# **2021 KENTUCKY CANCER NEEDS ASSESSMENT** The Story of Cancer in Kentucky

## **EXECUTIVE SUMMARY**

**OVERALL CANCER BURDEN**: Kentucky consistently bears one of the highest cancer burdens in the nation. In the most recent data (2014-2018), KY ranked first in overall age-adjusted cancer incidence rate (new cancer cases) and mortality rate (deaths), and among the top five states for multiple specific cancer sites.

**DISPARITIES**: Geographic disparities include elevated mortality among rural or Appalachian KY for several of the top 20 cancers, including the four sites with available screenings. Racial disparities exist in mortality for breast, prostate, colorectal, liver, myeloma, stomach and uterine (primarily of the endometrium) cancers.

**SOCIAL DETERMINANTS**: Low education and high poverty contribute to KY's high cancer burden, including high poverty rates among rural, Appalachian, Black and Hispanic Kentuckians. Forty of the 120 counties—mostly in Appalachia—have had "persistent poverty" across the past four decades. Despite higher poverty, the percentage of uninsured is lower than the US due to Medicaid expansion, except for Hispanic Kentuckians.

**RISK REDUCTION**: KY has higher incidence of tobacco-related, obesityrelated and HPV-related cancers than the US, especially lung, colorectal, oral, cervical and kidney cancers. KY ranks 2nd highest among states for smoking and 7th highest for adult obesity. Only about half of KY's youth are vaccinated against HPV, with lower coverage in rural areas. Environmental exposures are linked to six common cancers in KY.

**SCREENING**: Long-standing statewide efforts have led to KY being on par with the US in colorectal, breast and cervical cancer screening, although greater needs persist in rural and Appalachian areas. KY found early success in lung cancer screening since approval in 2015, now ranking 2nd highest in the US, but rates remain low with 4 out of 5 unscreened. Early detection improves survival for screenable cancers.

**TREATMENT AND SURVIVAL**: Recent advances in precision medicine have improved the effectiveness of cancer treatments, but are underutilized in KY. Similar to the US, relative survival for cancer—both overall and for major cancer sites—has improved over time. Survivors have a range of wellness, mental health, social support, financial and other needs.

**CALL TO ACTION**: Rewriting the story of cancer in KY will require a multi-faceted collaborative approach among partners across the state. This KY Cancer Needs Assessment is intended to inform planning for individual organizations and collaborative initiatives.

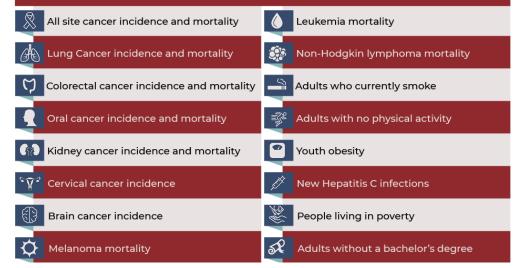
#### **PURPOSE:** To tell the current story of cancer in Kentucky.

Combining data and community perspectives, this story describes how social determinants of health, behaviors and biology intersect to produce the current state of cancer burden and disparities in Kentucky, and it highlights opportunities to rewrite the story.



Source: USDA; Appalachian Regional Commission

### Kentucky is among the Top 5 worst states for:



### Kentucky Cancer At-A-Glance, Incidence & Mortality

Rankings		DISPARITIES												
"Within KY" = "Among US S	= rankings of States" = KY's		INCIDENCE					MORTALITY						
Colored blocks ind group in each com	KY All vs US All	Black KY vs US All	Black KY vs White KY	KY vs Urban KY	App KY vs Non-App KY	KY All vs US All	Black KY vs US All	Black KY vs White KY	Rural KY vs Urban KY	KY vs Non-App KY				
[	IN	CIDENCE	MORTALITY			Blach	ack	Rural k	× √	Σ	Black	ack	ural F	o K≺
	Within KY	Among US States	Within KY	Among US States			<u> </u>	Ru	Api			Ē	ц В	App
All Cancer Sites	n/a	1	n/a											
Female Breast	1	*	2	16										
Prostate	2	*	3	*										
Lung and Bronchus	3	1	1	1										
Colon and Rectum	4	2	4	4										
Melanoma of the Skin	5	7	16	3										
Corpus Uteri	6	*	19	*										
Urinary Bladder	7	10	10	5										
Kidney and Renal Pelvis	8	4	12	2										
Non-Hodgkin Lymphoma	9	12	9	1										
Leukemia	10	8	6											
Thyroid	11	ון	*	13										
Oral Cavity and Pharynx	12	2	15	3										
Pancreas	13	9	5	10										
Cervix Uteri	14	1	18	10										
Ovary	15	*	8	*										
Liver and IBD	16	17	7	14										
Brain and ONS	17	2	11	13										
Myeloma	18	16	14	17										
Stomach	19	14	17	*										
Testis	20	*	* 18											
Esophagus	*	11	13	16										
Uterus, NOS	*	*	20	*										

\* = Ranked lower than 20th

### Kentucky Cancer At-A-Glance, Opportunities for Action

Colored blocks indicate evidence-based risk reduction strategy or clinical practice

	OPPORTUNITIES FOR ACTION												
			RISK REI	DUCTION			CLINICAL						
	Tobacco	Obesity	HPV	Hepatitis	HIV	Environment	Genetic Testing	Screening	Precision Med				
Female Breast													
Prostate													
Lung and Bronchus													
Colon and Rectum													
Melanoma of the Skin													
Corpus Uteri													
Urinary Bladder													
Kidney and Renal Pelvis													
Non-Hodgkin Lymphoma													
Leukemia													
Thyroid													
Oral Cavity and Pharynx													
Pancreas													
Cervix Uteri													
Ovary													
Liver and IBD													
Brain and ONS													
Myeloma													
Stomach													
Testis													
Esophagus													
Uterus, NOS													

IBD = Intrahepatic Bile Duct; NOS = Not Otherwise Specified

### Kentucky Behavioral Risk Factors & Screenings At-A-Glance

Colored blocks indicate a significantly higher proportion for the first group in each comparison (column) than the second.

Adult Risk Factors	All Race KY vs US	Black KY vs US	White KY vs US	Hispanic KY vs US	Female KY vs US	Male KY vs US	Rural vs Urban KY	App vs Non-App KY	Youth Risk Factors	All Race KY vs US	Black KY vs US		White KY vs US	Hispanic KY vs US	Female KY vs US	Male KY vs US
Currently smokes tobacco									No physical activity (youth)							
Currently uses smokeless tobacco									Obese (BMI 30+, youth)							
									Overweight or obese (BMI 25+, youth)							
No physical activity									Eats no fruits per day (youth)							
Did not meet CDC Physical Activity									Eats no vegetables per day (youth)							
guidelines									Currently vapes (youth)							
Obese (BMI 30+)									Ever vaped (youth)							
Overweight or obese (BMI 25+)										vs US	s US	s US	vs US	/s US	SUS	an KY kpp KY
Eats no fruits per day									Cancer Screenings	All Race KY vs US	Black KY vs US	White KY vs US	Hispanic KY vs US	Female KY vs US	Male KY vs US	App vs Non-App KY
Eats no vegetables per day										4		-	I	<u> </u>		A A A
									Met USPSTF Lung Cancer guidelines							
Had at least 1 drink, last 30 days									Met USPSTF CRC guidelines							
Unhealthy drinking									Met USPSTF Breast Cancer guidelines							
Average <6 hours of sleep per night									Pap test in last 3 years							

KyBRFS/BRFSS, 2016-2019 · YRBS, 2019

USPSTF = United States Preventive Services Task Force

### Contents



Section 3

Cancer-related Outcomes

- 26 Risk Reduction
- 31 Screening & Diagnosis
- 37 Treatment
- 40 Survivorship

### Section 1

#### Introduction

- 7 Purpose7 Top 10 Incidence
- 8 Top 10 Mortality
- 9 KY CNA Framework
- 11 KY CNA Use Guide

### Section 4

#### Call to Action

- 46 Summary
- 48 Community Prioritization
- 49 A Call to Action
- 50 Data Gaps
- 51 Research Opportunities

### Section 2

Social Determinants of Health

- 13 Society
- 18 Community
- 20 Environment

### Section 5

Acknowledgments & Citations

- 53 Acknowledgments
- 55 Data Sources
- 57 Research Cited

# INTRODUCTION



# **2021 Kentucky Cancer Needs Assessment**

#### PURPOSE

In 2021, a Steering Committee of several collaborating organizations conducted a comprehensive Kentucky Cancer Needs Assessment (KY CNA). The purpose of this statewide KY CNA is to tell the current story of cancer in Kentucky. The KY CNA also highlights opportunities to rewrite the story.

#### KENTUCKY HAS THE WORST CANCER BURDEN AMONG US STATES

Kentucky has a population of 4.4 million people and experiences, on average, 27,441 new cancer cases and 10,141 cancer deaths each year. Kentucky ranks highest among all states for both cancer incidence and mortality. Age-adjusted incidence rates (**Figure 1**) are significantly higher in KY versus the US for six of the top 10 cancers, most notably lung cancer (79% higher in KY, ranked highest among US states), followed by colorectal cancer (27% higher, ranked 2nd highest) and melanoma (18% higher, ranked 7th highest).

Age-adjusted mortality rates (**Figure 2**) are also significantly higher for six of the top 10 cancers in KY versus the US, particularly lung cancer (82% higher, ranked highest among US states), colorectal cancer (25% higher, ranked 4th highest) and leukemia (15% higher, ranked 4th highest). In addition, KY has significant cancer-related disparities among rural, Appalachian, Black and Hispanic populations, which are highlighted throughout the KY CNA.

#### 127.3 Female Breast \* 103.6 + 78.7% Prostate Lung and (1st) 88.1 Bronchus Colon and 47.7 (2nd) Rectum +.30.1%+ 27.2% 27.9 + 18.3% + 19.3% Melanoma (7th) + 14.6% + 2.5% + 2.6% - 0.1% \* 27.0 Corpus Uteri - 4.3% 22.2 Bladder (10th) KY higher than US KY similar to US Kidney and Renal Pelvis Non-Hodgkin Lymphoma Lung and Bronchus Colon and Rectum Female Breast Prostate Melanoma **Corpus Uteri** Leukemia Kidney and Renal Bladder (4th) 20.9 KY lower than US Pelvis Non-Hodgkin 19.6 (12th) Lymphoma (...) = Site ranking nationally, 1st-20th \* = Not in Top 20 for site nationally 15.8 Leukemia (8th)

### FIGURE 1. TOP 10 CANCER INCIDENCE IN KENTUCKY

Age-Adjusted Incidence

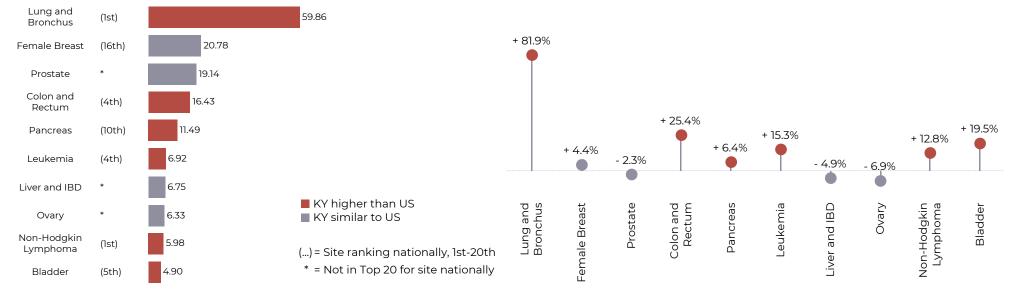
KCR/SEER/USCS, 2014-2018

Percent Difference in Rates, KY vs US

#### FIGURE 2. TOP 10 CANCER MORTALITY IN KENTUCKY



Percent Difference in Rates, KY vs US



#### WHY IS OUR CANCER BURDEN SO HIGH?

Drawing inspiration from several existing frameworks, we created the **Multilevel Determinants of Cancer-related Outcomes Framework** to guide planning of which data to include in the KY CNA, and to organize a coherent story of how social determinants of health, behaviors and biology intersect to produce the current state of cancer burden and disparities in Kentucky (**Figure 3**).

