

Kansas Cancer Prevention and Control Plan



2022-2027



STATE OF KANSAS

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GOVERNOR LAURA KELLY

My fellow Kansans:

I am pleased to support the 2022-2027 Kansas Cancer Plan. This plan was developed through extensive collaboration between the Kansas Department of Health and Environment and the Kansas Cancer Partnership. The 2022-2027 Kansas Cancer Plan provides a framework for our state's continuous effort to decrease the burden of cancer for our citizens.

Cancer is the second leading cause of death in Kansas. This detrimental disease impacts most of us, whether that be a cancer diagnosis of family, friends, or ourselves. The Kansas Cancer Plan is a call to action. The Kansas Cancer Partnership assists in this fight through the collaboration of various partners including but not limited to: multiple levels of government, public health workers, non-profit and community organizations, policymakers, and anyone with a vested interest in cancer, to decrease the burden of cancer and enhance the quality of life for survivors and their families.

This Kansas Cancer Plan outlines goals, objectives, and strategies for the next five years to improve cancer care. In addition, it addresses priority areas across the cancer continuum, including prevention, early detection and diagnosis, survivorship, and health equity. Each section illustrates the pathway toward improvement and the efforts to be made by the Partnership. The Plan also highlights the stories of those who have survived cancer and those who have been greatly affected by it.

On behalf of the state of Kansas, I extend my support and appreciation for the continued efforts in cancer prevention and care. I would like to recognize all the individuals who worked to develop this plan. Together, we can work to reduce the burden of cancer in Kansas.

Sincerely,

A handwritten signature in blue ink that reads "Laura Kelly".

Laura Kelly
Governor of Kansas

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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 please visit the website kscancerpartnership.org. This website also contains updates on activities and links to current, scientifically accurate information.

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South Central Regional Cancer Coalition

South East Regional Cancer Coalition

Dear Fellow Kansans:

As the Chair and Co-Chair of the Kansas Cancer Partnership (KCP), we are pleased to provide you with the 2022-2027 Kansas Cancer Prevention and Control Plan. We want to thank each of the individuals and organizations who contributed their time, talent and expertise in helping to develop this plan that provides a roadmap for reducing the burden of cancer in Kansas.

The last five years have seen significant accomplishments in cancer prevention, screening, treatment and survivorship, but the work is far from being done. Achieving the goals and objectives presented here will require working with and engaging non-traditional partners to identify and implement new strategies to reduce the disparities around cancer screening and treatment outcomes.

Key focus areas of the 2022-2027 Kansas Cancer Prevention and Control Plan include:

1. Prevention
2. Early Detection
3. Cancer Survivorship
4. Financial Burden and Health Equity
5. Advocacy and Policy

Most of us will at some point in our lives be impacted by cancer. For some it will be a personal diagnosis of cancer, while for others it will be a family member or friend who is diagnosed. Achieving the goals and objectives in this plan will ensure that all Kansans have excellent support systems within their communities, access to quality cancer care, and the resources needed to help deal with the many challenges of cancer.

The Kansas Cancer Partnership brings together individuals and organizations across the state to share information and resources and work towards a common goal of reducing the burden of cancer in Kansas. We welcome new members, and there are many opportunities to be involved. Please visit <https://kscancerpartnership.org/> for information on the different workgroups and regional coalitions and how to join the Kansas Cancer Partnership.

Sincerely,



Jennifer Bacani McKenney, MD
KCP Chair
Family Physician
Fredonia Family Care



Daniel Craig, MS, TTS
KCP Co-Chair
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Executive Summary

Cancer is Prevalent



Each year, on average, about 15,000 invasive cancers are diagnosed among Kansas residents.¹



More than 5,500 Kansans, on average die from cancer each year.¹

Social Determinates of Cancer

Social determinants of health (SDOH) are the conditions in the environments where people are born, live, learn, work, play, worship and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. SDOH also contribute to wide health disparities and inequities.²

Estimated New Cases

		Males	Females		
Prostate	2,038			Female Breast	2,362
Lung & Bronchus	1,009			Lung & Bronchus	955
Colon & Rectum	737			Colon & Rectum	629
Urinary Bladder	565			Corpus & Uterus, NOS	513
Melanomas of the Skin	557			Melanomas of the Skin	407
Kidney & Renal Pelvis	391			Thyroid	305
Non-Hodgkin Lymphoma	391			Non-Hodgkin Lymphoma	267
Oral Cavity & Pharynx	282			Kidney & Renal Pelvis	226
Pancreas	263			Leukemias	216
Leukemias	247	Pancreas	191		

Estimated Deaths

		Males	Females		
Lung & Bronchus	734			Lung & Bronchus	675
Prostate	286			Female Breast	411
Colon & Rectum	244			Colon & Rectum	205
Pancreas	234			Pancreas	183
Liver & Intrahepatic Bile Duct	153			Ovary	126
Leukemias	135			Leukemias	102
Esophagus	131			Non-Hodgkin Lymphoma	96
Non-Hodgkin Lymphoma	117			Liver & Intrahepatic Bile Duct	87
Urinary Bladder	111			Corpus & Uterus, NOS	82
Brain & Other Nervous System	104			Brain & Other Nervous System	69



In Kansas, the age adjusted cancer overall incidence rates were 15 percent to 35 percent higher for men than for women during the period of 2008- 2017.¹



Cancer mortality rates increase dramatically with age, with the highest rate among Kansans aged 85 years and older.¹

Cancer by Ethnicity



Kansans who are African American have significantly higher mortality rates than Kansans who are white.¹ Kansans who are of Hispanic ethnicity have significantly higher mortality rates than non-Hispanic Kansans.¹

¹ Ismail, A., Corbett, S., & Ahmed, F. (2021, February). Burden of Cancer in Kansas. Topeka; Kansas Department of Health and Environment.

² U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (n.d.). Social Determinants of Health. Healthy people 2030. Retrieved December 7, 2022, from <https://health.gov/healthypeople>

Helpful Information

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

Introduction

Purpose

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

- Addressing 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, 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, February 2021, 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.

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 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 2022, there were regional coalitions in the north central, south central, and southeast areas of the state, with a fourth coalition in southwest Kansas due to COVID 19.

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 and population density in cancer control.
2. **Financial Burden:** Decrease the number of Kansans who report financial problems as a barrier to accessing cancer care.
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.
4. **Workforce Diversity:** Improve diversity of the public health and clinical health care workforce.
5. **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.
6. **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).
7. **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.

Prevention:

Prevent cancer from occurring or recurring.

1. **Tobacco Use**
 - a. **Adults** – Reduce the percentage of adults who use cigarettes, e-cigarettes and any tobacco products.
 - b. **Adults with Medicaid** – Reduce the percentage of adults with Medicaid who smoke.
 - c. **High School Students** – Reduce the percentage of high school students who use cigarettes, e-cigarettes and any tobacco products, which is a known risk factor of cancer.
2. **Healthy Behaviors**
 - a. Increase healthy behaviors to mitigate cancer risk factors among Kansas' youth and adults.
 - b. **Adults** – Reduce the percentage of adults in Kansas who are overweight or obese, which is a known risk factor of cancer.
3. **Radon**
 - a. Increase the percent of Kansas homes tested and mitigated for radon during purchase or construction.
4. **Human Papilloma Virus (HPV)**
 - a. Increase HPV immunization rates to prevent HPV-related cancers.

5. **Ultraviolet (UV) Radiation**
 - a. **Sunburn** - Reduce the percentage of Kansans who report sunburn.
 - b. **Indoor Tanning** - Reduce the percentage of Kansans who use indoor tanning devices.
6. **Breastfeeding**
 - a. Increase the proportion of parents who ever breastfeed their infants and who breastfeed in accordance with recommendations.

Early Detection & Diagnosis:

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

1. **Lung Cancer**
 - a. Increase the percentage of high-risk populations (current and former smokers aged 50-74 years old) who had a discussion with their provider about lung cancer screening.
2. **Breast Cancer**
 - a. Decrease late-stage breast cancer diagnosis.
 - b. Decrease late-stage breast cancer diagnosis among African Americans.
3. **Colorectal Cancer** – Decrease age-adjusted colorectal cancer mortality rate.
4. **Prostate Cancer** – Decrease the age-adjusted prostate cancer mortality rate.
5. **Cervical Cancer** – Decrease the age-adjusted cervical cancer mortality rate.

Post-Diagnosis & 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**
 - a. Improve the physical and psychosocial health of people who have had a cancer diagnosis and their care givers.
 - b. Increase cancer care team's knowledge and access to resources supporting the physical and psychosocial health of cancer survivors.
2. **Treatment Summary/Survivor Care Plan**
 - a. Improve access to survivorship care for cancer survivors in Kansas.
 - b. Increase cancer care team's knowledge and access to survivorship care from diagnosis through the lifespan.

