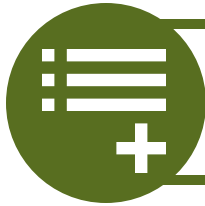

Kentucky Cancer Consortium Cancer Survivorship Series

A series of data, information and resources about cancer survivorship in Kentucky.





An Introduction of the Survivorship Series

February 2022



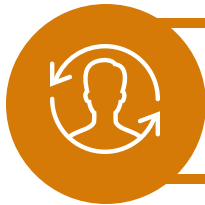
Cancer Survivorship Definitions and Kentucky Data

April 2022



Quality of Life Challenges

June 2022



Quality of Life Optimization

August 2022



Patient Navigation Perspectives

October 2022



KCC Partner Needs and Resources

December 2022

What is the KCC Cancer Survivorship Series?

One of the Kentucky Cancer Consortium's key priorities is **cancer survivorship**. The Kentucky Cancer Needs Assessment includes data that helps describe the landscape of cancer survivorship in Kentucky. KCC hosted a "partner conversation" in June 2021 to listen to patient navigators, community health workers, and other KCC partners to understand the current practice of addressing cancer survivor's needs.

Cancer survivorship is big, complex, and ever-changing. We learned we need to start with clear definitions of "cancer survivor" and "cancer survivorship," share digestible data about cancer survivors in Kentucky, include practical summaries of relevant research, and guidance on how to connect with others working in this area. Another area of interest included where to find resources and support, and how to select and implement strategies to support cancer survivors. We will share Kentucky data and what we learned from our partner conversations in a series of mini-reports designed for our KCC partners in Wednesday's Word throughout 2022.

The Survivorship Series will provide data, partner input, and resources about cancer survivorship in Kentucky.

introduction

data

quality of life


quality of life II

navigation

partners

Wondering how you can use the information from this series?

Not everyone is comfortable with the term “survivor” and depending on the stage at diagnosis and a number of other things, folks may not identify as a “survivor.” Partners who work with people with a cancer history (i.e. cancer survivors) should consider the following key takeaways:



Ask

Ask individuals what term they prefer in the same way that you ask people their preferred name (e.g. Jess vs Jessica).



Adopt

Adopt inclusive language for the population. It is important to understand the population/community-level communication approach might need to differ from the approach for any one person.

Defining Cancer

Primary cancer: a term used to describe the original, or first, tumor in the body.

Cancer cells from a primary cancer may spread to other parts of the body and form new, or secondary, tumors.

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/primary-cancer>

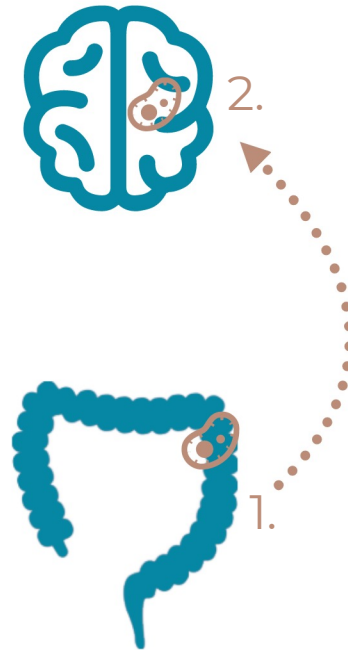


Note: There are two different types of tumors: benign (non-cancerous) tumors and malignant (cancerous) tumors. A benign tumor is composed of cells that will not invade other unrelated tissues or organs of the body, although it may continue to grow in size abnormally. A malignant tumor is composed of cells that invade or spread to other parts of the body. <https://www.cancer.gov/about-cancer/understanding/what-is-cancer>

Defining Cancer

Metastasis: the spread of cancer cells from one place where they first formed to another part of the body.

In metastasis, cancer cells break away from the original/primary tumor, travel through the blood or lymph system, and form a new tumor in other organs or tissues of the body.

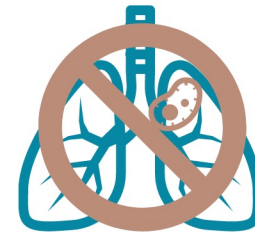


<https://www.cancer.gov/publications/dictionaries/cancer-terms/search/metastasis/?searchMode=Beginns>

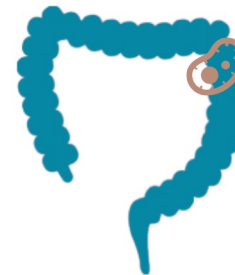
Defining Cancer

Second primary cancer: a term used to describe a new primary cancer that occurs in a person who has had cancer in the past.

Second primary cancers may occur months or years after the original (primary) cancer was diagnosed and treated.



*Primary cancer that has been treated and no longer exists



*A new primary cancer that has developed

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/secondary-cancer>

Defining Cancer Survivor

"Many continue to struggle with how to define "survivor," or whether to use it at all. We recognize that the term **"cancer survivor" may be seen differently by people based on their own experiences.** Battlefield and war analogies that one often hears can seem to imply that a person who succumbed to their disease didn't "fight" hard enough or long enough to "win" their "battle." We respect that everyone who is affected by cancer can choose to identify with the term they feel best describes their experience whether it be "survivor," "thrivor," "person living with cancer," any other term that resonates, or even no label at all."

National Coalition for Cancer Survivorship

"The term cancer survivor refers to **anyone who has ever been diagnosed with cancer** no matter where they are in the course of their disease."

American Cancer Society

"An individual is considered a cancer survivor from the time of diagnosis, through the balance of life. **There are many types of survivors, including those living with cancer and those free from cancer.** This term is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals."