Social Determinants of Health (SDOH) reflect the context in which an individual lives. SDOH include three components that interact with each other:

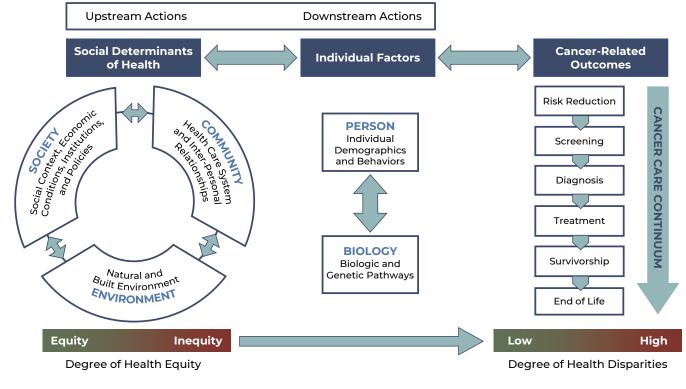
- Society encompasses social context (culture; social norms; the meaning of socially-constructed concepts like race, ethnicity and gender; etc.), economic conditions (median income, unemployment, etc.), institutions (education system, criminal justice system, etc.) and policies (Affordable Care Act, Medicaid, institutional policies, etc.).
- **Community** includes the health care system (primary care, hospitals, cancer clinics and other facilities) and inter-personal relationships (family, neighborhoods, etc.).
- Environment consists of both the natural environment (water, air, soil, etc.) and substances that individuals are exposed to through these means, as well as "built" environment constructed by humans (roads, sidewalks, parks, buildings, etc.).

#### FIGURE 3. MULTILEVEL DETERMINANTS OF CANCER-RELATED OUTCOMES FRAMEWORK

Individual Factors refer to an individual's internal makeup and actions; specifically, how a person's individual demographics (age; biological sex; self-identified gender, race, and ethnicity; etc.) and behaviors (all of the actions people do every day) interact with their internal Biology (biologic functioning and genes within one's body) with the potential to produce mutations in the body that can result in cancer.

SDOH, individual behaviors and internal biology all interact with each other to produce population-level **Cancerrelated Outcomes**, spanning the cancer care continuum from Risk Reduction (primary prevention) to Screening (secondary prevention), Diagnosis, Treatment, Survivorship and End of Life.

#### Within a given society or community,



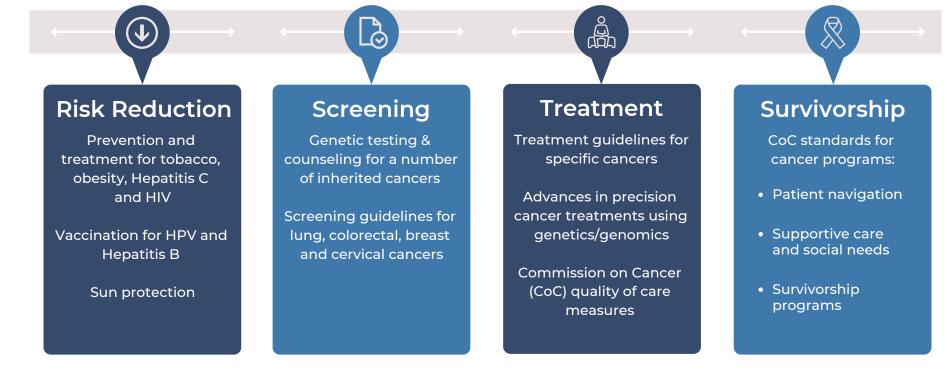
SDOH have varying degrees of health equity (or inequities) in how they do or do not create external constraints on an individual's possible behaviors throughout their lifespan, dependent on the social groups the individual belongs to (such as rural/urban or Appalachian/non-Appalachian residence, or their racial and/or ethnic background). Thus, the **degree of health equity** in SDOH largely determines the resulting **degree of health disparities** observed across social groups for population-level Cancer-related Outcomes.

#### WHAT CAN WE DO ABOUT IT?

The KY CNA provides actionable information that can be used by a wide range of stakeholders to rewrite the story of cancer in Kentucky. **Figure 3** points out how collective actions can impact Cancer-related Outcomes, with **Upstream Actions** targeting changes in the broad context of SDOH, and **Downstream Actions** targeting individual-level behavior changes. The KY CNA focuses primarily on **evidence-based guidelines and practices** across the cancer care continuum, with examples provided in **Figure 4**.

The **Call to Action** section of this report outlines examples of how organizations and people can use the KY CNA in many ways to address identified needs and respond to community-driven priorities and solutions. The KY CNA will guide development of Kentucky's next statewide Cancer Action Plan (KY CAP) for 2022-2027. In addition, public and private organizations and entities from multiple sectors can use the KY CNA to inform their strategic planning, program planning and evaluation activities; to engage community members; to educate decision makers; and to stimulate new collaborative research.

#### FIGURE 4. EXAMPLES OF EVIDENCE-BASED GUIDELINES AND PRACTICES



#### **CNA RESOURCES**

**Data Sources.** The KY CNA combines data from the Kentucky Cancer Registry (KCR) with multiple existing data sources. Focus groups with lay community members from diverse demographic groups and regions complement the existing data with lived experiences. In addition, 111 organizational representatives and 51 lay community members participated in a series of community prioritization activities—called concept mapping—which provided community-driven insights on high priority needs and strategies to address them.

**Appendices and Toolkit.** The KY CNA includes an appendix with data tables corresponding to the data visualizations included in this report. Following release of this report, supplemental appendices will be made available with additional data visualizations, a report of the focus group findings, and a report of the concept mapping prioritization activities. In addition, a KY CNA toolkit will be provided with standalone graphics that can be used for presentations, newsletters, and social media dissemination.

**Data Portal.** In addition to this report, the KY CNA web-based data portal provides interactive tools for users to select indicators and generate custom maps and tables, as well as links to the KCR website and KY CAP.

This document uses certain colors to represent the populations of different geographic and racial groups being considered:



Group comparisons in this document are made between the following pairs:

- KY compared to US
- Rural KY (RUCC > 3) compared to Urban KY
- Appalachian KY compared to Non-Appalachian KY
- Black KY compared to White KY
- Hispanic KY compared to Non-Hispanic KY

At times, group comparisons are analyzed for significant differences using non-overlapping 95% confidence intervals. Significance is denoted as follows:

- ★ = Significantly higher than all sex, all race US
- ▲ = Significantly higher than comparison group
- ▼ = Significantly lower than comparison group

On all data maps featuring gradiant scales, the gradiant is oriented so that the light end represents areas that are doing better, and the dark end represents areas that are doing worse. For example:

Better Worse
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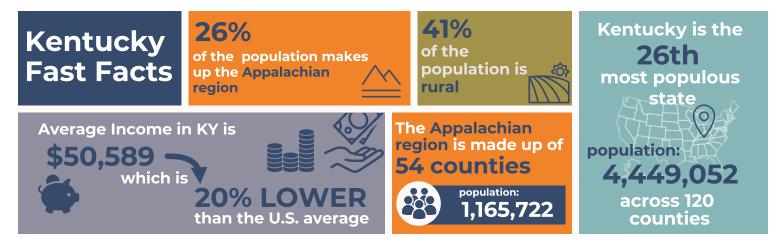
#### Abbreviations and Acronyms

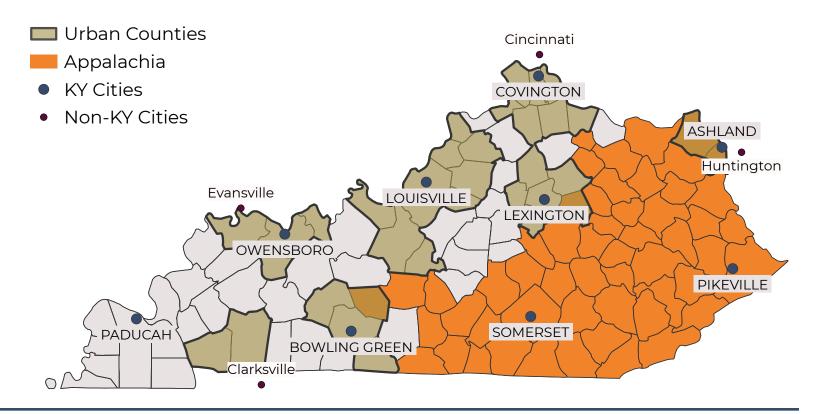
ACS	American Community Survey
BRFSS	Behavioral Risk Factor Surveillance System (CDC)
CDC	Centers for Disease Control & Prevention
CHFS	Kentucky Cabinet for Health & Family Services
CHRR	County Health Rankings & Roadmaps
ERS	Economic Research Service (USDA)
FCC	Federal Communications Commission
FEMA	Federal Emergency Management Agency
HP 2030	Healthy People 2030
HRSA	Health Resources and Services Administration
KCR	Kentucky Cancer Registry
KFF	Kaiser Family Foundation
KyBRFS	Kentucky Behavioral Risk Factor Survey
NFHL	National Flood Hazard Layer (FEMA)
NIH	National Institutes of Health
NIS-Teen	National Immunization Survey—Teen (CDC)
NNDSS	National Notifiable Disease Surveillance System (CDC)
SEER	Surveillance, Epidemiology, and End Results Program
USDA	United States Department of Agriculture
USPSTF	United States Preventive Services Task Force
YRBS	Youth Risk Behavior Surveillance System (CDC)

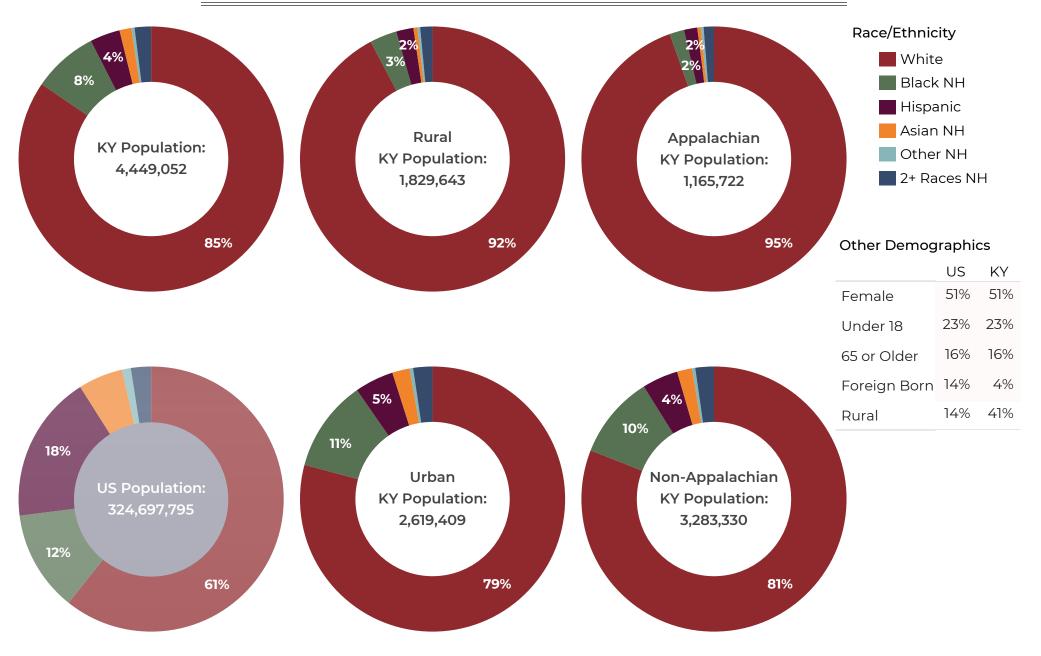
# SOCIAL DETERMINANTS OF HEALTH

"You know it just seems pitiful that people have to die because they're poor.... It just seems like there's some things that are broken." (Rural KY, female, age 55)