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.¹ This status is, “measured in terms of income, education and/or health insurance status.”⁸ 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.⁸

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 ¹	≤ high school ²	Uninsured ³	Frontier/Rural	Urban/Semi-Urban	African American ⁴	Hispanic	Non-Hispanic	Male	Female
Screening										
Colorectal	✓	✓	✓	✓						
Breast	✓	✓	✓	✓						
Cervical	✓	✓	✓							
Lung	✓									
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									✓	

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.^{3,4} In Kansas, annual expenditures related to cancer are estimated to be \$1,213,000,000 annually.⁵

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.⁶ 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.¹

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.⁷

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

³ 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

⁴ 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>

⁵ 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.

⁶ 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>

⁷ 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.⁸

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.⁹

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.

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.

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

⁹ 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.¹⁰



kscancerpartnership.org

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.

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

¹⁰ 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.¹¹

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

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.

¹¹ 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.¹² 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.¹³

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

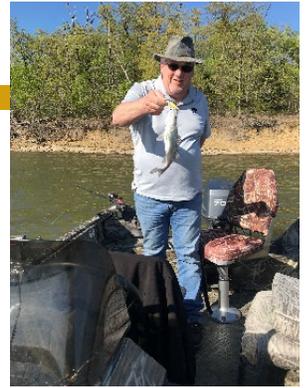
1. Map clinical trial participation by cancer treatment center in Kansas, determine areas of need and tailor provider and patient education to increase participation.
2. Implement culturally appropriate messaging about cancer clinical trials to influence patient shift towards acceptance of clinical trials.
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.

¹² 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>

¹³ 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.

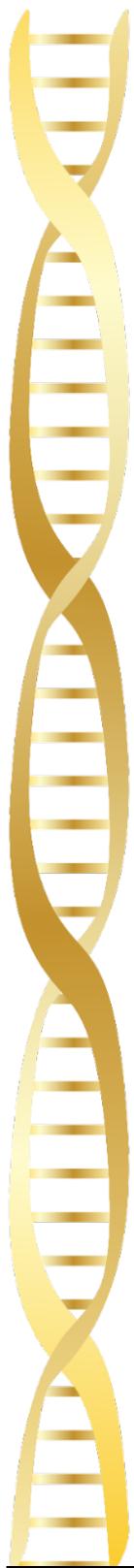
Ovarian cancer: About 1.2% of women in the general population will develop ovarian cancer sometime during their lives. By contrast, 39%–44% of women who inherit a harmful *BRCA1* variant and 11%–17% of women who inherit a harmful *BRCA2* variant will develop ovarian cancer by 80 years of age.

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.¹⁴



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).

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)

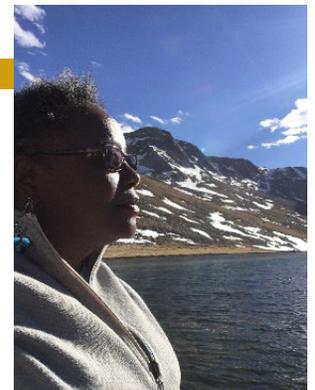
Baseline:	Target:
33.7% (2021)	40.0%
15.1% (2021)	30.0%

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

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.



¹⁴ 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.

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.

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.

early detection works	call to see if you qualify for a free screening
	Toll Free: 1-877-277-1368 www.cancerkansas.org

Prevention

Goal: Prevent cancer from occurring or reoccurring.

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.

Tobacco

You are twice as likely to die as a cancer patient or survivor if you smoke and it increases to four times more likely if you are a heavy smoker. Cigarettes account for at least thirty percent of all cancer deaths. Cigarette smoking is linked to 80-90% of lung cancer occurrences as well as linked to 80% of lung cancer deaths. Lung cancer is the leading cause of cancer death for both men and women.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!

1 - 8 0 0 - Q U I T - N O W (7 8 4 - 8 6 6 9)

[KSquit.org](https://ksquit.org)

Resources are available for people who want to quit smoking or vaping. Call 1-800-QUIT-NOW (784-8669) or visit ksquit.org.

Objective 9a. Tobacco--Reduce the percentage of adults who use cigarettes, e-cigarettes and any tobacco products.

Objective 9b. Tobacco Health Equity--Reduce the percentage of adults with Medicaid who smoke. (Health Equity Objective)

Performance Measures (2021 KS BRFSS, KS Tobacco Quitline, National Jewish Health)

1. Kansas adults who currently smoke
2. Kansas adults who used e-cigarettes in the past 30 days
3. Kansas adults who smoke cigarettes or use any smokeless tobacco product
4. Kansas adults with Medicaid who smoke.
5. Kansas adults with Medicaid who registered with the Kansas Tobacco Quitline
6. Percent of Medicaid patients receiving smoking cessation pharmacotherapy each year
7. Rate of discussing smoking cessation medication with provider by health plan

Baseline:	Target:
15.6% (2021)	13.0%
6.6% (2021)	5.0%
20.5% (2020)	17.0%
39.7% (2021 BRFSS)	30%
300 (2022, National Jewish Health)	330
3.3% (2021, Medicaid)	20.0%

¹⁵ NIDA. 2021, April 12. What are the physical health consequences of tobacco use?. Retrieved from <https://nida.nih.gov/publications/research-reports/tobacco-nicotine-e-cigarettes/what-are-physical-health-consequences-tobacco-use> on 2022, November 18

<u>Health Plan:</u>	<u>Baseline:</u>	<u>5-Year Target:</u>
KanCare	52.54 (Medicaid 2021)	59.54
Aetna	45.45 (Medicaid 2021)	51.45
Sunflower	63.22 (Medicaid 2021)	71.22
United Health Care	47.66 (Medicaid 2021)	53.66

Strategies

1. Identify opportunities to align Kansas Cancer Partnership member agencies with existing Community Health Workers on social referral systems in Kansas communities.
2. Increase referrals to and participation in evidenced-based tobacco cessation services for all tobacco users, including cancer survivors.
3. Collaborate with organizations including Early Detection Works that work with low-income populations to increase referrals to Kansas Tobacco Quitline services to encourage cessation of tobacco use.
4. Encourage cancer treatment organizations to establish a provider web referral policy to the Kansas Tobacco Quitline.
5. Encourage cancer treatment organizations to establish a training policy requiring employees to complete Kansas Tobacco Cessation Help online provider training.
6. Promote Kansas Tobacco Quitline and additional tobacco cessation resources at lung cancer screenings and the Kansas Cancer Partnership website.
7. Support collaboration between KS Tobacco Use Prevention Program, University of Kansas Medical Center, Department of Population Health and KS Breast and Cervical through KCP to increase numbers of staff who obtain KS' new Tobacco Treatment Specialist certification.
8. Increase referrals to free lung cancer screenings.
9. Support collaboration between Kansas Cancer Partnership and the Comprehensive Cancer and Control Program with the Tobacco Free Kansas Coalition.
10. Establish baseline data and targets on the proportion of adult Medicaid beneficiaries who smoke that receive smoking cessation counseling and/or smoking cessation pharmacotherapy.
11. Use methodologies previously established to estimate the number of smokers in the Medicaid program then crosswalk with Medicaid data in Division of Finance to estimate annual rate of smoking cessation treatment for smokers in the Medicaid program.
12. Examine variance in estimated treatment rates by region and health plan; relate rates of treatment to areas of high tobacco use.
13. Work with KanCare health plans on performance improvement plans related to smoking cessation.

Objective 9c. Reduce the percentage of high school students who use cigarettes, e-cigarettes and any tobacco products, which is a known risk factor of cancer.

Performance Measures (2019 KS YRBS)

1. Kansas high school students who currently smoke
2. Kansas high school students who used e-cigarettes in the past 30 days
3. Kansas high school students who smoke cigarettes or use some type of other tobacco product every day or some days

Baseline:

5.8% (2019)

22.0% (2019)

25.8% (2019)

Target:

4.0%

15.0%

20.0%

Strategies

1. Promote My Life My Quit youth cessation program for teens aged (13-17) that provides dedicated line, text coaching and website.
2. Support RESIST youth led tobacco use statewide advocacy events, activities and marketing strategies.
3. Support state and local zoning and licensing initiatives to restrict youth access to tobacco products in the retail environment.

Healthy Behaviors

People who are overweight or obese are at greater risk of 13 types of cancer as well as greater risk of death from the disease. A 2019 study illustrated that, for the year 2012, excess body weight accounted for approximately 3.9% of all cancer.¹⁶ 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.¹⁷



Objective 9c. Reduce the percentage of high school students who use cigarettes, e-cigarettes and any tobacco products, which is a known risk factor of cancer.

