. (2019, September 20). Retrieved February 3, 2023, from <https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-pdq>

### Performance Measures (KS BRFSS)

1. Kansans reporting not seeing a doctor because of cost in the past 12 months
2. Kansans reporting financial barriers to accessing cancer screening services
3. Kansans reporting financial barriers to accessing cancer diagnostic services
4. Kansans reporting financial barriers to beginning, adhering to, or completing cancer treatment

Baseline:	Target:
9.9% (2021)	9.0%
1.9% (2020)	1.5%
10.0%(2020)	8.0%
9.7% (2020)	8.0%

### Strategies

1. Collaborate with community health workers, financial navigators and patient health navigators to improve awareness to lessen financial barriers to cancer services.
2. Support, promote and enhance effective programs that increase access to cancer screening, diagnosis, treatment and follow up services.
3. Assess the number of facilities that implement strategies to reduce the financial burden of cancer patients and document successful models for replication.
4. 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.
5. Educate patients and providers about insurance mandates to ensure patients are not billed for wellness and preventive services.
6. Develop and provide free professional education with CME/CNE’s that includes information on cultural humility and competency, financial assistance, financial toxicity and treatment outcomes.
7. Identify partners that have contact with newly unemployed and/or newly uninsured to provide information on resources for accessing health services while uninsured.
8. Develop and support a user-friendly coalition website resource page that includes links to local resources and links to national webpages with information in other languages 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

### Carol Morast

When I went for my routine mammogram in October 2019, I wasn’t expecting anything more than the normal in and out routine and letter in the mail letting me know everything was normal. However, this screening proved to be different. Soon after, I received my breast cancer diagnosis and my treatment plan that included chemotherapy, mastectomy, and radiation. I never let them tell me what stage the cancer was. I was too focused on being well. I had total response to chemotherapy, and all the cancer was gone when I had my mastectomy. I rang the bell on December 1, 2020. In 2021, I underwent DIEP Flap reconstruction surgery and two revision surgeries. Today, I remain a cancer survivor.

Cancer has greatly impacted my financial life. People often think about how much it costs for doctor visits, treatment plans, etc. The cancer center had a financial advisor meet with me to go over financing options. I

had good insurance. That part was covered. On the other hand, days of not being able to work because of chemo, fatigue, hospital stays, or post-surgery recovery times added another layer of financial stress.

I would get chemo on a Tuesday and not be able to return to work until Sunday, and I went through that cycle every 3 weeks where I basically had no income coming in for a week. When I went to the hospital with sepsis, again 3 days without pay. When I went to the hospital with a blood clot, 4 days without pay. When I had my 2 revision surgeries where I had to miss work for 2 weeks each time, I had no pay. If there were any resources available to me to help pay the bills, no one ever spoke to me about them. I've used up my savings and my retirement (even though I've not retired) and maxed out my credit cards to survive. Being a single person, if I didn't work, there was no money coming in to pay my normal bills or buy groceries.

In most of my career, I worked in a corporate job where I made a decent living. However, I worked a retail job when going through cancer treatment and am still there today. I thought as soon as I finished reconstruction surgery last year, I would easily find a job back in my career field where I would make a more substantial income. I began asking about resources to help me prepare for reentering the job market. (Crickets....I was told there really isn't anything.) I now have a huge gap in my resume, no money to take training to fill that gap, and lots of questions about applications and interviews, especially in regard to disclosure of a former cancer diagnosis as a disability. It would be fantastic if there were resources available to help get me started.

I was very excited to start my survivorship, but I don't feel I've survived the financial part yet. I've not been able to return to any of my normal activities. I work as much as possible and also do gig work to try to help make ends meet. Most weeks, I'm lucky if I have grocery money. It's an embarrassing secret that I've kept from friends and family because I don't want them to worry. Today, I still carry the financial burden of having gone through cancer treatment.

## Advancing Public Policy

Public policy is an intricate part of change that can happen regarding cancer. It can affect people with cancer and the cancer care system including but not limited to funding for research and government programs, regulations of insurance coverage and accessibility, payment for care through Medicaid and Medicare, review and approval of cancer therapies, and measurement of quality health care.<sup>8</sup>

The American Society of Clinical Oncology advocates on a wide range of policy related issues. As the nation's leading professional organization representing oncologists and other cancer care providers, they strive to ensure that all patients with cancer have access to high-quality and high-value care. Some of the areas in which they believe need advancement and are working to advance are access to care, clinical trials, drug shortages, federal funding for cancer research, quality cancer care and value in cancer care.<sup>9</sup>

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### ***Objective 3. Advancing Public Policy - Improve cooperation, coordination, and collaboration among organizations and federal, state, tribal, county and local governments to support community-oriented cancer control.***

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#### **Performance Measures (KS BRFSS)**

1. Percent of Kansans adults who are uninsured

**Baseline:**

8.8% (2021)

**Target:**

7.0%

#### **Strategies**

1. Advance policies that increase access to necessary cancer services for all Kansas based on the social determinants of health and regardless of location, insurance status, race, ethnicity, language and lack of information/awareness.