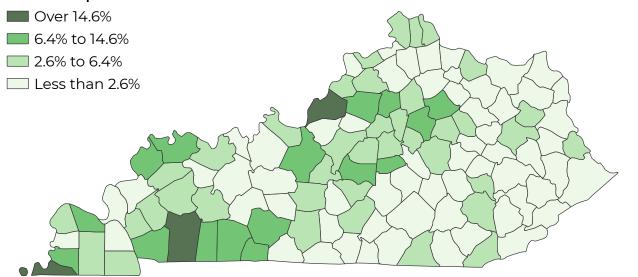
PADUCAH, KY



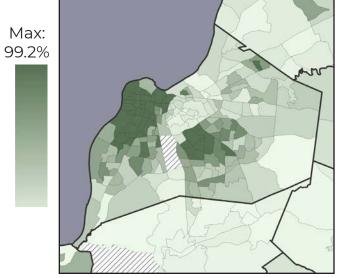




#### Black Population as % of Total

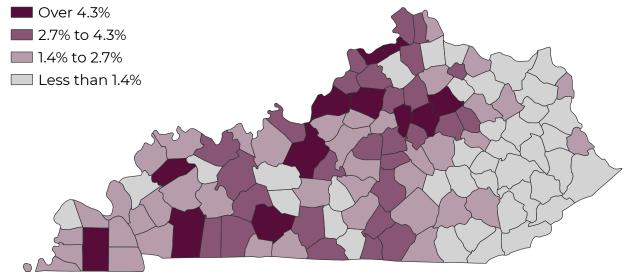


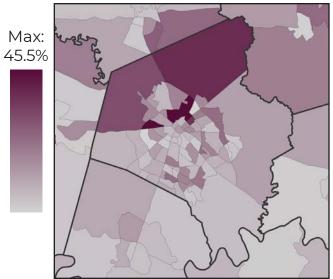
### Jefferson County (46.5% of KY Black Population)

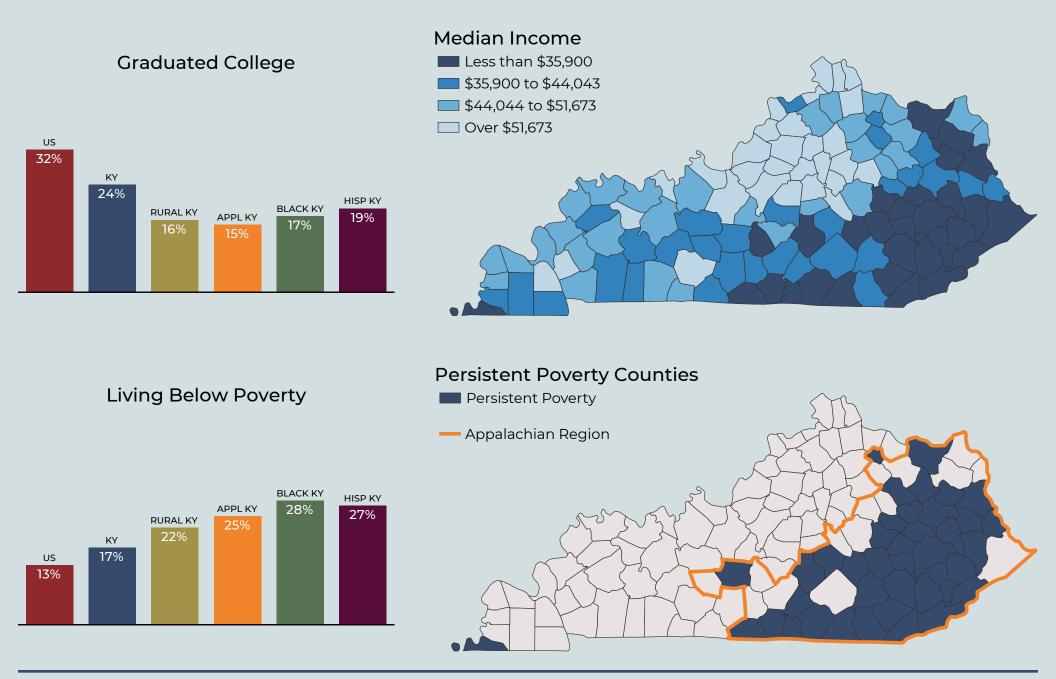


Fayette County (14.1% of KY Hispanic Population)

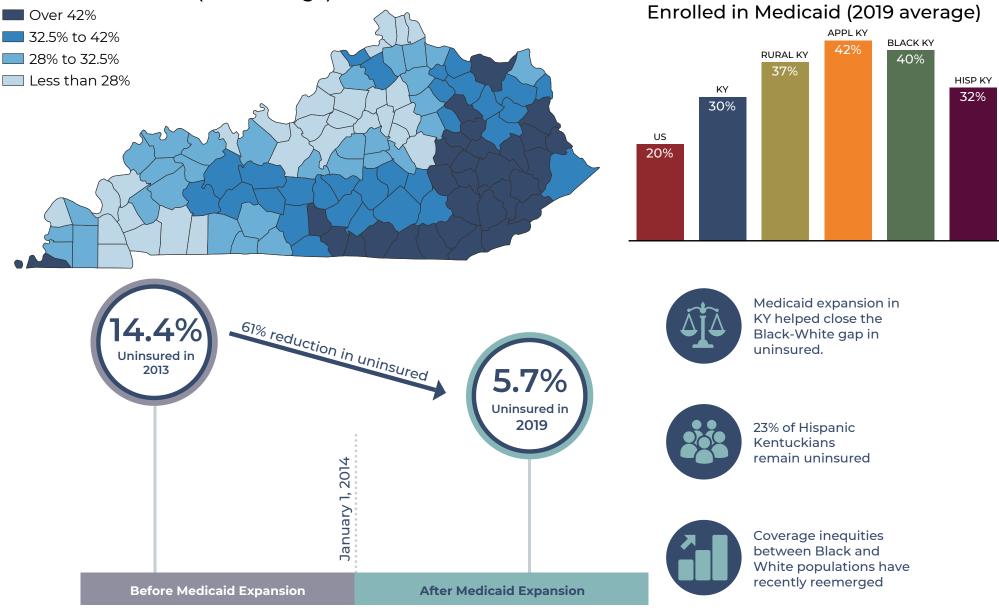
Hispanic Population as % of Total





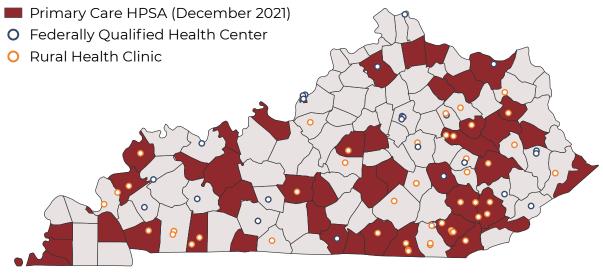


#### Enrolled in Medicaid (2019 average)



## Social Determinants of Health — Community

#### Health Professional Shortage Areas



#### What is a geographic Health Professional Shortage Area (HPSA)?

A shortage of providers for an entire group of people within a defined geographic area.

#### Kentucky Colon Cancer Screening & Prevention Program (KCCSP)

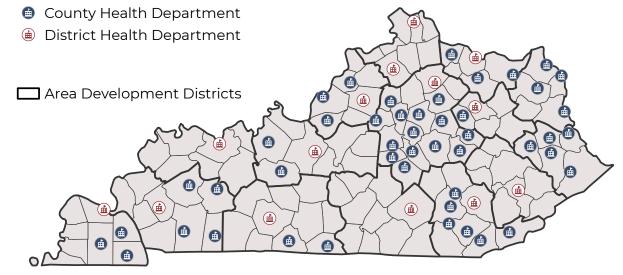


ELIGIBLE PARTICIPANTS: Individuals, ages 45 to 75, who are uninsured or underinsured and with individual income at or below 300% of the FPL. High-risk individuals may qualify at a younger age.



SERVICES OFFERED: Stool-based testing available for participants statewide. Colonoscopy available for certain highrisk individuals.

### Kentucky Public Health Services



HRSA, 2021 · KY CHFS, 2021

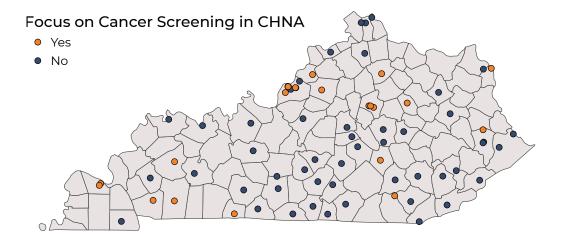
## SOCIAL DETERMINANTS OF HEALTH — COMMUNITY

# CHNA

#### **Community Health Needs Assessment**

The Affordable Care Act requires all non-profit and tax-exempt hospitals to perform a CHNA every three years (some for-profit hospitals will choose to complete one as well). The purpose of a CHNA is to:

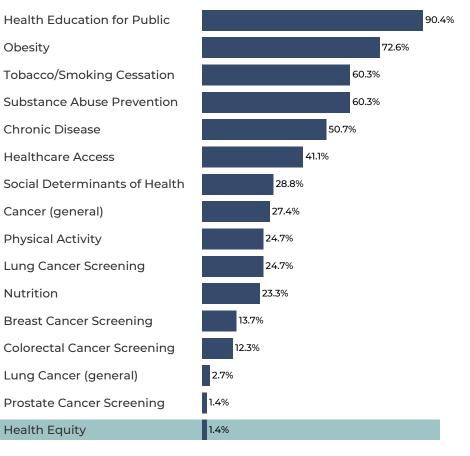
- Identify and analyze the health needs—both real and perceived—in the hospital's service area
- Assess the current efforts targeting these health needs in the community and prioritize ones to focus on
- Formulate a plan for how to address the prioritized needs over the next 3 years



#### Hospital CHNAs in Kentucky



#### Priorities and Strategies on CHNAs



## **Examples of Environmental Risks**

For information about more hazardous substances and their potential for causing cancer, visit ToxFAQs at www.cdc.gov/TSP

# Radon

Naturally occurring odorless and colorless radioactive gas

Inhaled through the air in all environments, but indoor settings with high concentrations and long exposure times, such as schools and homes, are a particular concern

Exposures in indoor settings can be lessened using mitigation systems to ventilate gas

High levels of exposure can increase risk of lung cancer

### Arsenic

Occurs naturally and through man-made processes

Exposed by ingesting small amounts in food and water, or breathing contaminated air

Reduce exposure by using clean water sources in areas of high contamination, or wearing masks and carefully handling items from high-risk workplaces

Can increase the risk of certain cancers, such as lung, bladder and skin

## Polychlorinated biphenyls

Man-made compounds formerly used in some electrical devices and appliances (banned in US in 1977, but remains in older equipment and contaminated environments)

Exposed by eating food or breathing air that is contaminated, or contacting compounds leaking from older equipment

Limit exposure by heeding safety advisories and avoiding unsafe handling of older appliances and electrical equipment

Increases risks of liver, gallbladder and brain cancers

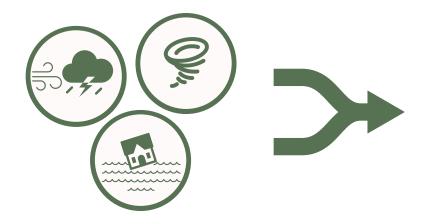
### **UV** Radiation

Electromagnetic radiation put off by the sun and certain man-made sources

Enters skin cells through unprotected exposure to UV rays

Minimize exposures outside by covering exposed skin when possible or using high SPF sunscreen