Performance Measures (2021 KS BRFSS)

1. Percentage of adults who are overweight or obese
2. Percentage of people who participated in any physical activity such as running, calisthenics, golf, gardening, or walking during the last month

Baseline:

70.5% (2021)

76.4% (2021)

Target:

60.0%

85.0%

Strategies

1. Promote evidence based clinical care and research opportunities for patients, providers, organizations and employers.
2. Conduct a social marketing campaign to increase public awareness of effects of obesity, on health.
3. Expand the knowledge and skills of medical care providers to conduct nutrition screening and counseling regarding sugar-sweetened beverages consumption.
4. Engage and support healthcare professionals in counseling and referral of applicable patients on healthy eating and physical activity.
5. Implement workplace supports for breastfeeding employees, as measured by the number of employers who have achieved the Gold level "Breastfeeding Employee Support Award".

Objective 10b. Increase healthy behaviors to mitigate cancer risk factors among Kansas' youth and adults.

¹⁶ Obesity and cancer fact sheet. National Cancer Institute. (2022, April 5). Retrieved November 18, 2022, from <https://cancer.gov/about-cancer/causes-prevention/risk/obesity/obesity-fact-sheet>

¹⁷ National Institute of Health 2016. Increased physical activity associated with lower risk of 13 types of cancer. Accessed through [Increased physical activity associated with lower risk of 13 types of cancer | National Institutes of Health \(NIH\)](#)

Vegetable Photo from Kossuth, C. (2021, September 16). *National childhood obesity awareness month: Help kids eat the rainbow*. CHCCC. Retrieved February 28, 2023, from <https://www.communityhealthcenters.org/national-childhood-obesity-awareness-month-help-kids-eat-the-rainbow/>

Performance Measures

Adults (KS BRFSS & KS WIC):

1. Consumed at least one fruit serving per day
2. Consumed at least one vegetable serving per day
3. Participated in physical activities other than their regular job in the past 30 days
4. Participated in physical activities or exercises that follow the American Cancer Society's guidelines for cancer prevention during the past month
5. Percent of non-Hispanic black infants enrolled in WIC exclusively breastfeeding through six months of age

Baseline:	Target:
56.3% (2021)	75.0%
80.3% (2021)	85.0%
76.4% (2021)	85.0%
27.0% (2019)	35.0%
10.7% (2021, MCH Bureau)	12.2%

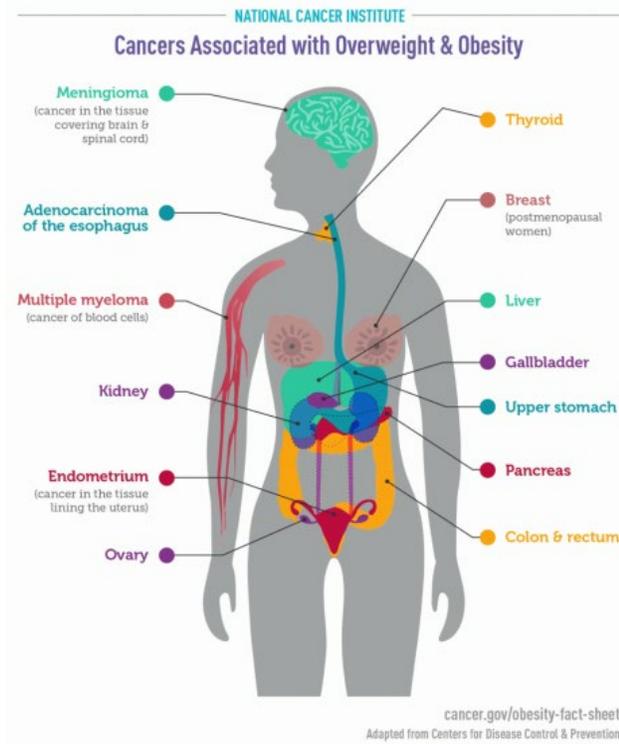
High School Students (KS YRBS):

1. Consumed fruit in the past 7 days
2. Consumed vegetables during the past 7 days
3. Drank soda or pop one or more times a day in the past 7 days
4. Participated in physical activity at least 60 minutes per day in the past 7 days

Baseline:	Target:
93.1% (2019)	100%
94.6% (2019)	100%
9.2%	8.0%
46.9% (2019)	60.0%

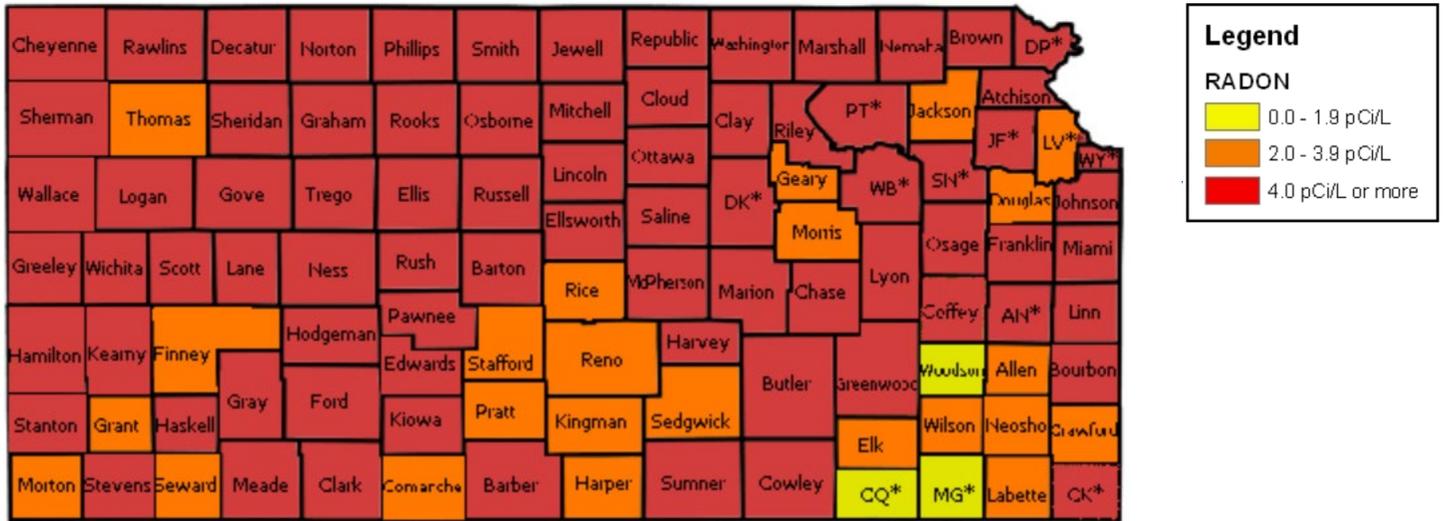
Strategies

1. Collaborate with food policy councils to implement policies and procedures that increase access, affordability and availability of healthy food and beverages in KCP member organizations, worksites, schools, and childcare settings.
2. Implement policies and procedures that increase access, affordability and availability of daily physical activity opportunities in Kansas Cancer Partnership member organizations, worksites, schools, and childcare settings.
3. Expand usage of Supplemental Nutrition Assistance Program/Electronic Benefit Transfer, and Senior Farmers Market Nutrition Programs.
4. Eliminate or reduce the Kansas food sales tax.
5. Create a community asset mapping process to identify and monitor obesity reduction efforts for determining gaps and opportunities to supplement local obesity effort.
6. Disseminate messaging about being physically active within a population that experiences higher rates of obesity or lower rates of physical activity.
7. Disseminate messaging to improve nutrition literacy within a population that experiences higher rates of obesity or lower rates of fruit and vegetable consumption.
8. Increase the number of communities implementing master bike/pedestrian plans intended to increase biking and walking.
9. Increase access to peer and professional lactation support across Kansas, specifically support provided by Black, Indigenous and other people of color.
10. Promote community garden initiatives.



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. It is estimated that there is about 20,000 lung cancer deaths per year in the US that are radon related.¹⁸



Source: Copyright 2018, KDHE and Kansas State University.

Objective 11. Increase the percent of Kansas homes tested and mitigated for radon during purchase or construction.

Performance Measures (KDHE Radiation Program)

1. Homes tested for radon during purchase
2. Kansas cities that have adopted building codes requiring radon-resistant building techniques
3. Number of Radon Measurement Providers certified
4. Number of Radon Mitigation Providers certified

Baseline:	Target:
39% (2021)	50.0%
12 (2020)	20
250 (2022)	275
84 (2022)	92

Strategies

1. Adopt policies on radon disclosure upon real estate transaction.
2. Adopt health and habitability regulations to include radon standards.
3. Provide radon technical information to building code jurisdictions that are considering adopting radon resistant new construction.
4. Increase the number of real estate professionals trained in radon risks.
5. Increase demand for radon testing and mitigation through increased public awareness with social marketing campaign targeted toward property owners.
6. Coordinate consistent messaging with radon stakeholders about radon in homes, schools and childcare centers.
7. Educate to reduce environmental exposures to substances or chemicals linked to cancer.