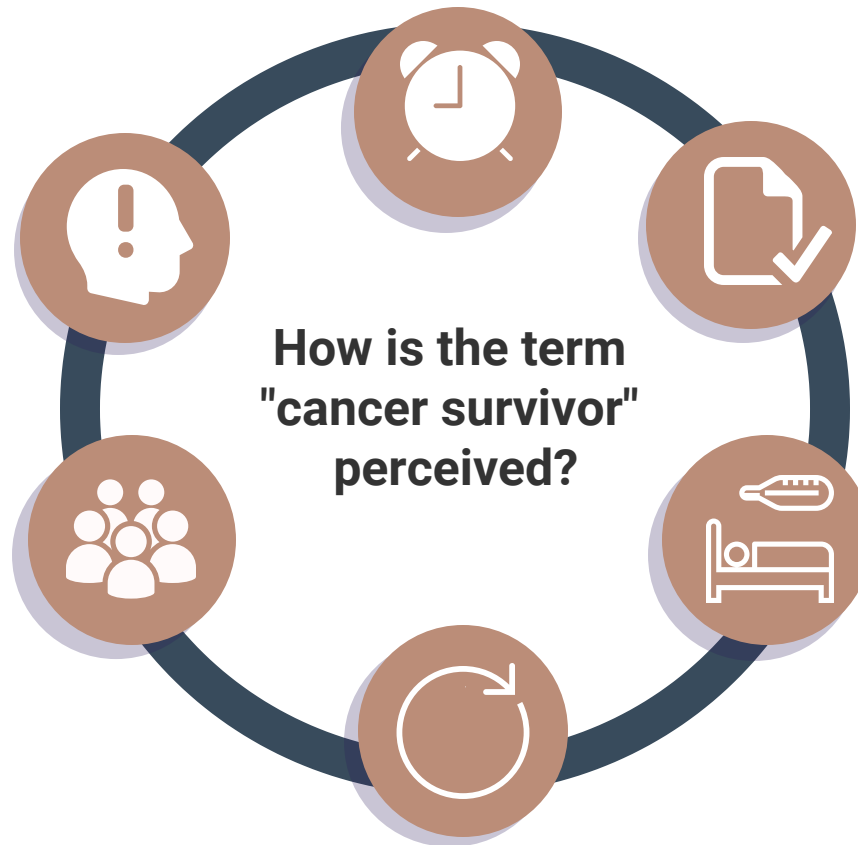
National Cancer Institute of Health Division of Cancer Control and Population Sciences

introduction — data

quality of life — quality of care — navigation

patient care

Some individuals were unsure if enough time had passed to be considered "in the clear" and a survivor. (Clegg, 2016)



Adoption of the "survivor" identity increased when individuals perceived themselves as having a "very good prognosis" or recalled being told they were cured. (Cheung, 2016)

Some individuals felt their cancer wasn't "bad enough" or "traumatic enough" to use the title. (Clegg, 2016)

Survivor as a term is tied with trauma, and not everyone finds cancer traumatizing or traumatizing in the same way. (Bell, 2013)

Some identified as survivors because:

- They had cancer in the past
- Someone else, such as a clinician said they were a survivor
- They felt life was different before and after cancer
- They find a sense of community by self-identifying as a survivor

(Clegg, 2016)

Some said that they felt using the term was "tempting fate" and would lead to recurrence. (Cheung, 2016)

Estimated Number of Cancer Survivors (Prevalence)

Here we use the term "prevalence" to refer to the total number of people in the population who have previously been diagnosed with cancer and who are alive today.



United States
16,920,370



Kentucky
254,780

5-Year Relative Survival

Relative Survival

The percentage of people with cancer still living five years after diagnosis compared to a matching cancer-free population.



This gives a measure of survival that factors out other causes of death. Relative survival can be measured for either a general cancer diagnosis or for specific cancer sites.

All Site Relative Survival

67.9%

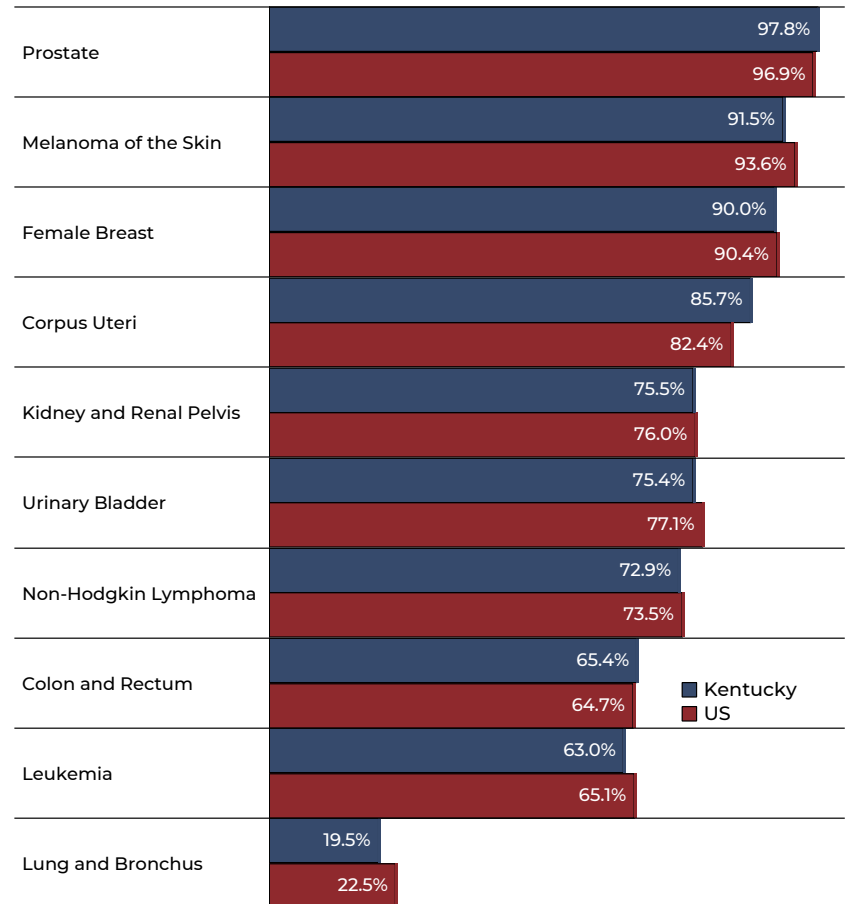


63.1%



Source: 2021 Kentucky Cancer Needs Assessment
Data: KCR/SEER 2012-2018

Relative Survival of Top 10 Incidence Rate Cancers



Significant Disparities in Relative Survival



Kentucky differs from the US in

- liver (25% lower survival)
- lung (13% lower survival)