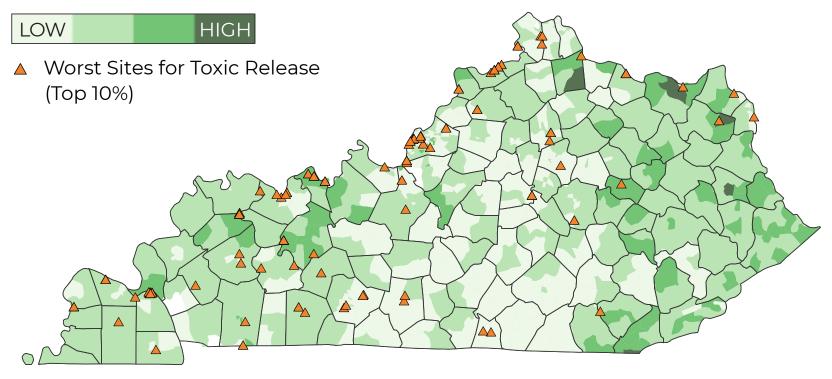
Prolonged and frequent exposure can increase risk of skin cancers, including melanoma

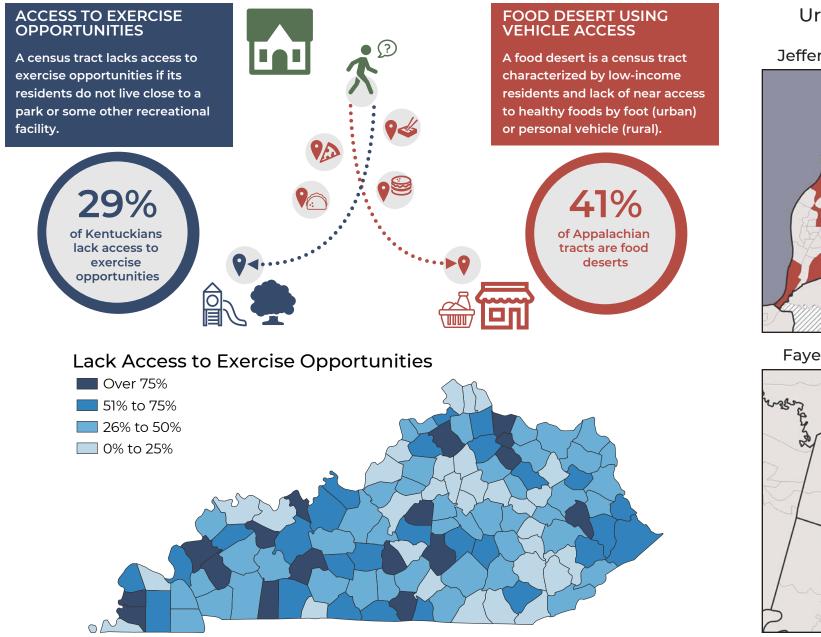


Natural disasters have the potential to disrupt and contaminate water supplies. They can cause power outages at water treatment facilities and introduce waste and other impurities into drinking water.

There is also a risk to air quality from bacteria found in floodwaters and mold in damaged structures.

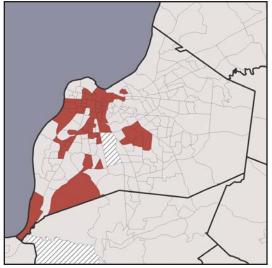
### Flood Risk



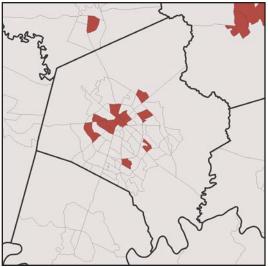


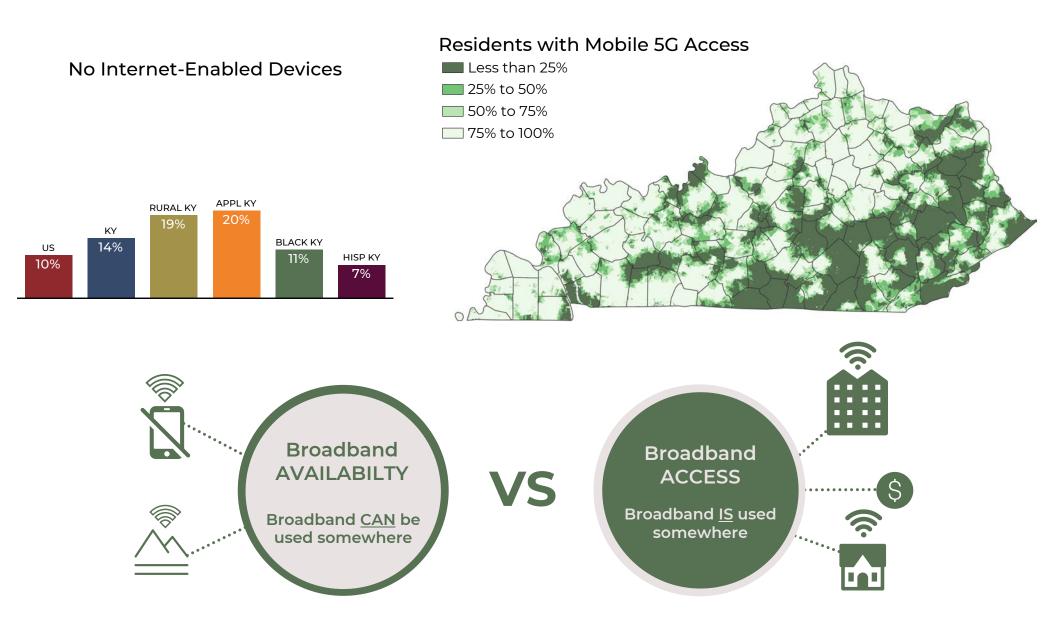
### **Urban Food Deserts**

#### Jefferson County (Louisville)



#### Fayette County (Lexington)





Though broadband may be *available* in certain locations, the cost of *accessing* it through one's home or business may still create a barrier to use.

# SOCIAL DETERMINANTS OF HEALTH — OTHER NEEDS

# Focus Groups helped identify other areas of concern that are harder to capture with the available data, such as:

### **Transportation and Childcare Issues**

**66** I remember having clients that didn't have bus fare, so they couldn't get [to cancer screenings], or they didn't have childcare, so they couldn't make appointments. There are always blocks to people getting help.**?** (Urban KY, female, age 73)



### Societal Views on Gender

(6 [A surgeon I met with after my diagnosis] said, 'I don't understand why a young, pretty woman like you wouldn't want to have [breast reconstruction].' There is pressure to meet traditional gender stereotypes in reconstruction, and how you deal with that sort of thing. And also with fertility issues.... People offer a lot of opinions that are surprising—that they feel like it's their business to tell you what to do with your body. That's a big issue for women, even still today.

### **Financial Cost of Healthy Choices**

**66** It's expensive eating healthy. Our family tries to buy a lot of fresh fruits and vegetables, and my husband comments about how much it costs. And it is expensive if you want to be healthy. **99** (Urban KY, female, age 31)



# CANCER-RELATED OUTCOMES

"Even though they know that cancer is prevalent in our family, they just don't want to know. People don't want to know, because what you don't know won't hurt you, right? But it will." (Rural KY, female, age 45)

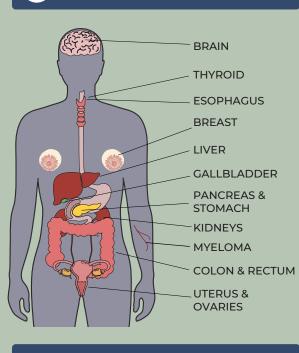


### **RISK REDUCTION — OVERVIEW**

### **Risk Factor-related Cancers**

Cancers in sites that demonstrate significant association with a given risk factor

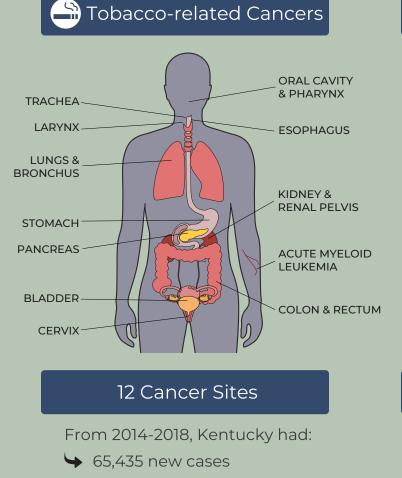
Obesity-related Cancers



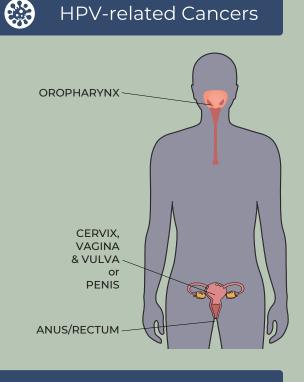
### 13 Cancer Sites

From 2014-2018, Kentucky had:

- ➡ 52,154 new cases
- ➡ 18,797 new deaths



→ 32,297 new deaths



6 Cancer Sites

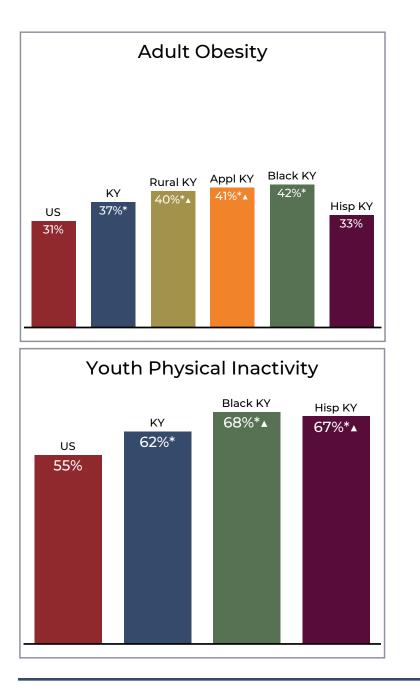
From 2014-2018, Kentucky had:

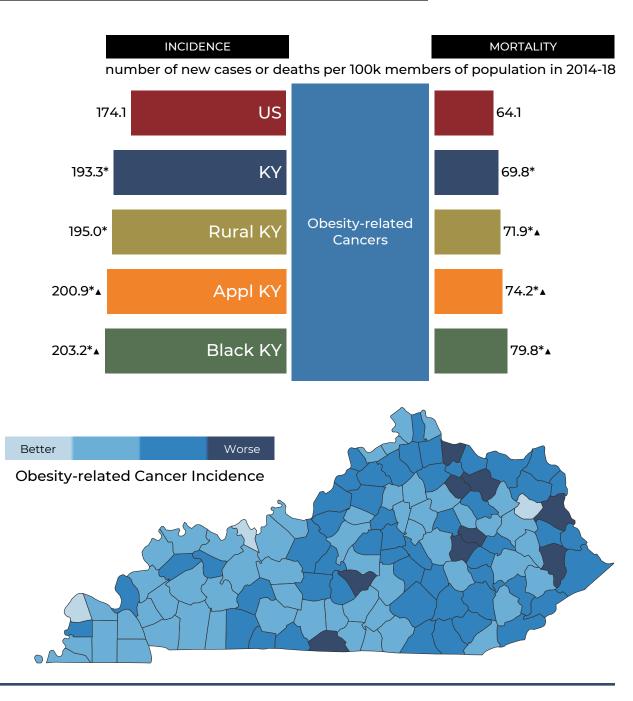
- ➡ 4,258 new cases
- ➡ 1,297 new deaths