¹⁸ Radon and cancer. American Cancer Society. (2022, November 1). Retrieved November 18, 2022, from <https://cancer.org/healthy/cancer-causes/radiation-exposure/radon.html#:~:text=Most%20radon-related%20lung%20cancers%20develop%20in%20people%20who,of%20cancer%20as%20well%2C%20such%20as%20childhood%20leukemia.>

8. Ask lung cancer stakeholders such as Tobacco Treatment Specialists and lung cancer screening centers to educate individuals on the risks of radon exposure and how to limit it.
9. Add a radon question during registration for tobacco cessation counseling.

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. More than four out of every ten cases of cancer caused by HPV occur in men. Additionally, women should get regular Pap tests as well as receiving HPV vaccine.¹⁹

Objective 12. Human Papilloma Virus (HPV) - Increase HPV immunization rates to prevent HPV-related cancers.

Performance Measures (NIS-Teen)

1. Kansas females aged 13 to 17 years who report having been vaccinated with three or more doses of the human papillomavirus vaccine

	Baseline:	5-Year Target:
≥1 dose:	70.2% (2021)	80.0%
Up to Date:	70.6% (2021)	80.0%

2. Kansas males aged 13 to 17 years who report having been vaccinated with three or more doses of the human papillomavirus vaccine

	Baseline:	5-Year Target:
≥1 dose:	83.2% (2021)	90.0%
Up to Date:	58.3% (2021)	70.0%

3. KanCare beneficiaries 13-17 years who have completed the human papillomavirus vaccine series

	Baseline:	5-Year Target:
KanCare	34.73 (Medicaid 2020)	TBD

Strategies

1. Add the HPV vaccine to physician recommended vaccines at wellness checkups for recommended populations.
2. 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.
3. Increase the knowledge of and communicate community norms and beliefs about the HPV vaccine in a focused area.

¹⁹ Centers for Disease Control and Prevention. (2022, February 28). Cancers caused by HPV. Centers for Disease Control and Prevention. Retrieved November 18, 2022, from <https://www.cdc.gov/hpv/parents/cancer.html>

4. Partner with the Department of Education to include HPV vaccination education to students and parents.
5. Promote use of the Vaccines for Children Program to provide free vaccinations for uninsured adolescents from low-income families.
6. Increase the number of providers and payer sources using reminder recall systems.
7. Increase the number of Kansas providers who complete provider assessment and feedback activities to increase clinic-level HPV vaccine rates.
8. Expand data sources for monitoring HPV and other vaccination rates through enhanced KS Behavior Risk Factor Surveillance System questions.
9. 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.
10. Use Medicaid and all-payer claims data to examine rates of simultaneous HPV-Tdap vaccinations and variability by health plan.
11. Feedback data on simultaneous HPV -Tdap administration to health plans and providers. Work with health plans on establishing performance objectives and developing performance improvement plans to improve HPV vaccinations.

Anne Zajic

I am a mother to three amazing little girls, Clara, and twins Julia and Katie. I am also wife to my wonderful husband Dean. I gave birth to my twins via cesarean section in November 2015. By December 2015, I had my six-week follow up visit. My OBGYN did a Pap test at that visit and reported that it was normal.



By February 2016, I began experiencing some odd symptoms and I wondered if they had anything to do with the tubal ligation I'd had during my c-section. In May 2016, I found that I had a "never ending" period. I contacted my OBGYN, and she ordered a sonogram to rule out endometriosis and ovarian cysts. After the sonogram, I was informed that nothing was found. I continued to bleed, and experienced fevers, exhaustion, and terrible cramps. Some days, the cramps caused me to double over in pain. I continued to call my OBGYN to report my symptoms, and eventually she decided that the best course of action would be to schedule an endometrial ablation. It was scheduled for August 12, 2016.

On the day of the procedure, I remember waking from anesthesia to overhear the post-op nurses mention that the procedure wasn't completed. I asked why, and my OBGYN informed me that she couldn't do the ablation because I had cervical cancer. I remember feeling as though the room was spinning. My OBGYN set up a CT scan and referred me to a gynecological oncologist.

After my initial CT scan, I was told that the cancer was confined to my cervix and the tumor appeared to be about 4cm. By the time I met with my oncologist and had a PET scan, my tumor measured approximately 6 cm and they found some possible lymph node involvement. I worried that the tumor was growing rapidly, and I felt nothing short of terrified. I was staged as 1b2, and my oncologist informed me that a hysterectomy was not the best option in my case. My treatment consisted of six cycles of chemotherapy, twenty-nine rounds of external radiation to my pelvis, and five rounds of brachytherapy concurrent with the last few rounds of external radiation. Treatment was hard on my body, and brought on nausea, exhaustion, and radiation burns.

I have been cancer free since November 2016, though I continue to manage some long-term side effects of the treatment, including gastrointestinal problems, lower back and hip pain, and early menopause. In addition to physical side effects, I have experienced severe depression and anxiety which I continue to treat.

The stigma I felt because of my diagnosis has given me reason to become a patient advocate for spreading the awareness of cervical cancer. Cervical cancer is often a result of a strain of the Human Papilloma Virus

(HPV), and today it is a very preventable illness. The HPV vaccine prevents cervical cancer and several other HPV-related cancers. By increasing vaccination rates, cervical cancer can and will be eliminated and I won't have to fear that my daughters may someday experience this difficult disease.

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.

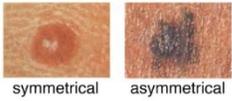
Objective 13a. Sunburn – Reduce the percentage of Kansans who report sunburn.

Performance Measures (KS BRFSS)

1. Percentage of adults who often use sunscreen or sunblock when they are outside on a sunny day for more than an hour
2. Percentage of high school students who most of the time or always wear sunscreen when they are outside on a sunny day for more than an hour

Baseline:	Target:
24.3% (2020)	40.0%
10.7% (2017)	20.0%

A Asymmetry: Moles that have asymmetrical appearance. If you draw a line through this mole, the two halves will not match.



B Border: Uneven, scalloped, jagged, or notched borders



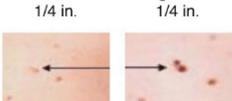
C Color: A mole with more than one color.



D Diameter: The diameter of the mole is usually larger than a pencil eraser, (1/4 inch or 6 mm). They can be smaller, though.



E Evolution: Moles that evolve suddenly in size, shape, color, elevation, crusting, itching, or other traits.



Strategies

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

Source: Dermatology and Skin Cancer Institute

Objective 13b. Indoor Tanning - Reduce the percentage of Kansans who use indoor tanning devices.

Performance Measures (KS BRFSS)

1. Kansas adults who use indoor tanning devices
2. Kansas minors who use indoor tanning devices

Baseline:	Target:
3.0% (2020)	2%
0.8% (2020)	0%

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.

Breastfeeding

In most women who breastfeed, there are hormonal changes during lactation that delays their menstrual periods. This reduces a woman's lifetime exposure to hormones which can promote breast cancer cell growth. Additionally, during breastfeeding, there is a shedding of breast tissue. This shedding can help remove cells with potential damaged DNA.²⁰

Objective 14. Breastfeeding – Increase the proportion of parents who ever breastfeed their infants and who breastfeed in accordance with recommendations.

Performance Measures (KS Breastfeeding Coalition)

1. Employers who have achieved the Gold-level "Breastfeeding Employee Support Award"
2. Breastfeeding friendly local health departments
3. Breastfeeding friendly physician practices
4. Breastfeeding friendly childcare providers
5. High 5 for Mom & Baby premier hospitals

Baseline:

162 (2022)

3 (2022)

19 (2022)

36 (2022)

24(2022)

Target:

194

28

23

43

29

Strategies

1. Promote and support the achievement of breastfeeding friendly designations for childcare providers, employers, hospitals, local health departments, and physicians.
2. Diversify the lactation support provider workforce through scholarships for Black, Indigenous, Latinx and Asian individuals to achieve lactation support provider certifications and/or credentials to increase access to culturally lactation congruent care.
3. Promote the *Breastfeeding Welcome Here* campaign to government entities, schools, businesses and all entities with spaced open to the public.
4. Increase access to clinical lactation care by increasing the number of International Board-Certified Lactation Consultants.
5. Raise awareness and promotion of lactation support provider certification programs.
6. Assist High 5 Mom & Baby Premier hospitals to achieve a Baby-Friendly Hospital designation.

²⁰ MD Anderson Cancer Center, & Cordeiro, B. (2014, October 9). Breastfeeding lowers your breast cancer risk. MD Anderson Cancer Center. Retrieved November 18, 2022, from <https://mdanderson.org/publications/focused-on-health/breastfeeding-breast-cancer-prevention.h19-1589046.html>

Stacy Stowe

I was 46 in the year 2020, the year of the Corona virus, and thought that I was going to get through the year as one of the lucky ones. Overall, for our family, it had been a truly great year. We were already a homeschooled family, so the kids were not impacted by school closures. I only worked part-time and was not dependent on the income and my husband was able to telework from home, which we all loved, and he was getting a promotion in November. As you can see, the year 2020 was full of blessings for my family.

