Kentucky Cancer Consortium Cancer Survivorship Series

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





April 2022



Cancer Survivorship Definitions and Kentucky Data

June 2022



Cancer Survivorship Domains and Outcomes

August 2022



COVID-19's Impact on Cancer Survivors

October 2022



Patient Navigation Perspectives

December 2022



KCC Partner Needs and Resources

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



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

<u>Primary cancer:</u> 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



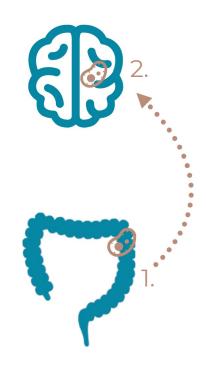
Note: There are two different types of tumors: benign (non-cancerous) tumors and malignant (cancerous) tumors. A benign tumor is composed of cells that will not invade other unrelated tissues or organs of the body, although it may continue to grow in size abnormally. A malignant tumor is composed of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

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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=Begins

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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

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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," "thriver," "person living with cancer," any other term that resonates, or even no label at all."

National Coalition for Cancer Survivorship

"The term cancer survivor to 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

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

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

How is the term "cancer survivor" perceived? 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 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 selfidentifying as a survivor

(Clegg, 2016)



Some said that they felt using the term was "tempting fate" and would lead to recurrence. (Cheung, 2016) Some individuals felt their cancer wasn't "bad enough" or "traumatic enough" to use the title. (Clegg, 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.





data

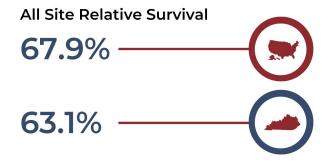
5-Year Relative Survival

Relative Survival

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

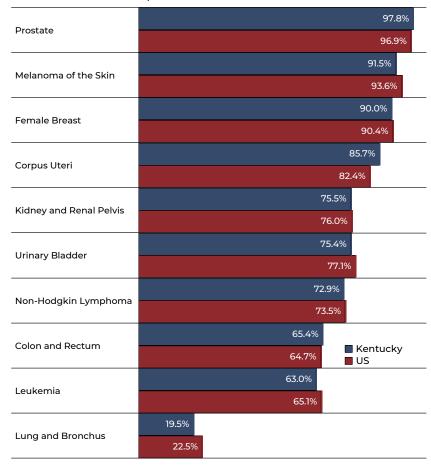


This gives a measure of survival that factors out other causes of death. Relative survival can be measured for either a general cancer diagnosis or for specific cancer sites.



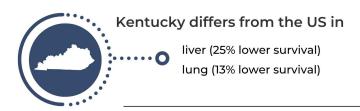
Source: 2021 Kentucky Cancer Needs Assessment Data: KCR/SEER 2012-2018

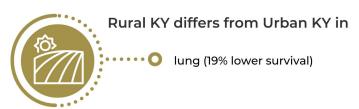
Relative Survival of Top 10 Incidence Rate Cancers

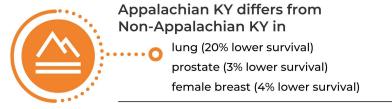


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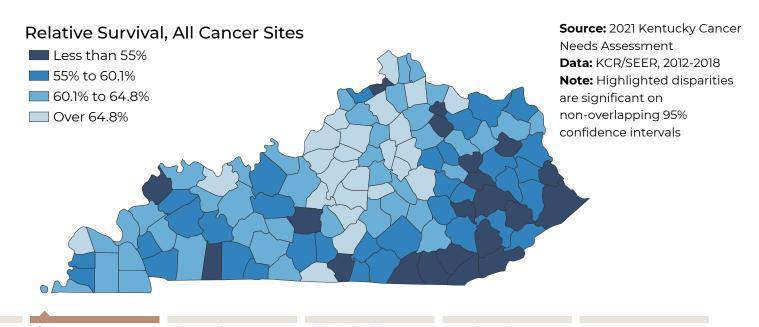
Significant Disparities in Relative Survival











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How can partners use the Cancer Survivorship Series?

We encourage you to use the information in the series to educate your staff, colleagues, and other partners about cancer survivorship.



Have ideas, information, or recommendations on cancer survivorship data?

Contact Jennifer Knight at Jennifer.Knight@uky.edu

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