KCR/SEER, 2014-2018

https://www.cdc.gov/cancer/uscs/public-use/predefined-seer-stat-variables.htm

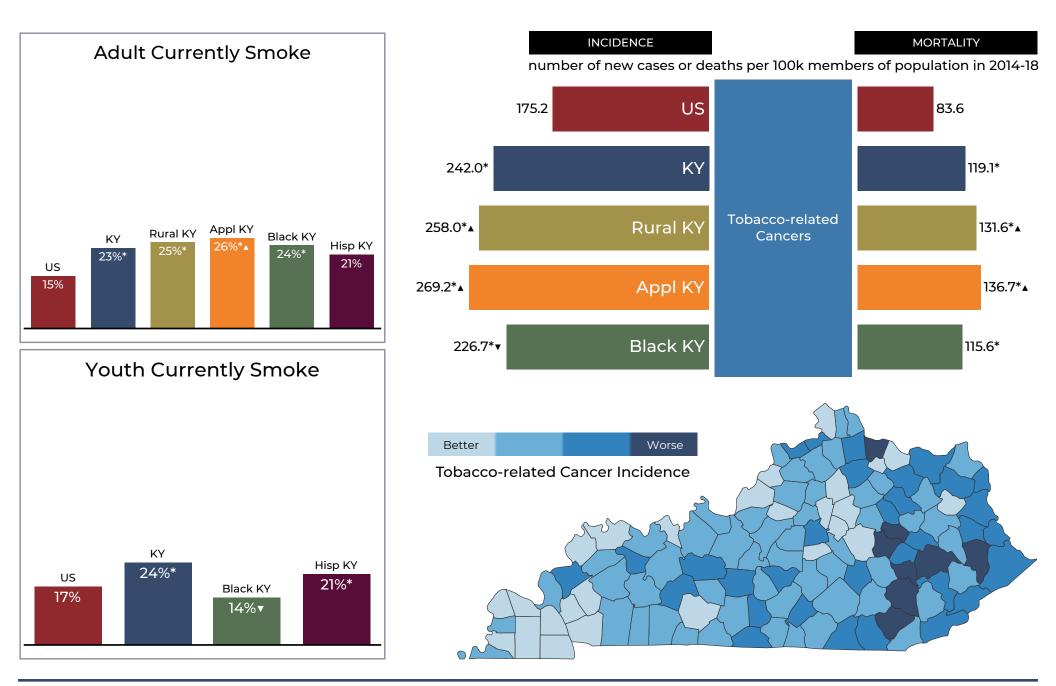
## **RISK REDUCTION — OBESITY-RELATED CANCERS**





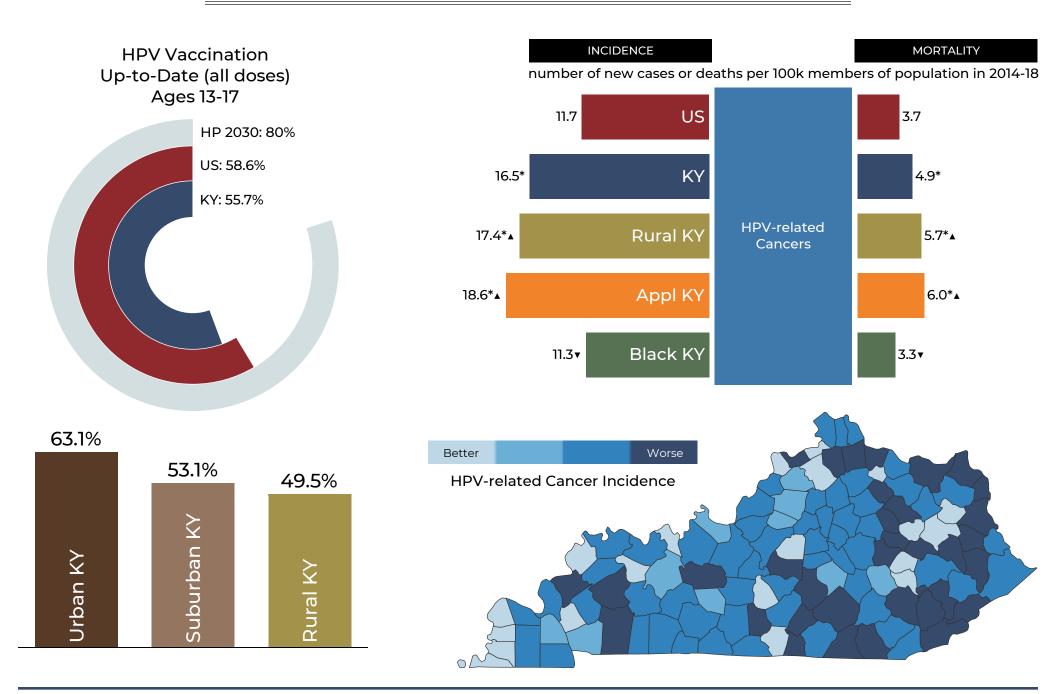
KyBRFS/BRFSS, 2018-2019  $\cdot$  YRBS, 2019  $\cdot$  KCR/SEER, 2014-2018 See legend on p. 11 for meaning of symbols \* and  $\blacktriangle$  Note: Incidence and mortality rates age-adjusted

## **RISK REDUCTION — TOBACCO-RELATED CANCERS**



KyBRFS/BRFSS, 2018-2019 · KCR/SEER, 2014-2018 See legend on p. 11 for meaning of symbols \* and ▲ Note: Incidence and mortality rates age-adjusted

# **RISK REDUCTION — HPV-RELATED CANCERS**



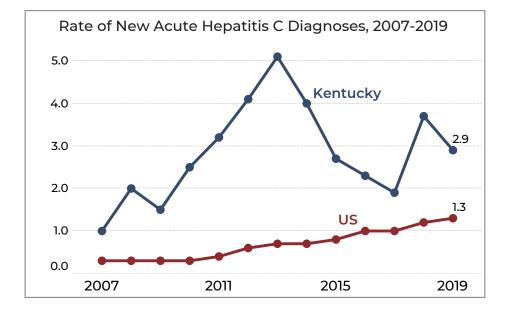
NIS-Teen, 2020 · KCR/SEER, 2014-2018 See legend on p. 11 for meaning of symbols \* and A Note: Incidence and mortality rates age-adjusted

## **RISK REDUCTION — INJECTION DRUG USE**

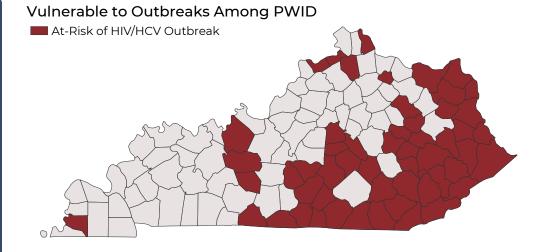


The Opioid Crisis of the early 2000's hit KY hard, leading to some of the nation's worst fatal drug overdose rates year after year. Resulting restrictions on opioid pain medication turned many to injecting heroin.

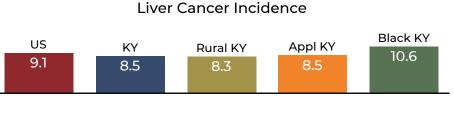
Today, people who inject drugs (PWID) are driving increases in Hepatitis C and HIV in KY—viruses with known links to certain cancers, such as liver and Non-Hodgkin lymphoma.



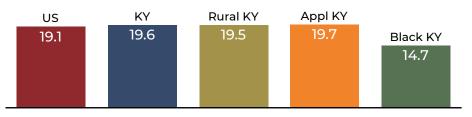
#### CDC NNDSS, 2021 · Van Handel et al., 2016 · KCR/SEER, 2014-2018



### Current Rates to Monitor for Future Impact



#### Non-Hodgkin Lymphoma Incidence



## SCREENING & DIAGNOSIS — GENETIC TESTING

### Genetic testing can detect inherited risk of cancer

Genetic testing can help identify mutations in your DNA that have a known association with certain cancers.

#### Examples of Genetic Mutations

### PTEN

Increased risk of breast, endometrial, kidney, thyroid and colorectal cancers

Associated with Cowden syndrome

#### MLH1, MSH2, MSH6, PMS2 or EPCAM

Increased risk of colorectal, endometrial, ovarian, stomach, and other cancers.

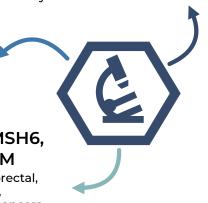
Associated with Lynch syndrome.

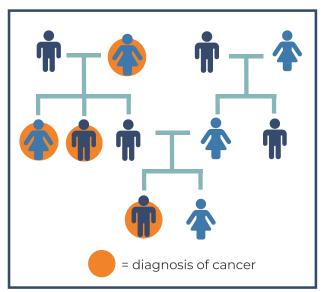
\*See Appendix I for additional mutations with known risks



ovarian, prostate and pancreatic cancers

Associated with Hereditary Breast and Ovarian Cancer Syndrome





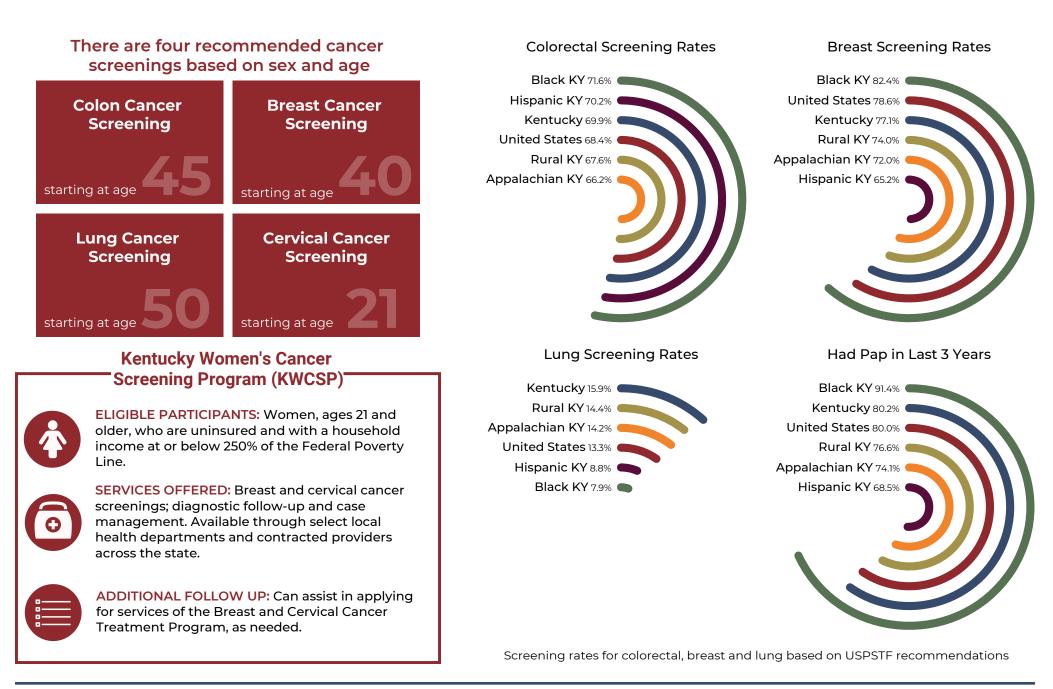
### Characteristics of inherited cancers

- Developing cancer at an early age (under 50s)
- Multiple generations with cancer
- Rare cancers (ex: ovarian, male breast, pancreatic)
- Family history of cancers with a known hereditary link (ex: breast/ovarian/prostate)