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<sup>8</sup> Staff, N. C. C. S. (2021, January 20). Policy. NCCS - National Coalition for Cancer Survivorship. Retrieved November 17, 2022, from <https://canceradvocacy.org/policy/>

<sup>9</sup> ASCO. (2022, November 3). Public policy advocacy. Cancer.Net. Retrieved November 17, 2022, from <https://cancer.net/research-and-advocacy/public-policy-advocacy>

2. Strive for equity integration in policy development and governance; work to embed health equity into legislation at all levels.
3. Make healthy food more affordable by introducing and/or supporting policies which lower the cost of healthy foods such as reduction of the food sales tax and/or a food sales tax credit.
4. Promote the new lung cancer screening guidelines that indicate screening should occur at the age of 50 and lowering the pack years to 20 for smokers.
5. Ensure that nothing in state statutes prevents any city or county from regulating tobacco within its boundaries, so long as such the local policy is at least as strict as the state statute.
6. Introduce Kansas T21, Tobacco tax increase at least \$1.00 and Prohibit the sale of all flavored tobacco products, including menthol.
7. Support state and local policies which promote best practices in vaccination policies for children and adults.
8. Adopt policies on radon disclosure upon real estate transaction.
9. Adopt health and habitability regulations to include radon standards.

## KCP Membership

The Kansas Cancer Partnership’s vision is to reduce burden and suffering from cancer in Kansas and enhance quality of life for all cancer survivors and their families. They will use a comprehensive approach that covers the cancer continuum from prevention to early detection, treatment and care, survivorship, and quality of life through the end of life. Membership is open to organizations and interest individuals with special expertise and commitment to reducing the human and economic impact of cancer in Kansas.<sup>10</sup>



kscancerpartnership.org

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### ***Objective 4. KCP Membership - Improve cooperation, coordination and collaboration among organizations and federal, state, tribal, county and local governments to support community-oriented cancer control.***

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#### **Performance Measures (Kansas Comprehensive Cancer Control Program Evaluation)**

1. Number of new collaborations (based on new member records)

Baseline:	Target:
4	10

#### **Strategies**

1. Partner with Kansas Department of Transportation, local governments and others. to improve access to transportation resources for those seeking cancer care.
2. Collaborate with the County/Community/Tribal Health Councils to promote awareness, screening, awareness and use at the population level.
3. Standardize the collection and reporting of race, ethnicity, preferred language and country of origin for cancer-related datasets.
4. Recruit new KCP members from communities which experience cancer disparities.

## Workforce Diversity

Training and workforce diversity are key if we want to eliminate disparities in the cancer health care field and to achieve health equity. With a lack of racial and ethnic diversity in the workforce and researchers there continues to be cancer health disparities. There have been enhancements in racial and ethnic diversity in

<sup>10</sup> KCP. (2017, October 23). Kansas Cancer Partnership. Kansas Cancer Partnership . Retrieved November 17, 2022, from <https://kscancerpartnership.org/wp-content/uploads/2021/11/KCP-Operating-Guidelines-Updated-10.23.2017.pdf>

cancer training through diversity-focused training and career development programs. Though these minorities are still underrepresented in cancer research and cancer care workers. With continued improvement in a diverse workforce there is a better likelihood of better care for these underrepresented groups.<sup>11</sup>

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**Objective 5. Workforce Diversity - Improve diversity of public health and clinical health care workforce.**

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**Performance Measures (Public Health Workforce Assessment 2021)**

1. Percent of males working in local health departments
2. Percent of minority individuals working in local health departments

Baseline:	Target:
11.0% (2021)	20.0%
16.6% (2021)	25.0%

**Strategies**

1. Train worksites on processes to improve workplace diversity (implicit bias training, updating job descriptions to be inclusive, placement of help wanted ads to reach diverse audience, facilitating inclusion of staff hired).
2. Collaborate with Technical Schools to provide Community Health Worker training for High School seniors in areas of need.
3. Promote and support pipeline programs in the sciences and health professions for students from underrepresented communities.