My family came in from out of town for my husband's promotion. I had just gotten out of the shower and was getting dressed when in the mirror I saw a big dent in my left side. Due to the location of the dent, I thought it was caused by the underwire in my bra. I stood in front of the mirror with my hand above my head flexing my pectoral muscles and moving my arm around to get a better look. Then I saw a small dimple in my left breast, two inches from the huge dent in my side. I decided to take a few pictures of the reflection in the mirror for reference.

I began googling, 'Dent in Breast'. The first thing that came up was, "It is not from your bra" and "get it checked". About that time my husband walked into the room, wherewith tremendous guilt I quietly showed him the pictures. You see this was HIS time and I didn't want to take the spotlight off him. He'd waited for more than 20 years for this promotion. I found myself telling him how sorry I was, and he simply insisted that I, at that very moment, get a mammogram scheduled. It had been two years since my last mammogram, so it was time anyway. On the phone, I explained that I have found two dents and was due for an exam, so she got me all set for an appointment the following week.

I went in for my appointment and the large dent was visible to the nurse, but the smaller dimple was undetected until I showed her the picture that I had taken. Then she located it on my breast herself. I was taken to the mammogram machine and then back to the exam room. The doctor came in and said that we needed to do a biopsy of a few suspicious locations and wanted to do them today. I called my very anxious husband and gave him the update. He chose to leave work and join me at the doctor's office.

As he waited for me out in the waiting room, I was having an ultrasound-guided biopsy done on several locations in my left breast. I asked the doctor what his thoughts were and that I wanted the truth. He said, "I think this is going to come back from the lab positive for cancer." A few silent tears dripped down my cheeks. My first thought was of the man waiting for me in the waiting room. This was going to devastate him. The nurse started to tell me what to expect from cancer treatment. I committed to myself at that moment that I was going to be brave. Then I saw my husband sitting there when I came out. I started sobbing. I was too young, small-breasted, and had nursed four children. I was not supposed to get breast cancer.

As the doctor had suggested, the labs did come back as Cancer. I had an MRI and then I had to go back in to get several more biopsies done of the breast due to the MRI findings. The large dent in my side was from an enlarged lymph node and was free of cancer. The small dimple that would have gone unnoticed was caused by a small cancerous tumor. Turns out, two cancerous tumors were in my left breast, deep against my chest wall, and in one of the sentinel nodes. I had a lumpectomy scheduled for the first week in January. The margins did not come back clear. I had invasive ductal carcinoma, invasive ductal carcinoma in situ, lobular carcinoma, and microcalcifications.

The waiting for the next step was brutal. Waiting for the gene testing results, the Oncotype score, and for the plan of treatment. The waiting was the worst. Time stood still. It was decided that I would have a left breast mastectomy and that there was no need to take the right breast. I had another surgery for my mastectomy in February, surgery for my port in March, and then six rounds of chemotherapy, three weeks apart.

I started to lose my hair about two weeks after my first treatment. I sobbed. It was the first time I had cried since the day I saw my husband sitting in the waiting room. I was so embarrassed about not having hair. I didn't even want to go out to the mailbox. I decided to be brave, hold my head high and keep living,

unashamed. It is humbling to realize that I had placed much of my identity into my hair. I choose to focus on joy instead.

I developed soars in my mouth, and a constant bad taste, that I still have. I gained weight from having low energy, food choices and steroids that I took to keep me from losing weight. There were days that I took all my energy to walk up a flight of stairs, but I made myself do it anyways. The hot flashes I began having because the chemotherapy damaged my ovaries became debilitating, affecting my sleep and what I could wear. After my treatments were over, I had a few more surgeries to finish the reconstruction of my breast and my hair started to grow back.

Now, when people see me, they don't see cancer. They don't see the scars that were left behind by cancer that would have taken my life if it had not been detected early. They don't see that my fingers and toes are numb and that I experience pain in my feet when I walk because of the neuropathy. They don't see the fear I have of cancer returning to my right breast. When I feel fear creep in, I choose to stand tall and find my joy. I beat breast cancer.

Stacy Stowe

Early Detection & 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.

Lung Cancer

Objective 15. Lung Cancer - Increase the percentage of high-risk populations (current and former smokers aged 50-74 years old) who had a discussion with their provider about lung cancer screening.

Performance Measures (KS BRFSS & Kansas Cancer Registry)

1. High risk population screened for lung cancer per USPSTF guidelines
2. Late-stage lung cancer diagnosis (regional + distant)

Baseline:

18.7% (2021)

35.3% (2018)

Target:

30.0%

30.0%

Strategies

1. Assess eligibility for lung cancer screening and include referrals to cessation programs, using a provider checklist as a possible resource.
2. Partner with Kansas Tobacco Quitline to encourage lung cancer screening and promote virtual Kansas Tobacco Cessation Help training.
3. Develop and implement a comprehensive public media campaign to promote lung cancer screening, particularly for African American males in urban areas.
4. Promote the My Life, My Quit cessation resources for adolescents.
5. 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.

Michelle Hills

All you need is a pair of lungs to be at risk—

Before my own lung cancer diagnosis, if someone were to ask me the odds, I would be diagnosed with Stage IV Lung Cancer, I would have guessed something along the lines of one in a million. What I didn't know, along with most, is that those odds are closer to 1 in 16. Lung Cancer is the public health crisis no one is talking about because we have been taught, if you don't smoke, you won't get lung cancer. No one is looking for lung cancer in an otherwise healthy 51-year-old competitive athlete.

During our "annual doctor date" in June 2018, my husband and I met with the Primary Care Physician for a routine physical. In passing my husband mentioned I had a little cough following a sinus infection the month before. We didn't think much of it and came home with a nasal spray and cough "pearls". We were totally unprepared for what unfolded over the summer.

As a never-smoker, the pathway to an accurate diagnosis became a long and difficult one consisting of multiple visits to primary care physicians, allergists and pulmonologists. Each physician had a different diagnosis and a different treatment plan, each with the expectation of resolving a progressively worsening cough.

By August 2018, I couldn't speak a full sentence without heaving coughing spasms. Two chest x-rays revealed an atypical pneumonia and some broken ribs. The doctors were stumped, and I was referred to another specialist in infectious disease. After a dozen appointments with three different physicians, a nurse practitioner ordered a CT scan and directed me to the nearest emergency room. She suspected I had a pulmonary embolism. At this point, I had lost count of the number of suspected diagnoses. I just wanted the cough to go



away. I hadn't slept through the night in months, and it was getting impossible to keep up with the demands of my job as a health care executive.

As we entered the Emergency Department, I wasn't overly worried, thinking I would receive fluids and antibiotics and be on my way home within a few hours. When the physician entered the room, there were a lot of words mentioned, but the only phrase I remember was "abnormal CT scan". With a suspected viral or fungal infection, I was admitted. As the viral studies came back negative over a 24-hour period, the first pulmonologist ordered a scope of my lungs called a bronchoscopy. However, the next day another pulmonologist canceled the procedure and ordered a biopsy for the following morning. The only thing I could think of at the time was, "Gosh, I'm really hungry, when can I eat?" My food had been held for almost 24 hours in anticipation of the bronchoscopy. I was told a biopsy would be the fastest way to identify a rare fungal infection.

My husband asked the hard question: Could this be cancer? It wasn't on the top of anyone's mind. I was a never-smoker, had no family history of lung cancer and my house had a radon remediation system. The doctors were still pursuing a fungal infection diagnosis. Even the interventional radiologist said they didn't think it was cancer and believed I'd aspirated during a coughing fit. I blurted out, "you guys have no idea what you're dealing with." I am from New Jersey so sometimes my verbal filters don't work that well, especially when I am hungry.

After a successful tissue biopsy, I wanted to go home. I was receiving intravenous fluids, antibiotics and an antacid. Nothing was helping and each day I felt worse. I saw no point in remaining in the hospital to just wait for CT results. So, I convinced the hospital team to let me go home and take the medications orally. I threw out the antacid, knowing there was no way I could have acid reflux disease.

Exactly 48-hours later, the phone call came. The pulmonologist said the ominous words, "you have adenocarcinoma, lung type". I wasn't exactly sure what that meant but it didn't sound good. In a way, I was relieved because we were finally getting to the bottom of this horrible cough.

We went to see the pulmonologist a few hours later where he indicated I had lung cancer, probably Stage III. He would organize a referral to an oncologist and recommended a course of chemotherapy. We were in shock. I began to sob. I asked about a second opinion. The pulmonologist was happy to arrange one.