Appalachian KY differs from Non-Appalachian KY in

- lung (20% lower survival)
- prostate (3% lower survival)
- female breast (4% lower survival)



Rural KY differs from Urban KY in

- lung (19% lower survival)

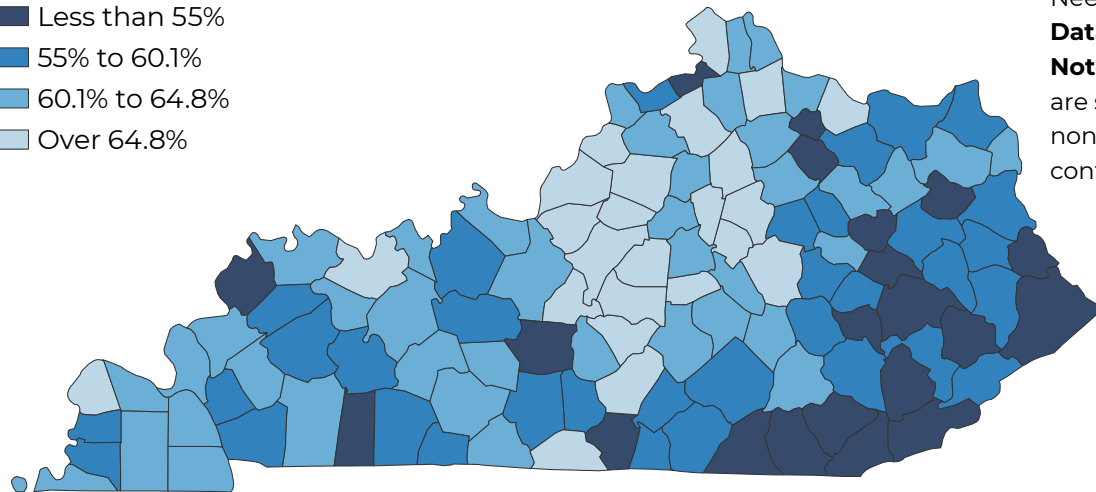


Black Kentuckians differ from White Kentuckians in

- female breast (10% lower survival)

Relative Survival, All Cancer Sites

- Less than 55%
- 55% to 60.1%
- 60.1% to 64.8%
- Over 64.8%



Source: 2021 Kentucky Cancer Needs Assessment

Data: KCR/SEER, 2012-2018

Note: Highlighted disparities are significant on non-overlapping 95% confidence intervals

What Is Health-Related Quality of Life?



“

"The overall enjoyment of life; an individual's sense of well-being and ability to carry out activities of daily living."

source: <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/quality-of-life>

—

introduction

data

quality of life

quality of life II

navigation

partners

Physical Well-Being

- Functional status
- Fatigue and sleep
- Overall physical health
- Fertility
- Pain
- Symptom burden
- Comorbidity



Psychological Well-Being

- Control
- Sense of worry
- Denial
- Avoidance
- Anxiety
- Depression
- Fear of recurrence
- Cognition/attention



Social Well-Being

- Family distress
- Roles and relationships
- Affection/sexual function
- Appearance
- Isolation
- Finances/employment



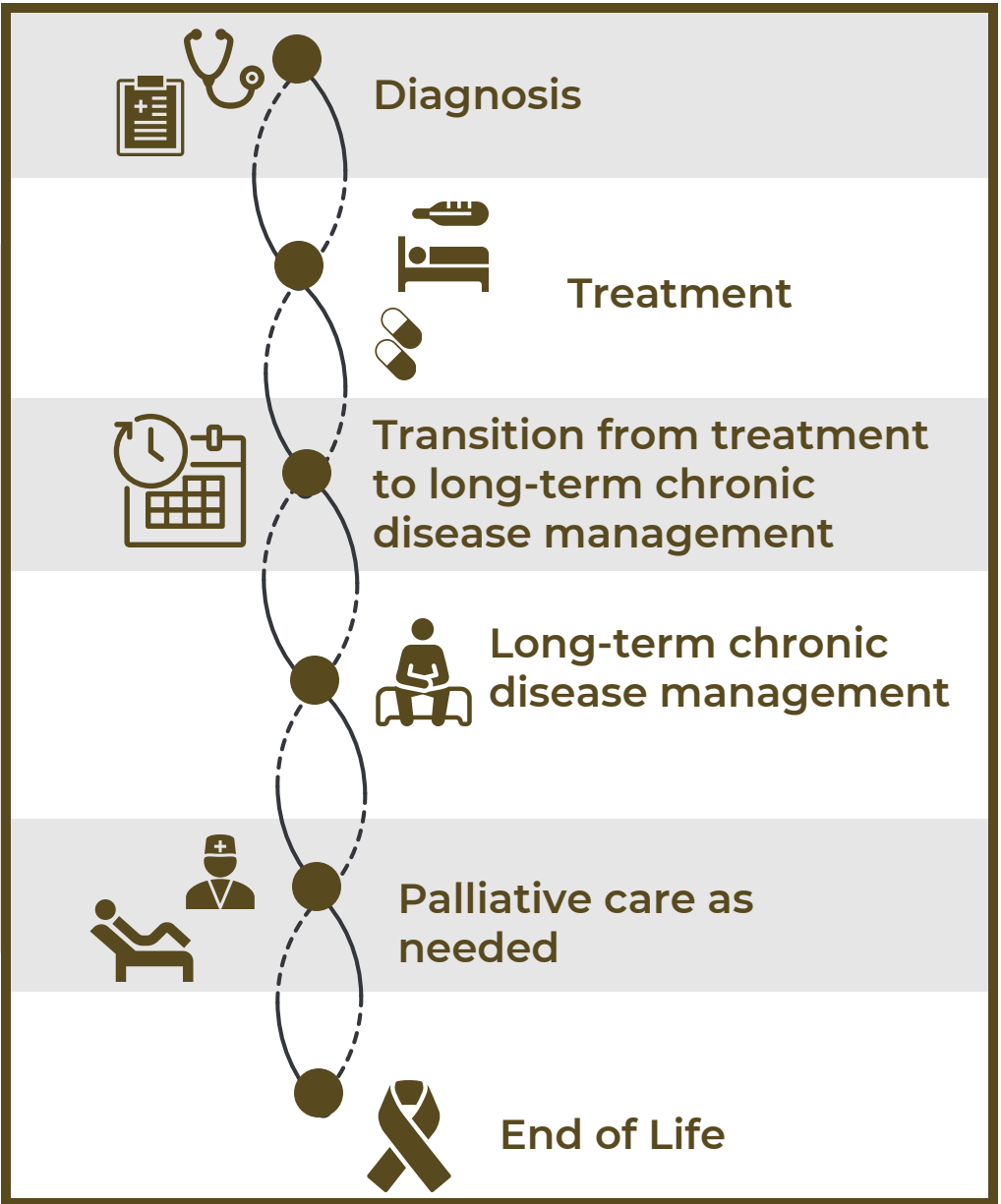
Spiritual Well-Being

- Meaning of illness
- Religious strain
- Strength of faith
- Transcendence
- Hope
- Uncertainty
- Inner Strength