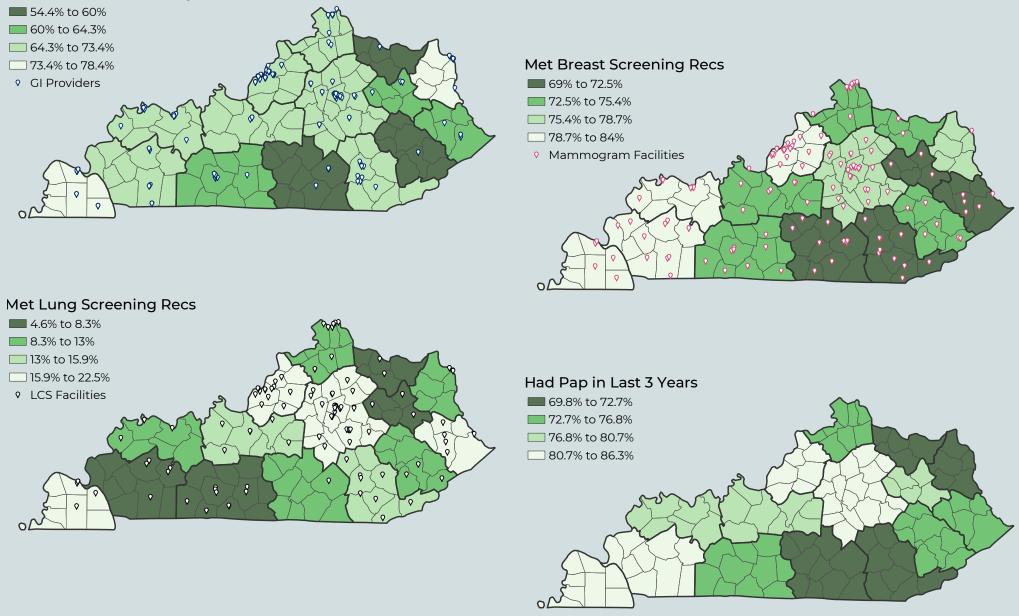
Genetic testing after a cancer diagnosis may also inform treatment options and can alert family members to their own inherited risks.

## SCREENING & DIAGNOSIS — SCREENING RATES



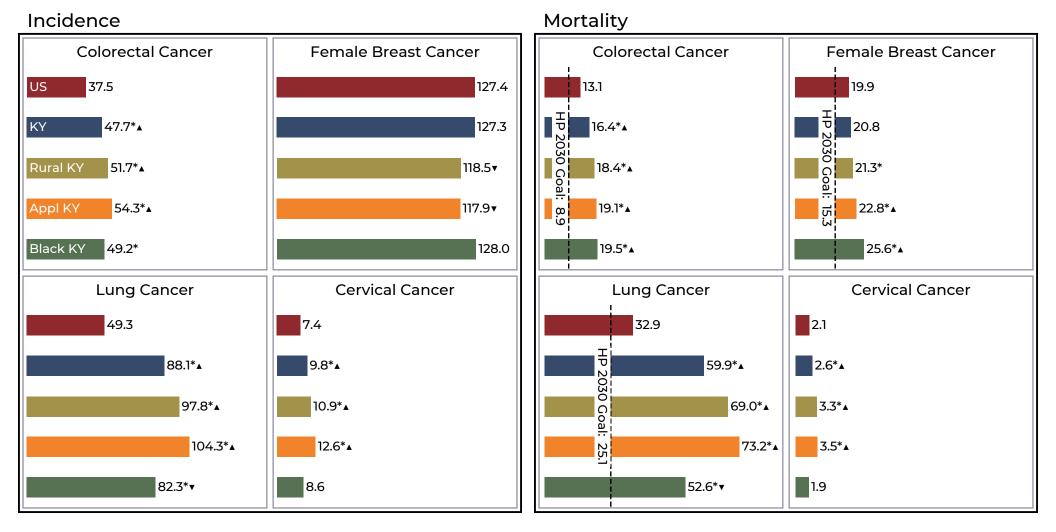
### SCREENING & DIAGNOSIS — SCREENING RATES

#### Met Colorectal Screening Recs



## SCREENING & DIAGNOSIS — INCIDENCE & MORTALITY

"[Sometimes] people say, 'Don't ask how they died,' but I think that that's important—when you find out somebody's experience. Because even if it's fear that causes you to get screened, it could save your life." (Urban KY, female, age 45)



Comparison groups: Rural KY vs Urban KY; Appalachian KY vs Non-Appalachian KY; Black KY vs White KY; Hispanic KY vs Non-Hispanic KY

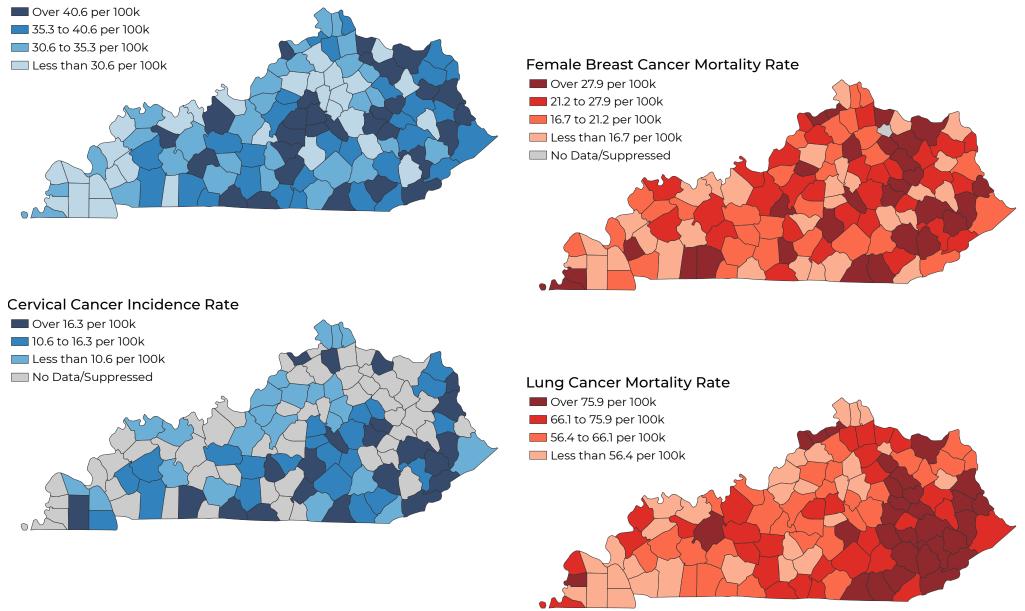
\* = Significantly higher than all sex, all race US; 🔺 = Significantly higher than comparison group; 🔻 = Significantly lower than comparison group

KCR/SEER, 2014-2018

Note: Incidence and mortality rates age-adjusted

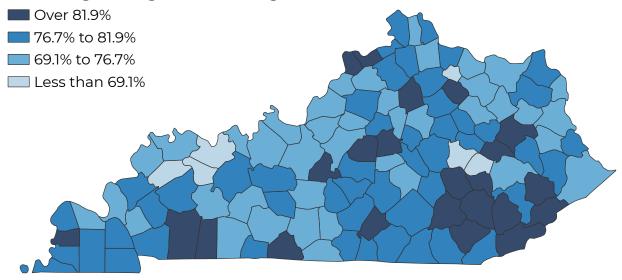
### SCREENING & DIAGNOSIS — INCIDENCE & MORTALITY

#### **Colorectal Cancer Incidence Rate**



### SCREENING & DIAGNOSIS — LATE-STAGE DIAGNOSIS

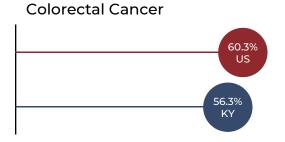
#### Late-stage Lung Cancer Diagnosis



#### Relative Survival by Stage of Diagnosis in KY

	Early Stage (Local)	Late Stage (Regional)	Late Stage (Distant)
Colon and Rectum	90.1%	72.8%	13.6%
Lung and Bronchus	54.5%	30.8%	5.1%
Female Breast	99.7%	84.1%	27.7%
Cervix Uteri	92.1%	58.3%	13.9%

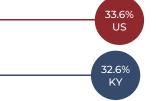
Percent Late-Stage Diagnosis for Screenable Cancers



#### Lung Cancer







#### **Cervical Cancer**



### **TREATMENT — CANCER CARE FACILITIES**

### **Commission on Cancer**

The Commission on Cancer (CoC) establishes standards for cancer programs to provide highquality coordinated care while improving survival and quality of life for patients.

Over 1,500 programs in the US (35 in Kentucky) have received CoC accreditation for their performance and continued excellence on these standards.

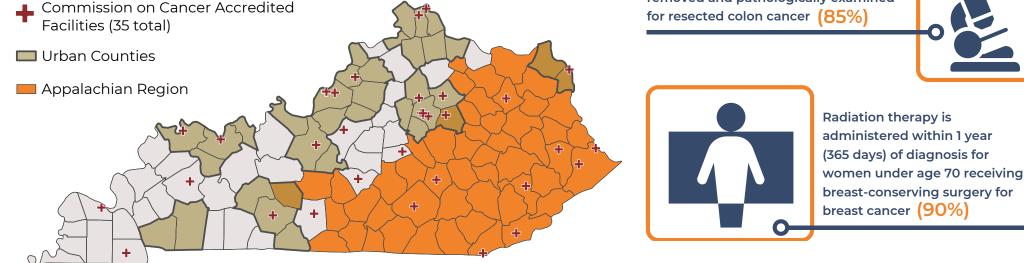
#### **Examples of CoC Quality of Care Measures** (with % expected performance rate)



Systemic chemotherapy is administered within 4 months to day preoperatively or day of surgery to 6 months postoperatively, or it is recommended for surgically resected cases with pathologic, lymph node-positive (pN1) and (pN2) non-small cell lung cancer (85%)

At least 12 regional lymph nodes are removed and pathologically examined



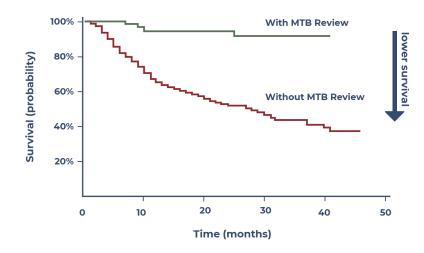


American College of Surgeons, 2022

### **TREATMENT — PRECISION MEDICINE**

### New, targeted approaches to cancer treatment

People are different; so are their cancers. Precision medicine allows doctors to match the characteristics of a patient and their cancer to the best available treatment options.



#### **Overall Survival of NSC Lung Cancer Patients, KY 2017-19**

#### **Advantages of Precision Medicine**

A Molecular Tumor Board (MTB) is an

together to interpret test results related to the characteristics of a patient and

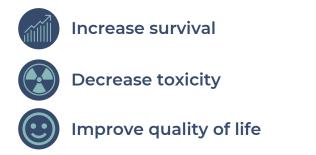
expert healthcare team that comes

MTB reviews have shown promise in

improving patient survival.

their cancer.

Research shows potential advantages of precision medicine vs. standard treatment approaches.