**Navigation as a Success**

As a Breast Health Patient Navigator, I have found that women who can connect a face to a service are more likely to complete recommended screenings. These women now can have Early Detection Works (EDW) and navigation explained to them as a source that will help them get scheduled for breast and cervical screenings without the barrier of having no insurance. Working with EDW, before I became trained as a navigator, there were many women who did not keep appointments for breast or cervical screenings.

I have been working with EDW and the Unified Government Public Health Department as a navigator for the past five years, and I can say that screening rates have increased due to personally speaking with them to get enrolled, Then asking what the best times and days for *them* to get to a mammogram appointment, if they need transportation, informing them which radiology location they will have the appointment, what to do to prepare for the appointment, and most importantly, an EDW voucher that will pay for the service and any diagnostic or additional imaging they may need, is all done before they leave the clinic, are some barriers removed.

I believe the ease for enrollment and the explanation of services covered for these women, is as invaluable to them, as it is to me using an insurance card, it makes them more confident when they have information about what will happen at the appointment, they know who to call if they have questions and tend keep appointments for screening services.

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<sup>11</sup> CancerDisparitiesProgressReport.org [Internet]. Philadelphia: American Association for Cancer Research; ©2022. 2022 November 17. Available from <http://CancerDisparitiesProgressReport.org/>.

## Clinical Trials

Today, people are living longer lives from successful cancer treatments that are the results of past clinical trials. Through clinical trials, doctors determine whether new treatments are safe and effective and work better than current treatments. They help improve the quality of life for people during and after treatment. When someone takes part in a clinical trial, they add to the knowledge about cancer and help improve cancer care for future patients. Clinical trials are the key to making progress against cancer.

*What are cancer clinical trials?* National Cancer Institute. (2021, November 1). Retrieved February 3, 2023, from <https://www.cancer.gov/about-cancer/treatment/clinical-trials/what-are-trial>

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.

Clinical trials are necessary for testing the safety and effectiveness of novel treatments. While these treatments are offered, only 2-3% of all cancer patients enroll in these trials. There are many barriers that come with participation in clinical trials. Health care professionals can have a lack of awareness of available trials and their attitudes when discussing these trials can influence the patient's response to participating.<sup>12</sup> Some of the most common reasons that patients have for not enrolling is the desire to have the standard protocol, a fear of side effects, financial concerns or insurance denial, and a dislike of participating in an experiment. Even with these fears, more than half of cancer patients offered a clinical trial do participate.<sup>13</sup>

### ***Objective 6. Clinical Trials - Increase the percentage of Kansas adults 18 and older who have been diagnosed with cancer and participated in a cancer-related clinical trial.***

#### **Performance Measures (KS BRFSS)**

1. Kansans whose health care providers have ever discussed clinical trials as a treatment option for their cancer
2. Kansans ever diagnosed with cancer and completed treatment who participated in a clinical trial as part of their treatment

#### **Baseline:**

TBD

3.2% (2021)

#### **Target:**

TBD

5.0%

#### **Strategies**

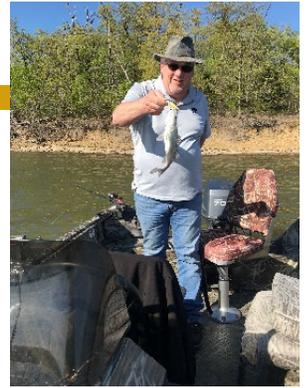
1. Map clinical trial participation by cancer treatment center in Kansas, determine areas of need and tailor provider and patient education to increase participation.
2. Implement culturally appropriate messaging about cancer clinical trials to influence patient shift towards acceptance of clinical trials.
3. Work with key patient groups at cancer treatment centers to provide culturally competent patient education about clinical trials.
4. Develop and disseminate education campaigns to inform the public about research, including clinical trials.
5. Develop and provide free professional education with CME/CNE's that includes information on accessing clinical trials.
6. Support translation of research findings into practice.

<sup>12</sup> Hamel, L. M., Penner, L. A., Albrecht, T. L., Heath, E., Gwede, C. K., & Eggle, S. (2016). Barriers to clinical trial enrollment in racial and ethnic minority patients with cancer. *Cancer Control*, 23(4), 327–337. <https://doi.org/10.1177/107327481602300404>

<sup>13</sup> Unger, J. M., Hershman, D. L., Till, C., Minasian, L. M., Osarogiagbon, R. U., Fleury, M. E., & Vaidya, R. (2020). "when offered to participate": A systematic review and meta-analysis of patient agreement to participate in cancer clinical trials. *JNCI: Journal of the National Cancer Institute*, 113(3), 244–257. <https://doi.org/10.1093/jnci/djaa155>

## Robert Towner

I am not one to go to the doctor, never really felt like anything was a good enough reason to go. One night I was having severe pain and vomiting, my family convinced me to go to the emergency room. It turns out that the pain was caused by Stage IV Colon Cancer. It was bad enough to prompt the doctor into saying, “We do not know how you are even still walking around with the amount of pain this would be causing you”. I didn’t know the warning signs, nor did I really feel like I was in that much discomfort on a daily basis. Some people just don’t feel it like others I suppose.