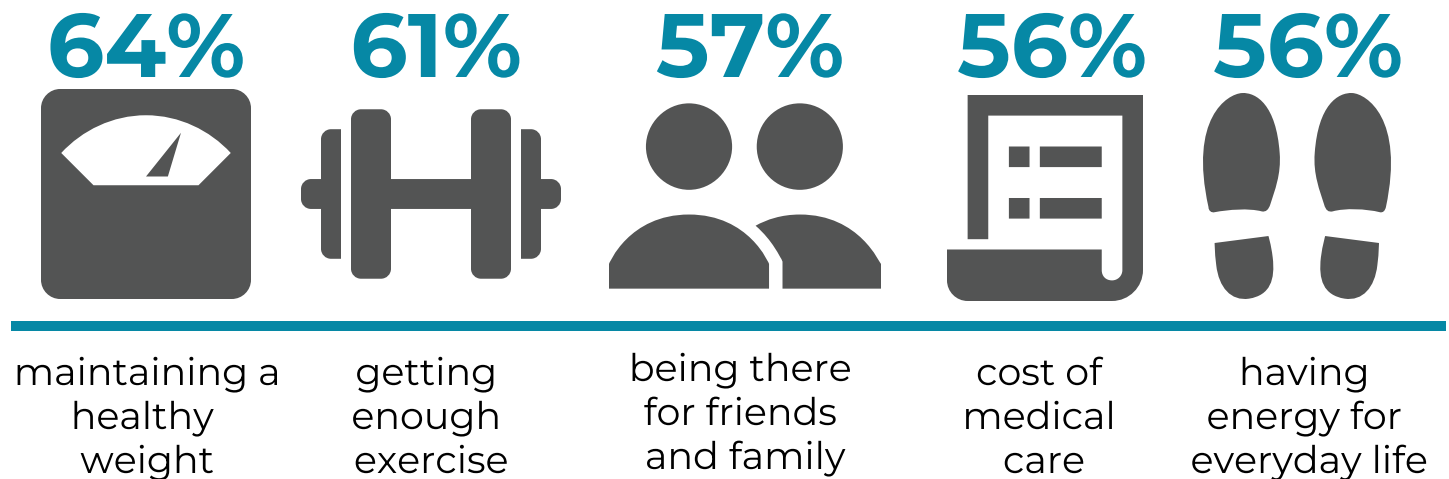


Quality
of Life

Individuals may go in and out of phases. This is not a linear process.

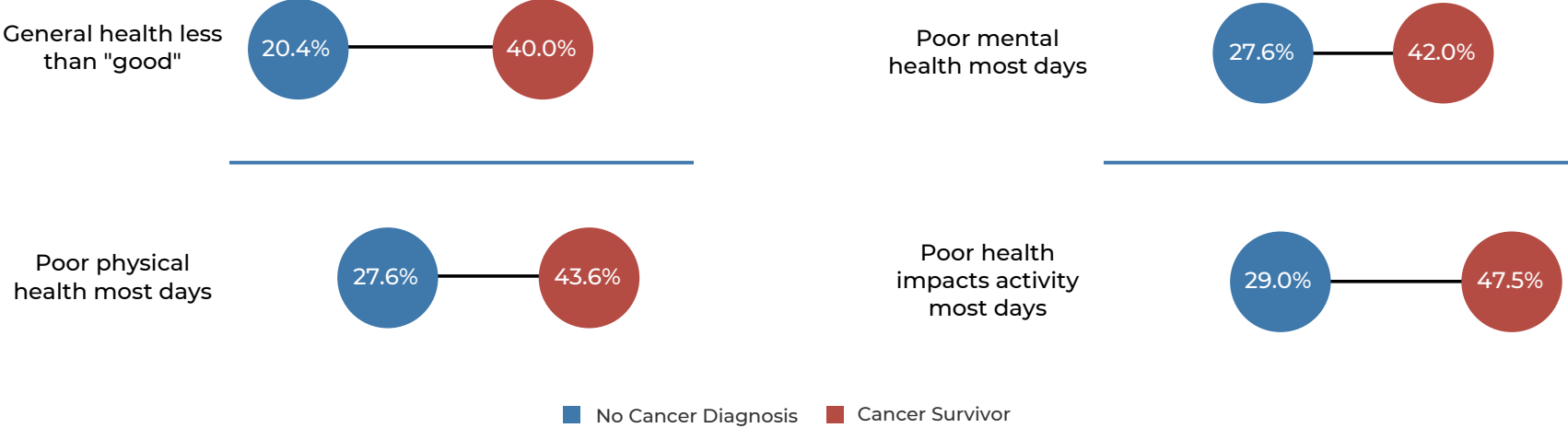


Top Concerns That Impact Quality of Life Among Cancer Survivors in the U.S.