#### **Disparities in Research**

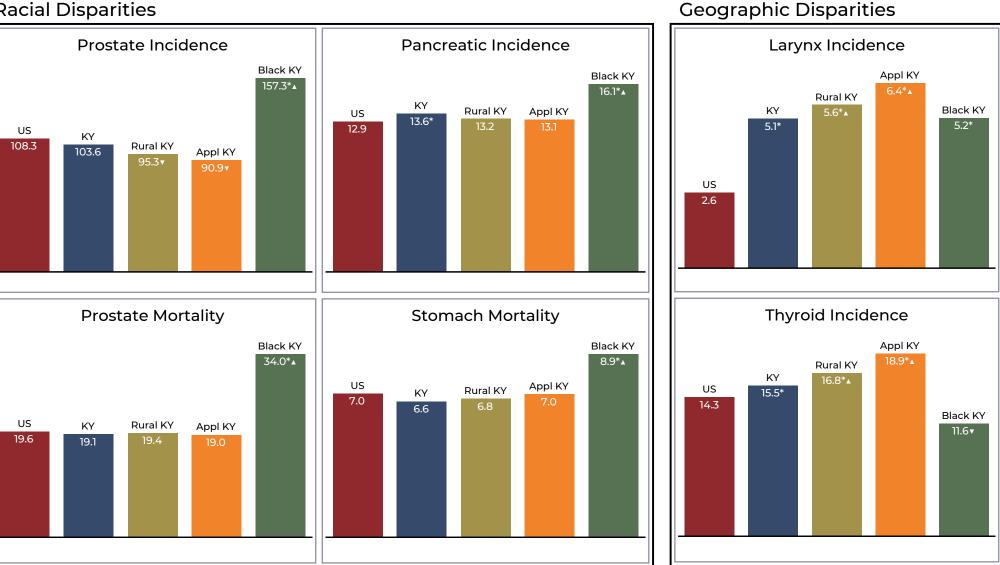
#### Why are minority and low-income patients with cancer underrepresented in precision medicine studies?

Likely because they are less often presented with the choice. Research from 2020 shows high study participation among these groups in Kentucky when given the option.

Huang et al., 2021 · Riggs et al., 2020a

### **TREATMENT — OTHER CANCER RATE DISPARITIES**

**Racial Disparities** 



Comparison groups: Rural KY vs Urban KY; Appalachian KY vs Non-Appalachian KY; Black KY vs White KY; Hispanic KY vs Non-Hispanic KY

\* = Significantly higher than all sex, all race US; ▲ = Significantly higher than comparison group; ▼ = Significantly lower than comparison group

KCR/SEER, 2014-2018

Note: Incidence and mortality rates age-adjusted

### SURVIVORSHIP — RELATIVE SURVIVAL

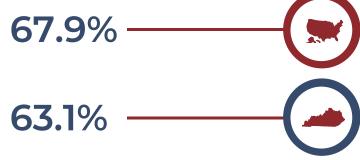
### **Relative Survival**

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



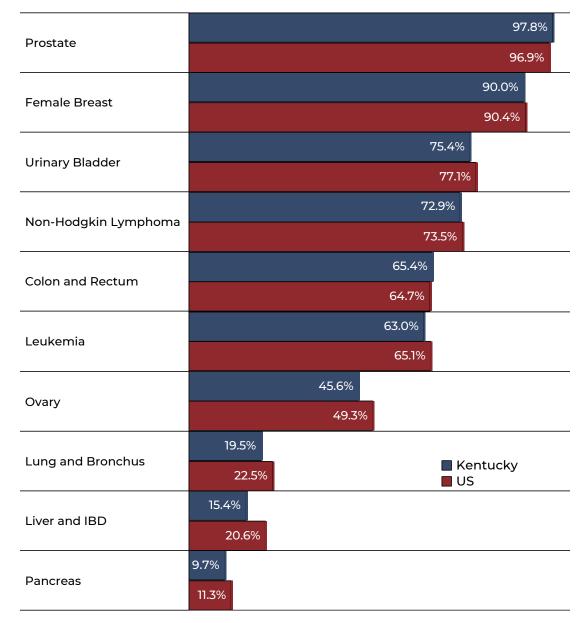
This gives a measure of survival that factors out other causes of death. Relative survival can be measured for either a general cancer diagnosis or for specific cancer sites.

#### All Site Relative Survival

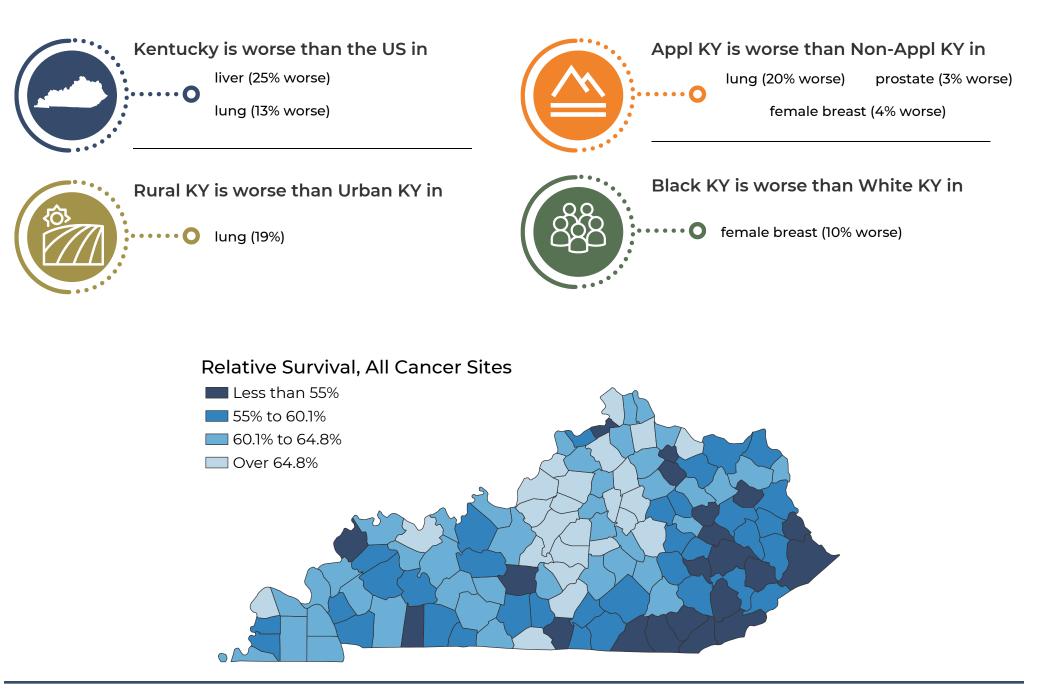


5-year relative survival across all cancers is significantly worse in Kentucky than the rest of the U.S.

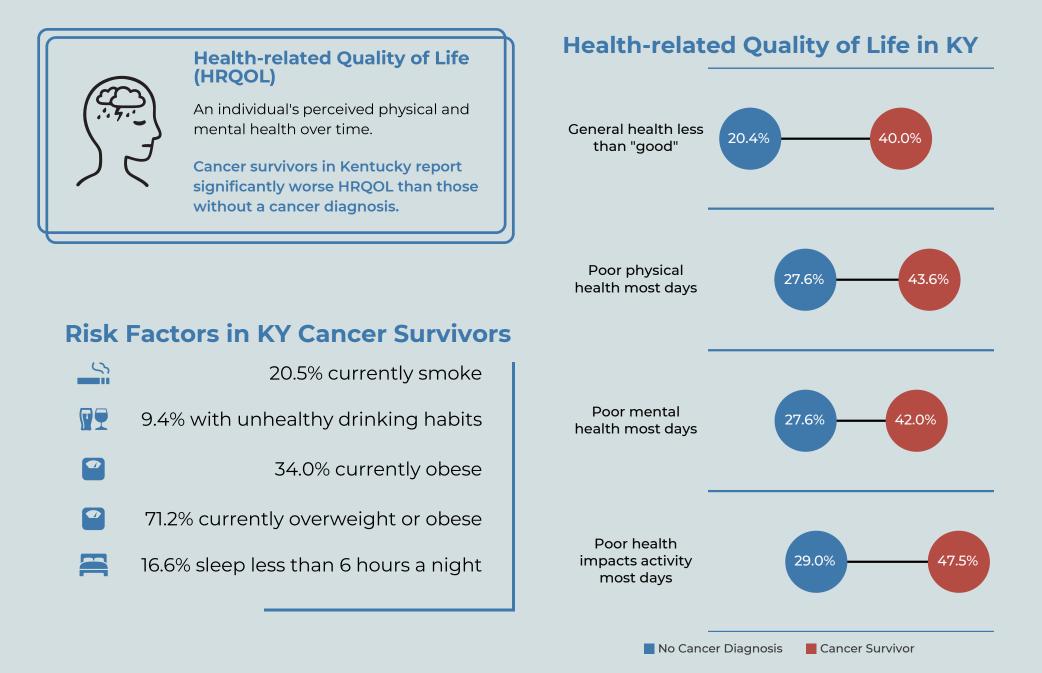
#### Relative Survival of Top 10 Cancers for Mortality



## SURVIVORSHIP — RELATIVE SURVIVAL DISPARITIES



### SURVIVORSHIP — NEEDS OF CANCER SURVIVORS



### SURVIVORSHIP — NEEDS OF CAREGIVERS

# Data on caregiver needs is not widely available. Testimony from focus group participants helps provide insight into areas of concern.

**((** I've never heard of support groups for caregivers. We asked my mom if she needed mental health counseling because of the stress of taking care of my dad and the fear that she lived with every day. She was starting to have nightmares about mixing up his medicine.... Because the focus was on the patient from the doctor's point of view, there wasn't anybody focusing on my mom and maybe her need of some help. **?** 



(Rural KY, female, age 55)



**66** [Getting support as a caregiver was] nothing that I actually thought about then.... I wish I would have.... I just felt that I was doing what I was supposed to do as a daughter or for your friend who needs you. That's what you're supposed to do: be there for your friend. But having gone through it, I realized it takes a great toll, because you're literally watching someone depart this life. **99** (Urban KY, female, age 56)

**66** There are tons of support groups out there for the caregivers, you just have to ask, but people don't.... We're so focused on the sick person that you don't want to spend any time on yourself. But if you don't take care of yourself, you're not going to be able to take care of them. **99** (Urban KY, female, age 65)



## CALL TO ACTION: REWRITING THE STORY

"A lot of people just don't understand why screening is important. People will only go to the doctor if they feel like they're dying, if they're really sick. They don't understand about these preventive measures." (Rural KY, female, age 30)

### MAMMOTH CAVE

Follow the steps below and use the contents in this section to impact change in your community and across the state.

Read the recap of key findings from the Social Determinants of Health and Cancer-related Outcome sections, which include data from existing sources and focus group interviews

Review input from stakeholder organizations and community members on ranking top needs in Kentucky and prioritizing strategies to address cancer-related needs **Community Prioritization of Needs** 

### A Call to Action

Summaries of Findings

Explore ways to use the results of the Kentucky Cancer Needs Assessment to help rewrite the story of cancer in your community and across the state

## SUMMARY — SOCIAL DETERMINANTS OF HEALTH



#### Key Needs Insights from Existing Data

#### Society

- Rural, Appalachian, Black, and Hispanic KY have higher rates of poverty than US
- 1 in 3 counties have >20% of people living in persistent poverty since 1980 (mostly in rural Appalachia)
- Fewer KY adults have a college degree than US (even lower among rural, Appalachian, Black, and Hispanic Kentuckians)
- 1 in 4 KY Hispanics uninsured; other KY population groups similar or better than US
- Approximately 1 in 3 in KY are on Medicaid

#### Community

 1 in 3 in KY counties are health professional shortage areas for primary care

#### Environment

- Some cancers linked to environmental exposures are more common in KY than US (e.g., lung, kidney, melanoma, leukemia, bladder)
- Significant food deserts exist in Appalachia and the urban core of KY's largest cities
- Rural and Appalachian KY have less access to broadband and internet-connected devices than the rest of the state



#### **Community-Driven Solutions** Insights from Focus Groups

#### Society

- Providing education on and opportunities for making healthcare more affordable
- Focusing on mental health and removing stigmas

#### Community

- Improving access to and availability of quality healthcare facilities, providers and support staff
- Encouraging an atmosphere of trust in healthcare settings
- Developing broad, community-based strategies for disseminating health information
- Supporting culturally appropriate health information, providers and services
- Improving access to advancements in healthcare service and treatment options (e.g. telehealth, genetic testing, etc.)

#### Environment

- Crafting policies to promote and protect health in the physical environment (e.g. smoke-free, clean water, etc.)
- Building infrastructure and economic policies that promote healthy living (e.g. affordable healthy foods and high-speed internet, area for physical activity, etc.)