My journey has been a long one. I was told that I had 2 years to live max. Immediately after that scan, they wheeled me into surgery. It was April 2020, the height of the pandemic. My family was not able to be there with me and I know that it killed them as much as it killed me to not have them there. Once I got out of the hospital, I had 6 months of chemo ahead of me. These were long days from 8am-5pm. No one was allowed back with me, but my daughter drove me to and from every time. Finally, my numbers were down, and I could stop chemo.

In December 2020, I had my second surgery which was a hot chemo bath in my abdomen. I participated in a clinical trial that they said would potentially give me a couple more years. The surgery went well but due to me being a smoker, I ended up in the ICU for about a week and unconscious for most of it. This time though I was allowed one visitor a day. The first night my daughter spent the night and came pretty much every day after with visits from my son and wife as well.

I was in remission for about a year and a half, technically I am still in remission because there is no tumor to be found. Though in April 2022, I was told that my markers were high, and I had the choice whether to start chemo again to get ahead of it or to let it be. I chose the fight. I continue to choose to fight be here for my kids and my grandkid. Even though I am still doing chemo, I am a survivor, a fighter, and heck of a family man. I do not let this diagnosis keep me from helping my son, spending time with my daughter and grandson, or from working (even if it is the day after chemo). There is nothing I can do to change the past, but I won’t let it keep me from living.

## Genetics

A woman’s lifetime risk of developing breast and/or ovarian cancer is markedly increased if she inherits a harmful variant in *BRCA1* or *BRCA2*.

**Breast cancer:** About 13% of women in the general population will develop breast cancer sometime during their lives. By contrast, 55%–72% of women who inherit a harmful *BRCA1* variant and 45%–69% of women who inherit a harmful *BRCA2* variant will develop breast cancer by 80 years of age.

**Ovarian cancer:** About 1.2% of women in the general population will develop ovarian cancer sometime during their lives. By contrast, 39%–44% of women who inherit a harmful *BRCA1* variant and 11%–17% of women who inherit a harmful *BRCA2* variant will develop ovarian cancer by 80 years of age.

National Cancer Institute; reviewed November 19, 2020

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.<sup>14</sup>



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**Objective 7. Genetics - Increase the number of adult Kansans who know their family history of cancer back through 2nd degree relatives (parents, siblings, children, grandparents, aunts, uncles).**

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**Performance Measures (2021 KS BRFSS)**

1. Kansas adults who have collected specific health history information from their family members to share with their health providers
2. Kansans with family history of cancer who report that they have received genetic counseling (breast, ovarian or colorectal cancer)

Baseline:	Target:
33.7% (2021)	40.0%
15.1% (2021)	30.0%

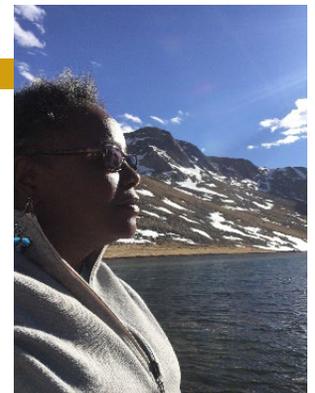
**Strategies**

1. Educate the public about the role of genetic testing and genetic counseling in cancer detection, diagnosis and treatment.
2. Identify partners willing to disseminate user-friendly tools for documenting family medical history.
3. Adopt 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.
4. Develop and disseminate culturally appropriate and user-friendly resources on genetic testing and counseling for patients who have been identified at high risk.
5. Increase education and awareness of genetic counseling and testing, and their roles in providing information on cancer risk management, screening and treatment.
6. Develop and provide free professional education with CMEs/CNEs that includes recommended guidelines for genetic testing and counseling delivered through educational settings used by primary care clinicians and oncology specialists.