Source: 2020 State of cancer survivor survey <https://www.curetoday.com/view/nccs-unveils-survivorship-data-from-nationwide-survey-of-cancer-survivors>

Health-Related Quality of Life Among Kentucky Cancer Survivors



Risk Factors for Kentucky Cancer Survivors



20.5% currently smoke



9.4% with unhealthy drinking habits



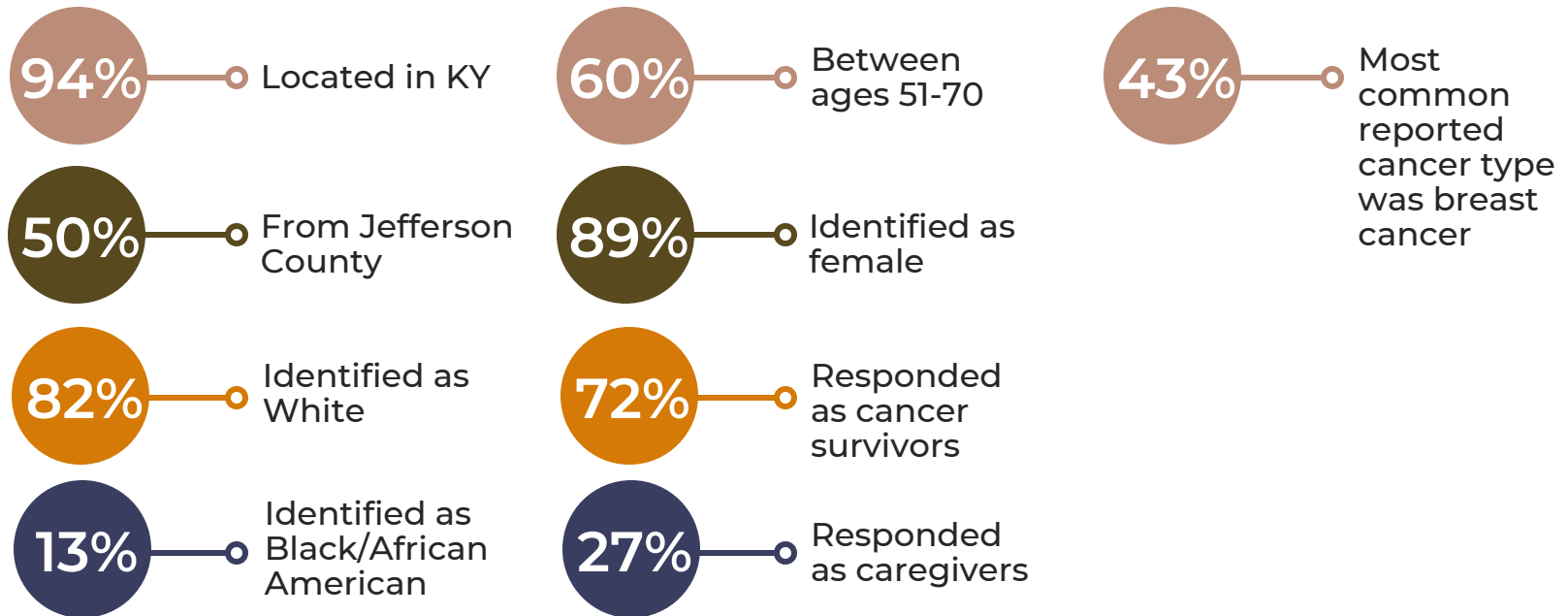
16.6% sleep less than 6 hours a night



71.2% currently overweight or obese

Source: 2021 Kentucky Cancer Needs Assessment
Data: Ky BRFSS, 2018-2019

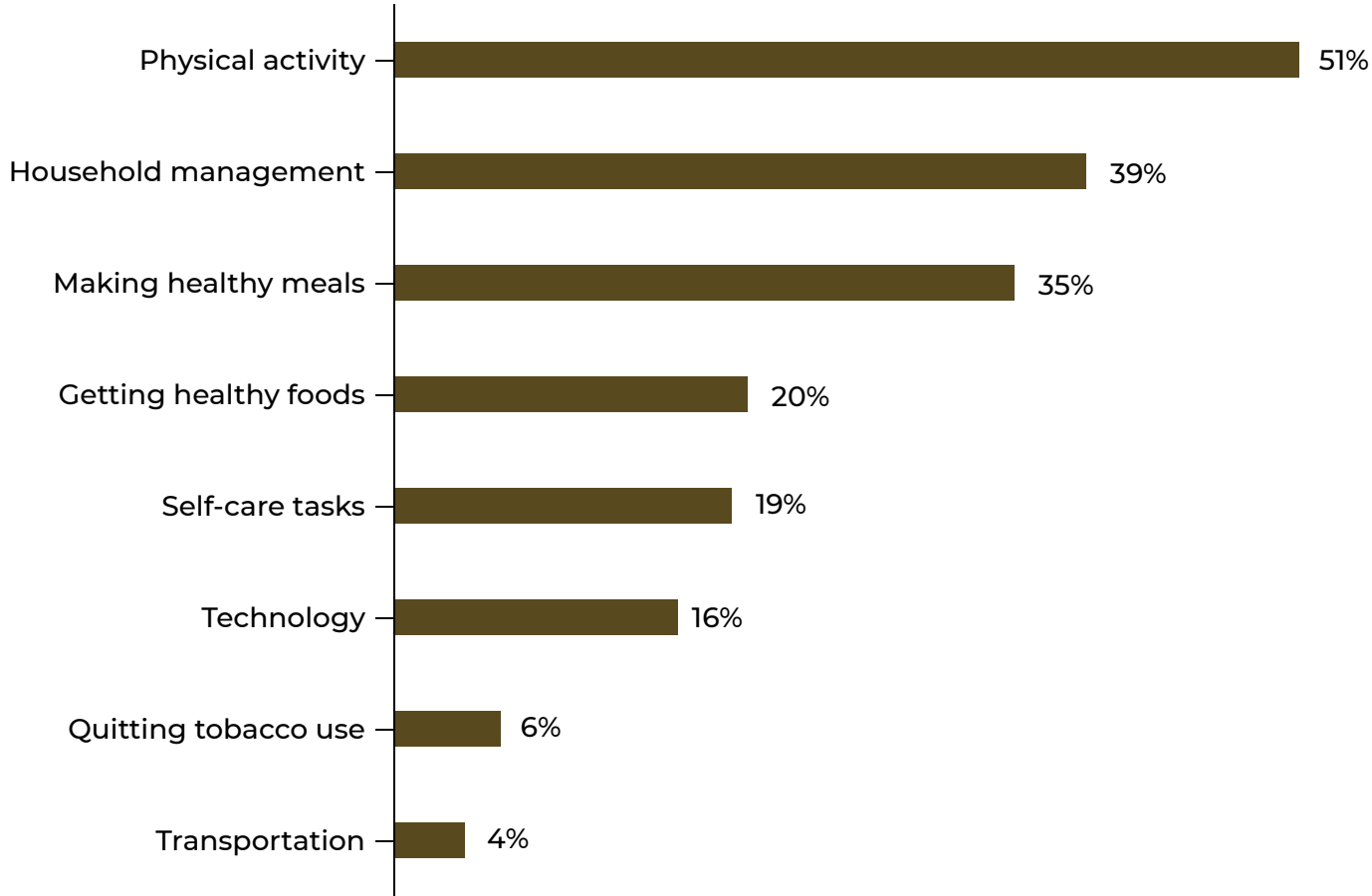
COVID-19 Pandemic Survey of Kentucky Cancer Survivors and Caregivers: Who Responded