Following a dizzying number of appointments, the news wasn't getting any better: Stage IV lung cancer. The initial biopsy did not reveal any "targetable mutations". Dr. Google was a scary place; with a prognosis of 6-12 months, I didn't see the point of treatment.

Somehow my oncologist got me comfortable with one round of chemotherapy while we waited for comprehensive biomarker testing to be completed by a specialty lab in Boston. Three weeks later, we finally had the correct diagnosis: ALK Positive Non-Small Cell Lung Cancer. This was a game changer. Rather than a course of chemotherapy, I started a targeted therapy where I take six pills a day. What could have been an imminently terminal disease turned out to be a treatable condition. My cough resolved immediately after one dose of therapy and I got the first full night of sleep in four months. Diagnosis is not prognosis.

Trying to put my life back together was equally complicated as I was unprepared for the initial response when sharing my story; the most common reaction by far was "I didn't know you smoked". Decades of public health initiatives have failed the primary care community. Each year over 40,000 people who have never smoked are diagnosed with a late-stage lung cancer.

It took almost four years to find my tribe at The White Ribbon Project. It's a grass root non-profit organization committed to changing the public perception of lung cancer. It is critically important to educate the public that anyone with lung can get lung cancer and no one deserves it.

Tricia Olson



My experience with the “C” word began when I was 20 years old, and my mom was diagnosed with breast cancer at 44. At that time there wasn’t the pink ribbon and all the awareness there is today. In fact, my mother waited a year to get a follow up mammogram due to cost. My mother being a pioneer in her own right tested drugs that are now utilized as regular treatment for HER2+ patients. This was one of her greatest blessings to provide hope and new medication opportunities for others afflicted with breast cancer. Although she passed away after 18 years of fighting and six reoccurrences, she was able to pay it forward for the warriors that are going through their cancer journey now.

I found myself at 45 with the same diagnosis as my mother. However, my story is a little different. I had my yearly mammogram a month before I discovered a lump during a self-examine. After a biopsy it was confirmed to be cancer. Due to this early detection, I was able to catch my cancer in an early stage and begin treating it. This may not have been the story if I didn’t do my self-examine. It is so important to do all your screenings and anything else that is needed to continue to find cancer early. I now have been able to celebrate my five-year cancer-free anniversary. This is something my mother was not able to do during her cancer journey.

Breast Cancer

Objective 16a. Breast Cancer – Decrease late-stage breast cancer diagnosis.

Objective 16b. Breast Cancer Health Equity– Decrease late-stage breast cancer diagnosis among African Americans.

Performance Measures (KS BRFSS & Kansas Cancer Registry)

1. Age-appropriate women who had a discussion with their health care provider about breast cancer screening
2. Mammography screening rates
3. Age-appropriate women in the Medicaid program that are up to date with mammography screenings
4. Late-stage breast cancer diagnosis (regional + distant) (Cases per 100,000)
5. Late-stage breast cancer diagnosis (regional + distant) among African Americans (Cases per 100,000)

Baseline:	Target:
82.8% (2020)	88%
73.4% (2020)	78%
48.7% (Medicaid 2020)	54.7%
41.9 (2018)	34
54.6 (2018)	34

Strategies

1. Coordinate and collaborate with the Kansas Early Detection Works Program to increase screening among low income and uninsured African American women, or who have less than a high school education.
2. Collaborate with programs that use community health workers in African American Communities to help accelerate navigation of low-income, uninsured people into cancer screening.
3. Support and advocate for public policy changes that expand the number of individuals who can access screenings as well as Comprehensive Care following a diagnosis.
4. Increase the proportion of people who discuss interventions to prevent cancer with their providers and had their understanding checked.

5. Work with Kansas managed care providers to increase screening among newly insured or under-insured women.
6. Develop quality improvement activities to increase clinical level screening rates
7. Develop and provide free professional education with CMEs/CNEs to clinicians that includes assessment of patient risk, use of current screening guidelines.
8. Work with KanCare health plans on strategies to increase rates of breast cancer screening.

Julie Stafford

Julie has been a PET/CT Technologist since 2007, which means that her job is looking for cancer. She has a family history of breast cancer, and her family has a history of the genetic mutation of the BRACA 1 gene. Her mother is not a carrier, so she is not either. In May 2015, she gave birth to her third son. While breastfeeding a couple of months later, she found a lump. Due to this being common in breastfeeding mothers, she didn't think much of it but still mentioned it to her doctor in September of the same year. They did an ultrasound. This showed that it was likely not cancerous and that she had one of two options either do a biopsy or do a follow up every six months. Since, she did not want to have anything invasive that could hinder breastfeeding, she elected to follow up in six months. In February 2016, there was another ultrasound performed but the lump had changed enough to look suspicious, and the doctors wanted to do a biopsy. She was still rather hesitant to do a biopsy. She wanted to wait until she was done breastfeeding, there would be a rather hefty insurance copay, and she was certain that it would be negative. She luckily had a very persistent doctors who recommended they do the biopsy. With the support from her husband, she did the test and she tested positive for triple negative breast cancer – an aggressive cancer. She started chemo, had a double mastectomy, a reconstruction, and more chemo. She was 33 when she was diagnosed and had three young children at the time. With her work in the cancer section, she does not share her story often but when she does it is only with patients that it would make a positive impact in their lives, to help them have hope. Julie is happy, healthy and cancer free.

Colorectal Cancer

Objective 17. Colorectal Cancer – Decrease age-adjusted colorectal cancer mortality rate.

Performance Measures (KS BRFSS, Kansas Cancer Registry, Kansas Vital Statistics)

1. Age-adjusted colorectal cancer mortality rate (Cases per 100,000)
2. Adults who are up to date with USPSTF colorectal cancer screening guidelines
3. Late-stage colorectal cancer diagnosis (regional + distant) (KCR cases per 100,000)

Baseline:	Target:
14.5 (2020)	12.0
69.7% (2020)	75.0%
22.5 (2018)	16.0

Strategies

1. Seek funding to provide no-cost CRC screening kits for populations that experience higher rates of colorectal cancer mortality and lower rates of colorectal cancer screening.
2. Provide technical assistance to help providers use their clinic Electronic Health Records systems to document clinic level screening rates.

- Develop and provide free professional education with CMEs/CNEs that includes dissemination of the American Cancer Society Colorectal Cancer Screening Toolkit and strategies for increasing clinic screening rates as part of quality improvement activities). Educational opportunities should be relevant to all members of a health care team including community health workers.

Colorectal Cancer (Average Risk)	Colonoscopy	Every 10 years	45-75
	Flexible sigmoidoscopy	Every 5 years	
	CT Colonoscopy	Every 5 years	
	Guaiac-based fecal occult blood testing (FOBT)	Every year	
	FIT = fecal immunochemical test	Every year	
	FIT-DNA = multi-targeted stool DNA test	Every 1-3 years	

Alice Marshall

In May 2015, my daughter suggested I see a dermatologist about a spot on my forehead. It was diagnosed as pleomorphic t-cell lymphoma. My dermatologist sent me to a lymphoma oncologist at The University of Kansas Cancer Center because this was a rare cancer. My husband suggested I go there since it is a National Cancer Institute Hospital. I completed 15 rounds of radiation, and the lymphoma oncologist ordered a CT. Before I was two blocks away from that appointment, he called my cell phone saying I had a tumor in my colon. He asked when I had my last colonoscopy. I am a "rule follower", so I had mine done at age 50 with "all clear". Dr. Yacoub told me I would have my next colonoscopy before I turned 60.



I then started seeing a GI oncologist (Dr. Al-Rajabi) at KU Cancer Center. He sent me to a GI oncology surgeon (Dr. Al-Kasspooles) Dr. Al-Kasspooles laparoscopically removed a little over a foot of my colon and 39 lymph nodes. My colon had 2 tumors. The largest was golf ball size. 20 of my lymph nodes were cancerous. I did 6 months of chemo but was not able to do all 12 rounds due to low blood counts and extreme difficulty with Oxaliplatin. CTs were every three months, and a spot in my lung that had been 0.4 cm grew to 0.9 cm 10 months after I had completed chemo.

I went to a KU thoracic surgeon who specializes in cancer. (Dr. Veeramachaneni) He removed the top lobe of my left lung and some lymph nodes. The pathology report found the spot to be colon cancer, and my lymph nodes were clear. I had the choice of doing chemo or not, and I chose to go with chemo for another 6 months. This time I did not do Oxaliplatin because my medical team feared it would kill me. My response to that was, "That kind of defeats the purpose of chemo." (Have to have a sense of humor with my team.)

On May 7, 2017, I had completed all 12 rounds of chemo, so I have had 20 rounds total of chemo when combining them all. CTs have been stable since June 2018. Now I am No Evidence of Disease. My team will continue to keep an eye on me with annual visits and labs, and I will let them know if there are symptoms that need to be checked. Dr. Al-Rajabi told me I should have a normal life expectancy.