### SUMMARY — CANCER-RELATED OUTCOMES



#### Key Needs Insights from Existing Data

#### **Risk Reduction**

- About 1 in 4 KY adults currently smoke, with higher rates in Appalachia (2nd worst state in US)
- 1 in 5 KY youth and 2 in 5 KY adults are obese (among worst in US)
- 1 in 3 KY adults physically inactive outside of work (3rd worst in US)
- Only half of KY youth are up-to-date on HPV vaccine
- Higher rates of cancers and cancer deaths related to tobacco, obesity and HPV in KY than the rest of US
- New Hepatitis C virus infection is among the highest in US (linked with opioid injection use and a known cause of liver cancer)

#### Screening & Diagnosis

- Rates worse in Rural KY for cervical screening and in Appalachian KY for cervical and colorectal screening
- Lung cancer screening rates are better than US, but only about 1 in 5 eligible KY adults are getting screened, and lower for Black KY
- Disparities in cancer mortality exist in Rural and Appalachian KY for lung, colorectal and cervical cancers

#### Treatment

- Racial disparities in cancer mortality exist for breast, prostate, colorectal, uterine and liver cancers in Black KY
- Precision medicine shows promise for improved survival

#### Survivorship

- Disparities in relative survival exist for lung cancer (rural and Appalachian KY) and breast cancer (Black KY)
- Cancer survivors have significant quality of life needs



#### **Community-Driven Solutions** Insights from Focus Groups

#### **Risk Reduction**

- Better educating individuals on cancer risks and risk reduction strategies
- Building health promotion into multiple aspects of the community (e.g. employer-based, local organizations, schools, etc.)
- Educating on why and how to stop smoking and providing assistance to be successful
- Addressing stigma and fatalistic beliefs about cancer

#### Screening & Diagnosis

- Making cancer screenings more accessible
- Addressing knowledge and attitude barriers to getting screened for cancer

#### Treatment

- Providing additional supports for cancer patients (e.g. mental health, spiritual care, transportation, etc.)
- Better educating cancer patients on the specifics of their diagnosis and treatment

#### Survivorship

- Coordinating cancer care to better serve patients
- Providing appropriate and accessible end of life options for cancer patients

## **COMMUNITY PRIORITIZATION OF NEEDS & STRATEGIES**

Stakeholder organizations and community members sorted and rated the key CNA findings into six identified themes. Two themes reflected needs. The needs they rated and discussed as most important are listed in blue box.

		у•С	overty • Racial, Rural and Appalachian disparities besity • HPV • Environmental exposures r
	Four themes reflected strategies to address the needs. Or Items in <b>BOLD</b> rated as p		tially easy to address.
1.	EQUITABLE ACCESSIBILITY Clear communication between healthcare providers and patients	1.	OUTREACH, EDUCATION & INTEGRATIVE SUPPORT Financial support for cancer treatment
2. Access to needed doctors and specialists		2.	Advocates or navigators to guide patients through cancer treatment Information on how to use insurance benefits
5. 6. <b>7.</b>	Communication across multiple doctors about a patient's care Insurance coverage of pre-existing conditions Out-of-pocket costs for cancer care Established relationship and trust with a healthcare provider Bringing cancer screening to local communities General trust or confidence in healthcare	5.	Information on now to use insurance benefits Information on ways to reduce risks of getting cancer Mental health, spiritual support, and other assistance programs for cancer patients/caregivers Information on who should get cancer screening and when
	PROACTIVE BEHAVIORS FOR IMPROVED HEALTH		Concerns, Beliefs & Stigmas
2. 3.	<b>Smoke-free policies for second-hand smoke exposure</b> Access to places to be active or exercise (ex. parks, sidewalks, gyms,) Health habits formed as children Building skills for healthy behaviors (ex. physical activity, sleep, healthy eating)	1. 2. <b>3.</b> 4. <b>5.</b> 6.	Reduce pollution in water, air, or soil that can cause cancer Reduce stigma around mental health <b>Include additional priority health issues</b> Address belief that changing behavior won't make a difference <b>Reduce fear or avoiding cancer screenings</b> Cultural beliefs about seeking healthcare

### A CALL TO ACTION

KY CNA findings will be used by the KY Cancer Consortium to inform development of the new KY Cancer Action Plan (CAP). Others can also use the KY CNA for planning, research and more! **CNA** Use data in grant How can I use the applications Use CNA toolkit for KY CNA findings? social media, newsletters and presentations Stimulate new research to fill Dive deeper into local data gaps and regional data on Enhance data with **CNA** web portal community member lived experiences and social needs Inform local and state governmental Use for local health department and leaders community hospital CHNAs Stimulate town hall conversations Use CNA web portal to Guide program planning and monitor data and strategic plans track impact of efforts

### DATA GAPS



### Areas where existing data is missing or incomplete

#### Data on cancer needs in the Hispanic community

 With a growing Hispanic KY population, KyBRFS needs to be collected in Spanish for non-English speakers for accurate data on this group. Kentucky does not currently publish Hispanic cancer incidence and mortality rates due to challenges with accurate Hispanic ethnicity information and unstable population estimates..

#### Data on the LGBTQ community and their cancer needs

• Very little data exists anywhere about the LGBTQ community, much less cancer-specific data. An important step is to modify data collection to include more than two genders.

#### Screening surveillance

 Tracking how a community and different population subgroups are doing on cancer screenings is of high importance. Larger KyBRFS sample sizes for minority populations and improved measures that match USPSTF recommendations for lung and cervical cancer screenings are needed to accomplish this.

#### Cancer survivor data

 Additional data is needed on the following for cancer survivors in Kentucky: physical, mental, spiritual and financial health; separation of melanoma from non-melanoma skin cancer diagnoses; breakdowns of other non-skin cancer site diagnoses. Data pertaining to the caregivers of cancer survivors would also be beneficial.

### **RESEARCH OPPORTUNITIES**



#### Addressing evidence and practice gaps through research

#### New scientific discoveries and knowledge

- Advance scientific understanding of risk factors that contribute to the development of cancer and ways to reduce their impact on individual cancer risk
- Develop new technologies for early detection of additional cancer sites with high mortality
- Discover more effective cancer treatments, including precision medicine approaches
- Advance scientific understanding of treatment side effects and management

#### **Evidence-based interventions**

- > Produce and disseminate evidence-based interventions for risk reduction behaviors
- Generate and disseminate strategies to improve the implementation of evidence-based clinical guidelines for cancer screening, treatment, and supportive care
- Generate and disseminate innovative strategies to overcome patient barriers to accessing and adhering to screening, treatment and survivorship care (e.g., patient navigation, telehealth, financial assistance, transportation support)

#### Social determinants of health and health equity

- Design and evaluate policy interventions to increase access to early childhood education, higher education and economic development in low-income, rural, Appalachian, Black and Hispanic communities
- Identify and evaluate interventions to address social determinants of health (e.g., transportation, digital connectivity, environmental justice) in low-income, rural, Appalachian, Black and Hispanic communities

#### **SECTION FIVE**

## **ACKNOWLEDGEMENTS & CITATIONS**

HURCHI

Kentucky has shown early successes in increasing lung cancer screening since it was approved in 2015—currently ranking 2nd highest and 3rd fastest growing in the US, and leading to a decline in the percentage of late-stage lung cancer diagnoses in the state.

### ACKNOWLEDGEMENTS

Thank you to all of the community partners and stakeholders who have been instrumental in producing this needs assessment. Rewriting the story of cancer in Kentucky will take all of our efforts, and we are excited to have such a strong network engaged in the work.

Kentucky Cancer Needs Assessment Steering Committee:

University of Kentucky, Markey Cancer Center, Community Impact Office (CIO) Pamela Hull, Lovoria Williams, Caree McAfee, Todd Burus, Natalie Wilhite, Jessica Thompson

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Kentucky Cancer Program East (KCP-East), UK Markey Mindy Rogers

American Cancer Society Rachael King, Elizabeth Holtsclaw, Julie Waters

#### Kentucky Department for Public Health

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- Kentucky Cancer Consortium (KCC), UK Markey Jennifer Redmond Knight, Elaine Russell
- KCP-West, University of Louisville Connie Sorrell, Elizabeth Westbrook, Jamie Smith

Foundation for Healthy Kentucky Allison Adams

University of Louisville Stephanie Boone

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UK Markey, Precision Medicine Center Jill Kolesar UK Markey, Cancer Clinic Services Justine Pickarski, Michael Gosky

UK Center for Appalachian Research in Environmental Sciences (UK-CARES) Ellen Hahn, Kelly Kennoy, Stacy Stanifer

#### KCP-West, University of Louisville

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#### UK Markey, Community Impact Office

Christine Stroebel, Madeline Brown, Jane Morgan, Lee Park, Keeghan Francis, Haseeb Ahmad, Alex Chang

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### **DATA SOURCES**

Surveillance, Epidemiology, and End Results Program (SEER), National Cancer Institute, National Institutes of Health

SEER is an authoritative source of information on cancer incidence and survival in the United States. SEER currently collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 48% of the U.S. population. The Kentucky Cancer Registry (KCR) has been reporting data into the SEER program since 2001.

#### \*\*\*

#### American Community Survey, 5-Year Estimates, 2015-2019 (ACS, 5-Year, 2015-2019), U.S. Census Bureau

ACS is a nationally representative sample of households that are randomly selected to participate. This survey provides population estimates of demographic information for various geographic areas.

#### Behavioral Risk Factor Surveillance System (BRFSS), Centers for Disease Control and Prevention (CDC)

BRFSS is a representative survey of adults in all states that collects data about health-related risk behaviors, use of preventative services, and chronic health conditions. The Kentucky Behavioral Risk Factor Survey (KyBRFS) is the state-specific version of the BRFSS for Kentucky.

#### County Health Rankings and Roadmaps (CHRR), National Center for Health Statistics

This resource compiles and calculates county-level community health data from a variety of sources, including estimates of life expectancy based on data from the National Vital Statistics System.

#### Economic Research Service, U.S. Department of Agriculture (USDA ERS)

The mission of USDA's Economic Research Service is to anticipate trends and emerging issues in agriculture, food, the environment, and rural America and to conduct highquality, objective economic research to inform and enhance public and private decision making. ERS research and analysis covers a broad range of economic and policy topics, including food/nutrition and poverty.

#### **\*\***

#### Federal Communications Commission (FCC)

The Federal Communications Commission regulates interstate and international communications by radio, television, wire, satellite, and cable in all 50 states, the District of Columbia and U.S. territories. An independent U.S. government agency overseen by Congress, the Commission is the federal agency responsible for implementing and enforcing America's communications law and regulations.

### **DATA SOURCES**

#### National Immunization Survey-Teen (NIS-Teen), CDC

NIS-Teen is an annual, nationally representative phone survey that collects immunization information on adolescents aged 13-17 years living in the U.S. and verifies immunization histories from health care providers.

\*\*\*

#### Youth Risk Behavior Surveillance System (YRBS), CDC

YRBSS is a self-administered national school-based survey system that collects data regarding health-related risk behaviors among 9th through 12th grade students.

#### Other Sources Used:

- Commission on Cancer, American
  College of Surgeons
- Health Resources & Services Administration (HRSA), Department of Health & Human Services
- Healthy People 2030 (HP 2030), US Department of Health & Human Services
- Kaiser Family Foundation (KFF)
- Kentucky Cabinet for Health and Family Services (KY CHFS)
- National Flood Hazard Layer, Federal Emergency Management Agency (FEMA NFHL)
- National Notifiable Diseases Surveillance System, CDC (CDC NNDSS)
- United States Preventive Services Task Force (USPSTF)

For data tables and additional information informing the contents of this document, please refer to 2021 Kentucky Cancer Needs Assessment: Appendix I

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