Highlights from the 79 Kentucky cancer survivors and caregivers who responded to the survey conducted in Spring 2021 by the Kentucky Cancer Program and the Kentucky Cancer Consortium.

COVID-19 Pandemic Survey of Kentucky Survivors and Caregivers: Top Concerns

Percent of respondents who reported a need for support and resources



American Cancer Society Cancer Survivorship Care Guidelines



Surveillance for
Recurrence



Screening for
New Cancers



Physical and
Psychosocial
Long-Term and
Late Effects
Management



Health
Promotion



Care
Coordination

**Use of
Guidelines
May Vary**

Depending on who you are and where you are working, you may be using these differently to meet the needs of cancer survivors.

introduction

data

quality of life

quality of life II

navigation

partners

Quality of Life: Optimization

Survivorship starts from the time of diagnosis and quality of life needs vary throughout the survivorship journey. For more information about quality of life, revisit last month's Survivorship Series: [Quality of Life Challenges](#).

It is helpful for cancer survivors to have a plan to address the [challenges](#) to their well-being. This series provides resources for those supporting cancer survivors.

introduction

data

quality of life

quality of life II

navigation

partners

Supporting Cancer Survivors



Screen



Ask Questions



Connect With
Resources



Follow Up



Continued Care

These are common steps that patient navigators take when assessing and supporting cancer survivors. This process can be used in the community or the clinic.

introduction

data

quality of life

quality of life II

navigation

partners



Screen



Ask Questions



Connect With
Resources



Follow Up



Continued
Care

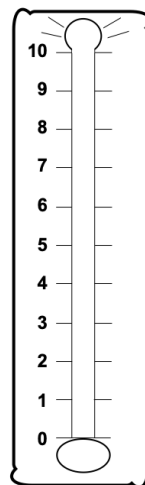
The first step is to screen, score, and understand the cause of distress. Being diagnosed with cancer and going through treatment can be stressful.

One tool that could be used is the [National Comprehensive Cancer Network Distress Thermometer](#)

NCCN Distress Thermometer

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Extreme distress



No distress

Additional tools are:

[Patient-Reported Outcomes Measurement Information System \(PROMIS\)](#)

[Patient Health Questionnaire \(PHQ\) Screeners](#)

[PhenX Toolkit](#)

02



Screen



Ask
Questions



Connect With
Resources



Follow up



Continued
Care

Asking questions is the second step that is often used to help understand which area(s) are causing the most distress.

- Ask questions that help prioritize which area(s) are the biggest distress concern that needs to be addressed first.
- Consider using the second step of the [NCCN Distress Thermometer](#) as a guide.

03



Screen



Ask Questions



Connect with
Resources



Follow Up



Continued
Care

Developing a plan to connect to resources is the third step. Many resources are available at free or reduced cost for cancer survivors.

- These resources will support their physical, psychological, social, spiritual, financial, and other needs.
- Specific examples are provided in the rest of the document.



Screen



Ask Questions



Connect With
Resources

04



Follow Up



Continued
Care

Follow-up for cancer survivors is important because there are long-term physical, psychological, social, spiritual, and financial challenges that impact quality of life.

- Ensure you have provided and obtained good contact information.
- Provide continued support and be available when they have questions.
- Find out if the resources you provided meet their needs.
- Check-in and rescreen for distress to see if they need additional resources.

introduction

data

quality of life

quality of life II

navigation

partners



Screen



Ask Questions



Connect With
Resources



Follow Up

05



**Continued
Care**

After treatment, cancer survivors need continued care. The [ACS guidelines](#) reflect current evidence and expert consensus to help primary care clinicians and other health care professionals provide comprehensive clinical follow-up care.



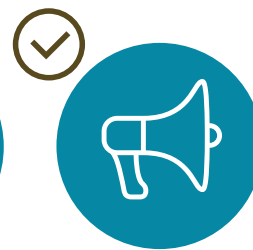
Surveillance for
Recurrence



Screening for
New Cancers



Physical and
Psychosocial
Long-Term and
Late Effects
Management



Health
Promotion



Care
Coordination

Resources to Address Quality of Life

- The following slides list resources that are available to survivors and highlight the quality of life needs that they address.
- Look for the color guide on each slide to determine which needs the specific resource addresses.



Some state-level resources include:

- Cancer Support Community Greater Cincinnati-NKY
- American Cancer Society
- KY African Americans Against Cancer
- Kentucky Cancer Link
- Friend for Life Cancer Support Network
- Gilda's Club
- Kentucky Cancer Program – Pathfinder

Physical

Here are some State and National resources to help cancer survivors with physical well-being.