Both of my children have had colonoscopies because of my history. My husband's parents both died from colon cancer, so it is also on his side of the family. There has not been any colon cancer on my side of the family until now.

Now I am a Colon Cancer Ambassador for Fight Colorectal Cancer. I am extremely grateful for that spot in May 2015, that probably helped to extend my life! Prayers, support, encouragement, and research have helped me with this challenge. I always end my social media cancer updates with Faith, Family, Friends, and Incredible Medical Team!

Prostate Cancer

"While we continue to find the smarter screening methods that are reliable, precise, and cost-effective, we continue to advocate shared decision-making in prostate cancer screening in order to work in our patients' best interests."

Tan, G.H., Nason, G., Ajib, K. et al. Smarter screening for prostate cancer. *World J Urol* 37, 991–999 (2019). <https://doi.org/10.1007/s00345-019-02719-5>

Objective 18. Prostate Cancer- Decrease the age-adjusted prostate cancer mortality rate.

Performance Measures (KS BRFSS, Kansas Cancer Registry, Kansas Vital Statistics)

1. Age-adjusted prostate cancer mortality rates (Cases per 100,000)
2. Discussion about advantages of screening
3. Discussion about disadvantages of screening
4. Late-stage prostate cancer diagnosis (regional + distant) (KCR cases per 100,000)

Baseline:

17.3 (2020)
47.1% (2020)
17.0% (2020)
20.4 (2018)

Target:

15.0
60.0%
25.0%
17.0

Strategies

1. Identify or develop and disseminate small media and social marketing communication campaigns to promote wellness visits that include discussions about prostate cancer screening, particularly for African American men in urban areas.
2. Work with Kansas managed care providers to increase discussions about screening among newly insured or uninsured patients.
3. 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.

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.

Cervical Cancer

The USPSTF recommends screening for cervical cancer:	Women aged 21-29 years old	Every 3 years	With cervical cytology alone
	Women aged 30 to 65 years old	Every 3 years	With cervical cytology alone
		Every 5 years	With high-risk human papillomavirus (hrHPV) testing alone
		Every 5 years	With hrHPV testing in combination with cytology
	Women aged 65 years and older	Can stop testing	

Objective 19. Cervical Cancer - Decrease the age-adjusted cervical cancer mortality rate.

Performance Measures (KS BRFSS, Kansas Cancer Registry, Kansas Vital Statistics)

1. Age-adjusted cervical cancer mortality rate (KCR cases per 100,000)
2. Kansas females who are up to date in cervical cancer screening according to USPSTF Guidelines
3. Late-stage cervical cancer diagnosis (regional + distant) (KCR cases per 100,000 persons)

Baseline:	Target:
2.5 (2020)	1.9
83.9% (2020)	90.0%
4.8 (2018)	3.0

Strategies

1. 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.
2. Implement or promote cervical cancer screening and HPV vaccination or referrals as recommended by American Society for Colposcopy and Cervical Pathology.
3. Identify or develop, and disseminate, a social marketing communication campaigns to increase community engagement for cervical cancer screening.
4. Develop quality improvement activities to increase clinical level screening rates.
5. Develop and provide free education about Early Detection Works for Community Health Workers.
6. Develop and provide free professional education with CMEs/CNEs that includes quality improvement activities to increase clinic level cervical cancer screening rates and HPV primary testing. Educational opportunities should be relevant to all members of a health care team including community health workers.

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 15% of cancer diagnoses happen before the age of 39.²¹ Survivors of childhood cancer need lifelong treatment as they are more likely to have side effects from some treatments. These side effects can come from the differences in the types of cancer and the treatments being more intense. These reasons can also lead to better response to certain treatments in children as well.²² Cancer is the second leading cause of death in children ages 1-14, only after accidents.²³

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.

²¹ Pandya, P. (2019, March). Cancer Survivorship Among Kansas Adults, BRFSS 2016. Topeka; Kansas Department of Health and Environment.

The American Cancer Society medical and editorial content team. (2019, October 14). What are the differences between cancers in adults and children? American Cancer Society. Retrieved November 22, 2022, from <https://cancer.org/cancer/cancer-in-children/differences-adults-children.html>

²² The American Cancer Society medical and editorial content team. (2019, October 14). What are the differences between cancers in adults and children? American Cancer Society. Retrieved November 22, 2022, from <https://cancer.org/cancer/cancer-in-children/differences-adults-children.html>

²³ The American Cancer Society medical and editorial content team. (2020, September 18). Key statistics for cancers in young adults. American Cancer Society. Retrieved November 22, 2022, from <https://cancer.org/cancer/cancer-in-young-adults/key-statistics.html>

Objective 20a. Quality of Life - Improve the physical and psychosocial health of people who have had a cancer diagnosis and their care givers.

Objective 20b. Quality of Life - Increase cancer care team's knowledge and access to resources supporting the physical and psychosocial health of cancer survivors.

Performance Measures (KS BRFSS & KCP Survivorship Workgroup Notes and Activity Evaluation Plans)

1. 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
2. Number of cancer survivorship resources and programs implemented and promoted through KCP and KCP members' organizations
3. Number of multidisciplinary health-care team members who participate in continuing education and professional development opportunities offered by KCP members

Baseline:	Target:
11.5% (2021)	10%
16 (KU Cancer Center)	18
522	600

Strategies

1. Identify and adapt existing national organization materials to provide professional education with CMEs/CNEs that includes information on the treatment, financial, emotional, and vocational needs of those living with stage 4 metastatic cancer.
2. Complete an environmental scan to assess current data, determine best practices, identify/develop curriculum and provide free professional education with CMEs/CNEs that includes physical activity and nutritional guideline, supporting care, and aspects that focus on cancer survivors across the cancer care trajectory.
3. Promote or develop professional education with CMEs/CNEs that includes regionally specific disparate populations and targeted evidence-based practices to improve survivors' quality of life.
4. Promote 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.
5. Enhance the KCP website to include a user-friendly web page with resources and programs to inform cancer survivors about physical activity, nutrition and the Kansas Tobacco Quitline.

Carly Flumer

Carly Flumer was diagnosed with Stage I metastatic and refractory papillary thyroid cancer at the age of 27 and again at the age of 31. She received her master's degree from Boston University in Health Communication while going through her first year of treatment, including multiple surgeries and radiation. While being diagnosed with the "C" word at such a young age was a surprise, as it would be to anyone. She found strength, support, and inspiration in sharing her cancer journey on social media. As a result of her health outcome, she looks to advocate for other cancer patients through education, research, and health literacy. She believes that there is power in developing a strong relationship with your care team, and having your provider understand your values and morals as a person, as well as recognizing what you are looking to get out of your cancer journey besides a cure (i.e. maintaining your quality



of life). Finally, she believes in asking questions of your care team (there are no stupid ones!) and expressing what you need of both your care team and your support system.

Treatment Summary/Survivor Care Plan

Treatment Summaries and care plans should contain the required American Society of Clinical Oncology components plus recommendations related to encourage positive mental health, tobacco cessation, physical activity, diet, and other healthy lifestyle behaviors to decrease the risk of cancer recurrence or other chronic diseases.



Source: Stanford Medicine

Treatment summaries will include information about care history: treatments you received, medication doses, surgeries, or any additional treatments that were given. Survivorship Care Plans organizes information about your recommended follow-up care plan. This can include how often you should have check-ups, the types of tests you will need, potential long-term late effects of the treatments received, and suggestions for healthy living.²⁶

Objective 21a. Treatment Summary/Survivor Care Plan--Improve access to survivorship care for cancer survivors in Kansas.

Objective 21b. Increase cancer care team’s knowledge and access to survivorship care from diagnosis through the lifespan.

Performance Measures (KS BRFSS & KCP Survivorship Workgroup Notes and Activity Evaluation Plans)

1. Patients who report receiving treatment summaries.
2. Cancer screening rates in cancer survivors.
 - a. Breast cancer screening
 - b. Cervical cancer screening
 - c. Colorectal cancer screening
 - d. Lung cancer screening

Baseline:	Target:
41.2% (2021)	50.0%
75.7% (2020)	80.0%
91.4% (2020)	95.0%
83.1% (2020)	90.0%
30.0% (2021)	35.0%

Strategies Related to Adult Cancer Patients

1. Collect information, resources and data from partners and organizations across Kansas that provide cancer survivorship programs, services, and support. This could include number of resources utilized, participants and survey responses from programs, tool kits accessed.
2. Educate cancer survivors to ask for treatment summaries and care plans that include cancer screening and follow-up and resources to promote positive mental health, tobacco cessation, physical activity,

²⁶ Asco cancer treatment and survivorship care plans. Cancer.Net. (2022, March 14). Retrieved November 30, 2022, from <https://cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans>

nutrition, and other healthy lifestyle behaviors to decrease the risk of cancer recurrence and other chronic diseases.