**Donielle Potts**

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All four of my grandparents were diagnosed with some form of cancer. It was hard to admit, but after genetic testing and reviewing my family history, I realized that cancer runs in my family. So, when I got diagnosed in 2016, I thought that was it! The test results showed I had stage 2, grade 2 breast cancer. To top it off, I had a clinical diagnosis of inflammatory breast cancer, which only has a 50% survival rate. I was nervous. Even though I was not afraid to face death, I did not want my fears to stop me from living. So, I went to work! The only way I know to squash fear is with knowledge. So, I did research from reputable sources. I read books and articles, asked questions, took pictures and notes, and frequented the local library.



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<sup>14</sup> American Cancer Society, 2016. Family Cancer Syndromes. Accessed through <https://cancer.org/cancer/cancer-causes/genetics/family-cancer-syndromes.html>.  
DNA clipart file, DNA file transparent free for download on webstockreview 2023. WebStockReview. (n.d.). Retrieved February 28, 2023, from <https://webstockreview.net/explore/dna-clipart-file/>

I got all the answers until I was not afraid anymore. I adopted the motto: “Feed your faith, and your fears will starve.” Several years and many procedures later, I am still here to fight another day. I want every cancer patient to know it is ok to be scared. Do not recoil, surrender, or give up. Find YOUR WHY. Why will you fight? Stare death in the face and dare to live!

While I recovered from the effects of chemotherapy and a double mastectomy, I looked in the mirror one day at a face and body I no longer recognized. I had to pull myself together for my husband, my family, and my medical team. Most important of all, I had to pull it together for myself. So, I got out my “weapons of war.” I opened a case and pulled out my implements. This time they had a greater purpose. This time besides the obvious beautifying strokes of my pencils and brushes, I used these tools for survival. I decorate my skin like an indigenous warrior. Every stroke and color has meaning and intent. It is a ritual, it is a rite of passage, it is ceremonial, and it is symbolic. When putting on my makeup, I began to call it:

### **WAR PAINT**

**Every stroke is a symbol of defiance of death**

**It hides blemishes and imperfections**

**It hides pain and sorrow**

**It masks fears and vulnerability**

**It gives me courage to be seen, when I’d rather hide**

**It gives me poise when otherwise I should fall to pieces**

**Although I’m changed inside and out...**

**It reminds me:**

**-I am feminine**

**-I am strong**

**-I am beautiful**

**-I am woman**

**I go to war every day I am alive; every moment I am awake**

**I paint my face like I am painting my soul**

By: Donielle Potts July 23, 2016

## **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 Masonic 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.

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***Objective 8. 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.***

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## Performance Measures (MCA, AONN, & KS Cancer Registry)

1. Number of members in the Masonic Cancer Alliance (MCA) state navigation network
2. Number of certified Academy of Oncology Nurse & Patient Navigators (AONN) in Kansas
3. Late-stage cancer diagnosis (regional + distant) (KCR cases per 100,000)

Baseline:	Baseline:
41 (2021)	58
2 (2021)	25
183.6	175

## Strategies

1. Promote training and certification for patient navigators.
2. Distribute a statewide directory of cancer survivorship resources electronically to patient navigators and promote use of the directory to address patient needs.
3. 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.
4. Provide professional development opportunities for patient navigators and community health workers to enhance core competencies for practice.
5. Assess professional learning needs of patient navigators using the GW Cancer Institute Navigation Competency Self-Assessment Tool.

## Leslie Springfield

Leslie Springfield is a Patient Navigator at a clinic. She was working with a woman who was extremely worried with the diagnostic tests, which progressed to a biopsy immediately. Leslie provided emotional support and education to explain the results and tests and support her through the process. She was diagnosed with breast cancer. Leslie helped her access KanCare through the Treatment Act, but the woman was also concerned about life after treatment, especially how she would financially support herself. As a single woman household working as a food server, she was worried about being able to perform the physical labor or expose herself to things that could be life-threatening to her, like COVID. Leslie learned about a covid-related resource that would pay for housing expenses up to a year, and got the woman connected with this assistance. These and other navigator resources helped the patient access treatment, manage her life and self-care, and feel emotionally supported to get through everything.

Another woman had completed her cervical screenings and diagnostics and was diagnosed with pre-cancerous cervical conditions requiring a LEEP procedure for treatment. She was almost lost to follow-up, because there was a confusion about her eligibility for the Treatment Act. After attempting to get her connected to KanCare and going back and forth, they learned she was not eligible. Leslie was new to the job and stepped in new to help the woman get through the process of applying for charity care, which included extra paperwork and documentation. The woman obtained treatment with the help of navigation.

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

<b>early detection works</b>	call to see if you qualify for a free screening
	Toll Free: <b>1-877-277-1368</b> <a href="http://www.cancerkansas.org">www.cancerkansas.org</a>