Physical Well-Being

- Functional status
- Fatigue and sleep
- Overall physical health
- Fertility
- Pain
- Symptom burden
- Comorbidity



[More: Quality of Life Challenges](#)

introduction

data

quality of life

quality of life II

navigation

partners

Physical: Health Promotion



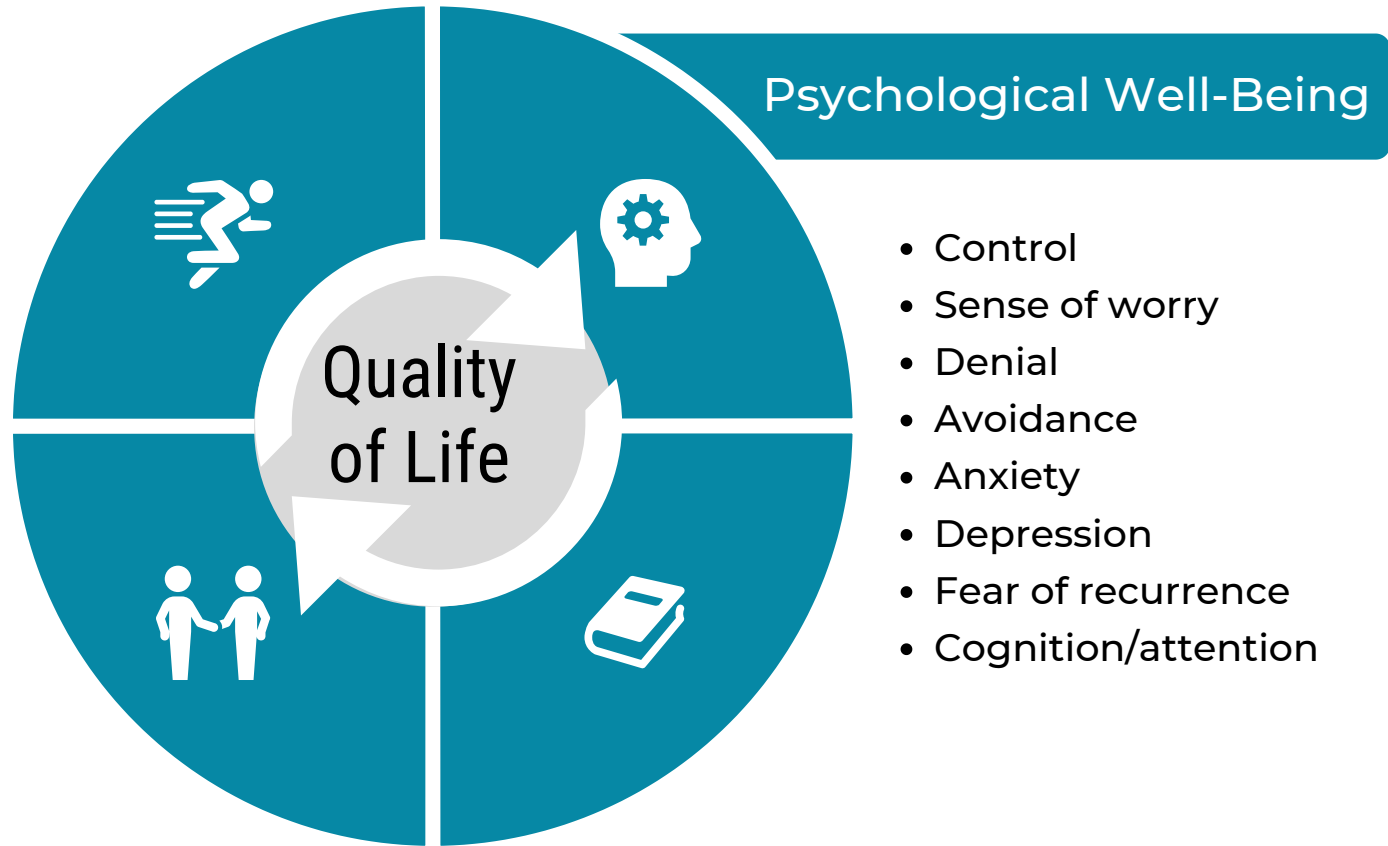
Here are some State and National resources to help cancer survivors with physical health promotion.

- Minimal alcohol use
- Abstinence from tobacco use
- Cardiovascular activity and strength training
- 150 minutes of cardio
- 2 days of strength training
- Healthy diet and nutritious foods
- Variety of fresh fruits and veggies
- Limit intake of processed and red meat
- Consume whole grains rather than refined grains



Psychological

Here are some State and National resources to help cancer survivors with psychological well-being.



[More: Quality of Life Challenges](#)

introduction

data

quality of life

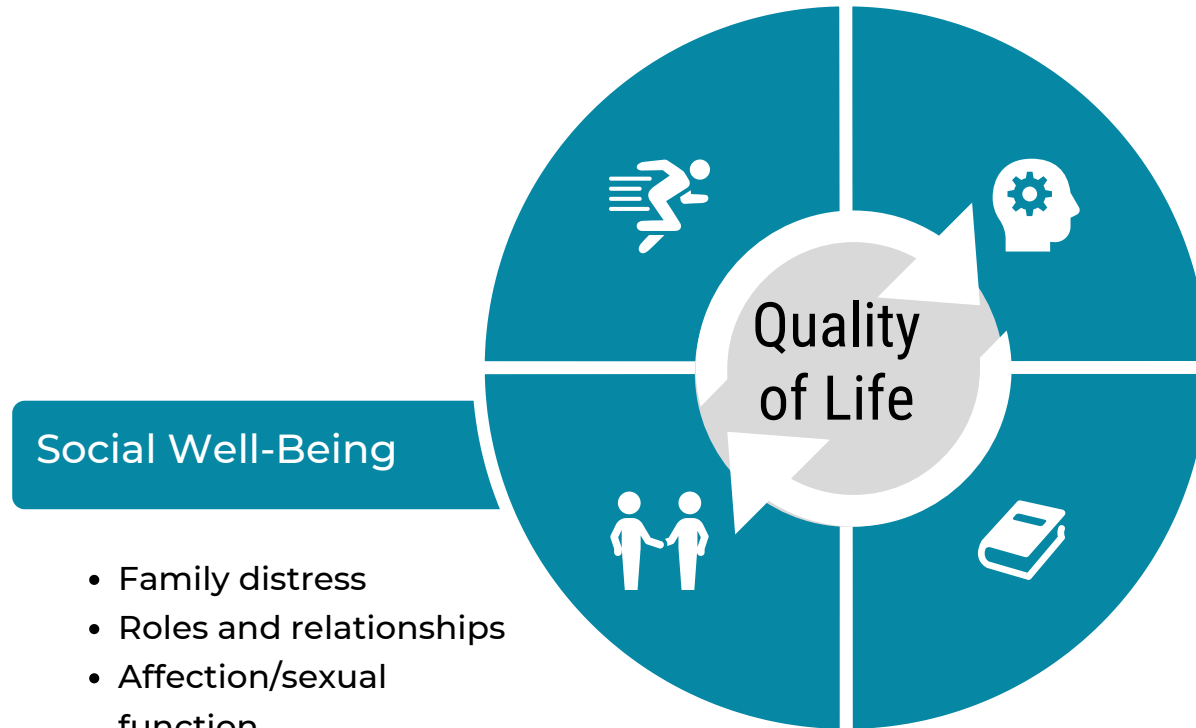
quality of life II

navigation

partners

Social

Here are some State and National resources to help cancer survivors with social well-being.