3. Provide a list of resources to aid providers in completing a cancer treatment summary and facilitate resources for the promotion of healthy lifestyle behaviors.
4. Identify and promote activities that target increasing rates of cancer screenings for survivors and providers to engage in. This includes utilizing the Early Detection Works Program.
5. Provide resources and professional development on the Kansas Cancer Partnership website.
6. Identify and adapt existing resources to provide free professional education with CMEs/CNEs on the importance of treatment summaries/summary of care and ways to improve provider-provider and provider-patient communication.

Press On Fund

Strategies Related to Childhood Cancer Patients (ages 0-19 years)



1. Increasing the cancer survivor and caregiver's awareness and access to survivorship resources and services by promoting existing resources.
2. 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.
3. Identify and promote free professional education with CMEs/CNEs that includes use of care plans for childhood cancer survivors, and resources for family and caregiver supports.
4. 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.
5. Provide resources and professional development on the Kansas Cancer Partnership website.

Layla Story by her mother Jessica Beckstrand

Layla was diagnosed with stage 4 neuroblastoma at 18 months old. Her hair was straight and so blonde it looked white. She had a big toddler belly that jiggled when she ran. Layla's laugh was louder than a freight train and her smile was bigger than the world.



On October 29, 2015, during a diaper change, her dad and I noticed her big toddler belly distended to one side instead of in the middle. Concerned was an understatement. Having the distention on the right side, we had fear of an enlarged liver. I took her into the nearest hospital to get an ultrasound, while her dad stayed home with her 3-year-old brother, and within 15 minutes we were on the phone with the chair of the hematology-oncology doctor at the children's hospital who told us the most heartbreaking words,

'We think Layla has neuroblastoma, an abdominal cancer.
I need you and her to get to the hospital right now.'

Those words, that sentence, is etched into my soul. It became a part of who I am as a momma. Our entire four-person family was turned upside-down, inside-out and stretched beyond anyone's wildest dreams. For the next almost two years, we had to watch, while only being able to hold her hand, as we laid her life into the hands of the best pediatric oncologists there are.

Cancer is the number one cause of death by disease in children in the United States.

Layla went through the ringer. Six rounds of chemotherapy. The tumor was the size of a small football and had metastasized into all the major bones in her body and surgery to remove it. She had 12 days of radiation to her abdomen and spine, more body scans, and fevers than I can count, 38 blood and platelet transfusions, two stem cell transplants and six rounds of immunotherapy.

In children, 'done with treatment' does not mean done with side effects or worry.

In February 2017, Layla was declared done with treatment. The lifelong effects that Layla will have as a result of front-line treatment is nothing short of debilitating. Survivorship for kids with cancer are told secondary cancers, hearing loss, heart disease, organ troubles, fertility struggles, hormonal imbalances and mental health struggles, are what they have to plan for. Over 90% of children that 'survive' cancer will have one or more of these secondary issues later on in life. The longer these children live, the higher the risk of developing side effects.

Layla is now a healthy 8-year-old girl in 3rd grade. She only remembers the good parts of the hospital, how she was treated by the staff, the bond that she formed with her brother taking care of her. She loves the outdoors, reading fiction books, visiting historical places and her family. Because of her treatment, Layla has hearing loss. She also has over fifty percent chance of developing a secondary cancer along with heart or liver disease and thyroid issues. It's not a matter of if, it's when.

Childhood cancer is not rare.

I want people to know is childhood cancer may be statistically rare, when you compare it to the adult population, but it is not rare. One in 285 kids will be diagnosed with cancer. There are more types of children's cancers than there are adult cancers. Research for childhood cancers needs to be at the forefront of what is funded at the state level and in the country. Seeing progress is the best way for us families to have peace of mind. And our kids deserve the best.

Palliative Care Program KDHE

Palliative and Hospice Care

Palliative Care: According to Kansas statute 65-1,260, "Palliative care' means an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." 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. They are not receiving curative care in these months.

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 nursing. Nineteen palliative care community champions decided to move forward to develop a 4-session ECHO series in collaboration with KU Telehealth/Project ECHO, KU Area Health Education Centers, the Masonic Cancer Alliance and Wichita Medical Research & Education Foundation.

Objective 22. Palliative and Hospice Care - Improve Kansas scorecard for access to Palliative Care services, as measured by Center to Advance Palliative Care.

Performance Measures (ELNEC attendance reports & Center to Advance Palliative Care)

1. Number of one-day ELNEC course attendees
2. Number of two-day Train-the-Trainer ELNEC course attendees
3. Number of one-day APRN ELNEC course attendees
4. Kansas counties providing professional educational opportunities in palliative care
5. Kansas palliative care report card

	Baseline:	Target:
1. Number of one-day ELNEC course attendees	1033	1100
2. Number of two-day Train-the-Trainer ELNEC course attendees	206	300
3. Number of one-day APRN ELNEC course attendees	73	90
4. Kansas counties providing professional educational opportunities in palliative care	26	35
5. Kansas palliative care report card	C	A

Strategies

1. Collaborate with the Palliative Care Team in KDHE to recruit and educate more Palliative Care practitioners in Kansas.
2. Collaborate with the Palliative Care Team in KDHE to provide educational trainings to practitioners and survivors.
3. Conduct an environmental scan that includes a heat map of providers and resources that are available.
 4. Promote attendance the 2-day ELNEC train-the-trainer course to train palliative care “champions” to drive local system change by recruitment through state and regional coalition partnerships.
 5. Implement statewide APRN 1-day ELNEC training in primary palliative care techniques/skills by offering in-person and internet-based courses.
 6. Collaborate with the Palliative Care Team in KDHE to increase the number and geographic dispersion of attendees at the 1-day ELNEC training course on palliative care for health care professionals by offering in-person and internet-based courses.

Treatment Standards

Treatment standards are evidence-based standards to provide guidance for best practices in cancer care. These can be used to inform policies and procedures in the healthcare setting, internal quality assessment, and external quality monitoring.²⁷

Objective 23. Treatment Standards - Increase the number of cancer patient care facilities in Kansas participating in nationally recognized quality improvement programs.

Performance Measures

1. The number of cancer care organizations across Kansas that participated in national performance and evidence-based standards program including but not limited to American College of Surgeons Commission on Cancer accreditation program, American Society of Clinical Oncology’s Quality Oncology Practice Initiative Certification Program or other quality/performance standards program.

Baseline:	Target:
15 care organizations	20

Strategies

1. Actively promote and align quality standards of care with national guidelines.
2. Support local/regional collaborations among cancer centers to create a community of practice supporting evidence-based cancer care.

²⁷ Cancer care standards. ASCO. (2021, October 20). Retrieved November 30, 2022, from <https://old-prod.asco.org/practice-patients/cancer-care-standards>
 Ribbon Image Credit to Mumswrite.com.au

3. Support cancer centers and hospitals throughout Kansas in their application for evidence-based quality improvement program accreditation or certification.
4. Increase provider use of evidence-based treatment guidelines by and through tele-mentoring, promoting awareness, education and advocacy efforts to increase the number of patients receiving the highest quality of care.
5. Support the development and implementation of system changes that improve quality of care for Kansas cancer patients at the local or state level, including data tools that help identify quality deficits and electronic health record tools that assist providers in delivering timely and accurate oncology patient care.
6. Engage with partners to identify and strategize to address variations in care due to access to screening, biomarker directed therapy, and healthcare disparities.

Tracy Mason

Tracy had gone to the local hospital when she noticed she needed a mammogram. She left this hospital with the information that she could have either an infection or an invasive cancer, and to come back in 30 days to see if the potential infection had cleared. Tracy was not satisfied with that answer and she called KU the next day. At KU, many tests were performed. She had several mammograms and ultrasounds, but nothing was picking up this 10cm tumor that was growing rapidly. Tracy was finally diagnosed in 2019 with a rare type of breast cancer: invasive lobular pleomorphic carcinoma HER2+.



This cancer is one that is mainly found in women older than 65 and it is one that grows rapidly. Her cancer grew in 5 days with no sign of stopping. Tracy found it a relief to finally know what is happening with her body. Her oncologist wanted to start chemo the next week, in preparation they did ECHOs, EEGs, Bone Scans, and PET Scans. She had her port placed and within 7 days, she had an allergic reaction to the port. She had a year's worth of chemo and 33 rounds of radiation. Tracy had mastectomies and countless surgeries such as reconstruction.

Looking back, she would not change anything. She believes that was equipped to handle a hard diagnosis, as she had underlying cardio and neuro muscular problems. She was not afraid to do what she had to do to survive, she was prepared to be stubborn. This diagnosis made her stronger than she already was, she had to be. She met some of the greatest people through cancer. She hopes that people who read this story get hope out of her experiences. She wants everyone to know that if she can do it you can too as well as it is okay to give yourself some grace.



Cancer Prevention and Control Programs

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