

Post-Diagnosis & Quality of Life throughout the Cancer Journey

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

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

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

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

¹⁷ National Cancer Institute 2014. *Cancer in Children and Adolescents*. Accessed through <https://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet#2>

Annabella's Journey

Told by her mother, Emily



“Our family’s faith sees us through this journey. Sometimes we feel helpless, but never hopeless.”

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

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

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

Wishes:

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

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

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

Quality of Life

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

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

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

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

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

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

Performance Measures (2014 KS BRFSS)

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

Baseline

25%

5 Year Target

20%

Strategies

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

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

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

Treatment Summary/Survivor Care Plan

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

Key ASCO **treatment summary** components:

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

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

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

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

Performance Measures

Patients who report receiving treatment summaries (KS BRFSS)

Patients who report receiving resources for healthy lifestyle behaviors (TBD)

Baseline	5 Year Target
TBD	TBD
TBD	TBD

Strategies related to adult cancer patients

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

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

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

Palliative and Hospice Care

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

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

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

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

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

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

Strategies

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

Treatment Preferences for Advanced Cancer

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

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

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

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

Performance Measures (Center for Practical Bioethics (CPD))

Number of Kansas TPOPP training attendees

Baseline

104

5 Year Target

520

Number of TPOPP Toolkit downloads from CPB website

88

440

Number of Kansas communities active in Kansas-Missouri TPOPP Coalition

10

100

Strategies

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