- Family distress
- Roles and relationships
- Affection/sexual function
- Appearance
- Isolation
- Finances/employment

[More: Quality of Life Challenges](#)

Financial



Here are some State and National resources to help cancer survivors with financial well-being.

Cancer survivors may experience financial issues that impact quality of life in multiple ways:

- Income
- Debt
- Loss of income
- Out-of-pocket costs
- Impact on mental health (financial toxicity)

This may result in avoiding treatment or medications due to cost.

Source: Altice CK, Banegas MP, Tucker-Seeley RD, Yabroff KR. Financial Hardships Experienced by Cancer Survivors: A Systematic Review. J Natl Cancer Inst 109:2017. PMID: PMC6075571

Spiritual

Here are some State and National resources to help cancer survivors with spiritual well-being.



[More: Quality of Life Challenges](#)

introduction

data

quality of life

quality of life II

navigation

partners

What is the definition of a patient navigator for cancer survivorship?

A patient navigator works with the patient and the medical team to eliminate barriers to care, and improve timeliness of care from screening through survivorship. The navigator is a patient advocate and may be tasked with assisting with financial needs, educating patients on long-term side effects and communicating needs to the medical team. (from AONN, ASCO)

Who is a patient navigator?

- A staff member of a hospital or health system
- Social worker, nurse, CNA, CMA, front desk scheduler
- May or may not be called a patient navigator
- Varies depending upon facility
- May be more than one person
- May be someone who has other job responsibilities



introduction

data

quality of life

quality of life II

navigation

partners

What are some common roles for patient navigators for survivorship?



Develop relationships with patients and families.



Follow-up referrals to other practitioners and services.



Inform patients.



Encourage patient wellbeing and quality of life (future screenings, diet, nutrition).



Act as the liaison between patient and provider.



Offer multiple opportunities to ask questions and direct resources.



Provide a smooth transition between Oncologist and PCP.



Consider structural barriers to access care services and follow-up (transportation, sick days, finances, insurance, etc.).



Provide a survivorship care plan, or encourage patients to utilize them.



Set navigation parameters. Establish the time your services begin and end. Where do patients find services before and after you begin?

Successes: Coordination of Care

A newly diagnosed pancreatic cancer patient was noted to have an aneurysm on workup imaging. After noting this, the navigator was able to arrange the surgeon to see the patient in the Medical Oncology office the same day, which facilitated an admission and quick surgical intervention. The patient was then discharged without complication and able to start on treatment for her early diagnosed pancreatic cancer without significant delay.



- Stephanie, Nurse Navigator, St. Elizabeth Healthcare, Edgewood, KY

Successes: Accessing Resources

A Small Cell Lung Cancer patient on surveillance was not able to afford her depression medication, so she slowly weaned herself off without notifying anyone. One of her caregivers informed the navigator that she was having significant emotional struggles. The navigator reconnected with the patient and after some investigation, was able to find the medication through GoodRX for less than \$10.

- Stephanie, Nurse Navigator, St. Elizabeth Healthcare, Edgewood, KY





We asked Kentucky patient navigators about their greatest challenges



Unidentified roles and responsibilities



Lack of dedicated staff time to meet all of the needs and provide follow up



Lack of communication and coordination with staff and clinicians



Cost and availability of hard-copy materials



May not be called a patient navigator



Lack of physician buy-in



Patient understanding that survivorship care begins at diagnosis and continues through the rest of their life




We asked Kentucky patient navigators about what resources were most often requested



Transportation
*Most requested
*Hardest to find



Financial resources
*Most requested
*Hardest to find



Education/information
(cancer-specific,
nutrition, physical
activity)



House/lodging



Medical resources: home
health, hearing aid,
medical supplies



We asked Kentucky patient navigators about their challenges meeting patient needs




The top three challenges we heard:



Finding local resources



Lack of computer literacy



Time to follow up on referrals

What do you wish patients understood earlier in the cancer journey?

- Survivorship care is not over when treatment is complete
- Follow-up treatment and managing side effects is part of survivorship care
- It is okay to ask about financial resources
- Cancer is traumatic
- Relationships with spouse and others may change
- Counseling for survivors and their families is important and resources are available - many at no cost

What is needed to improve?

- Planning for survivorship should be a priority throughout the entire journey
- A multi-disciplinary approach is needed with strong leadership
- Patient navigator roles and responsibilities need to be clearly defined
- Physician support for navigation and survivorship as essential parts of the cancer care continuum
- Increased use of navigation metrics to inform and support programs
- Empowered navigators who advocate for their program and patient needs

introduction

data

quality of life

quality of life

navigation

partners





Getting connected

- **Kentucky Oncology Navigator Network**

- **Mission:** The mission of the Kentucky Oncology Navigator Network of AONN+ is to provide networking, collaboration, education and professional development opportunities to local nurse and patient oncology navigators in order to be advocates for patients and caregivers and improve the quality of life cross the cancer continuum.
- **Vision:** The vision of the Kentucky Oncology Navigator Network is to promote a network of innovative health care professionals by building relationships between primary care providers, oncologist, surgeons, nurses, social workers caregivers and patients that will reduce health disparities in the cancer patient population of Kentucky.
- **Get connected** https://uky.az1.qualtrics.com/jfe/form/SV_9FZYDswpoPkI5FH
- **Membership** – Membership is for anyone. You do not have to be connected to a specific facility or program and does not have to have the title of Patient navigator (can be a nurse, social worker, CNA, front desk officer worker coordinating appointments)