







2021 Kentucky Cancer Needs Assessment





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No financial relationships or conflicts to disclose.

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KY CNA Objectives

- 1. Compare the burden of cancer in Kentucky versus the U.S. and identify health disparities.
- 2. Examine how social determinants of health influence the burden of cancer and cancer disparities in Kentucky.
- 3. Identify data gaps and action opportunities for cancer risk reduction, screening, and survivorship.
- 4. Provide actionable information to guide Kentucky's new statewide Cancer Action Plan and the strategic plans of stakeholder organizations across Kentucky.

KY Cancer Needs Assessment (CNA)

Cancer Needs Assessment:

Analyze Existing Data

Cancer incidence and mortality

Screening and risk behaviors

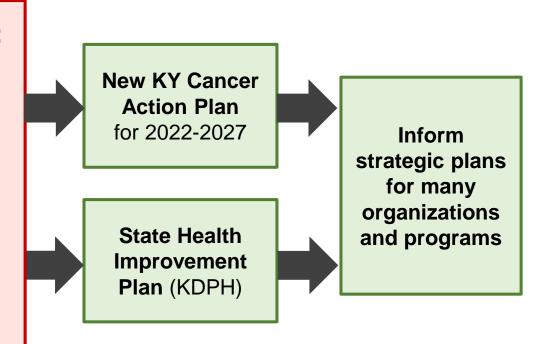
SDOH and health disparities

Gather Stakeholder Input

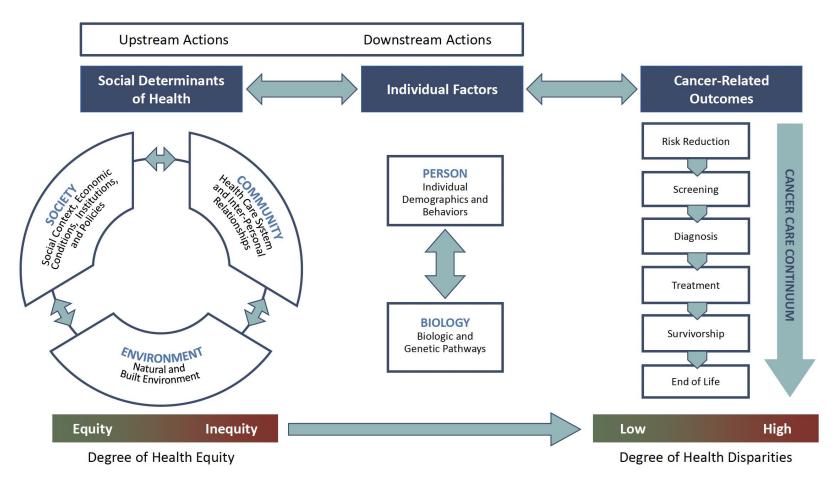
CNA Steering Committee, KCC members, DCC members

Focus groups: Community members

Review Resources and Assets



Conceptual Framework



Multilevel Determinants of Cancer-Related Outcomes Across the Cancer Care Continuum

Your Input during Today's Presentation

Throughout the presentation, please think about:

- 1. SURPRISES and new insights from the data
- 2. GAPS in data for future attention
- 3. ACTION opportunities suggested by the data

Make notes to share out loud during discussion, or share your ideas in the chat box in this format to label the type of idea:

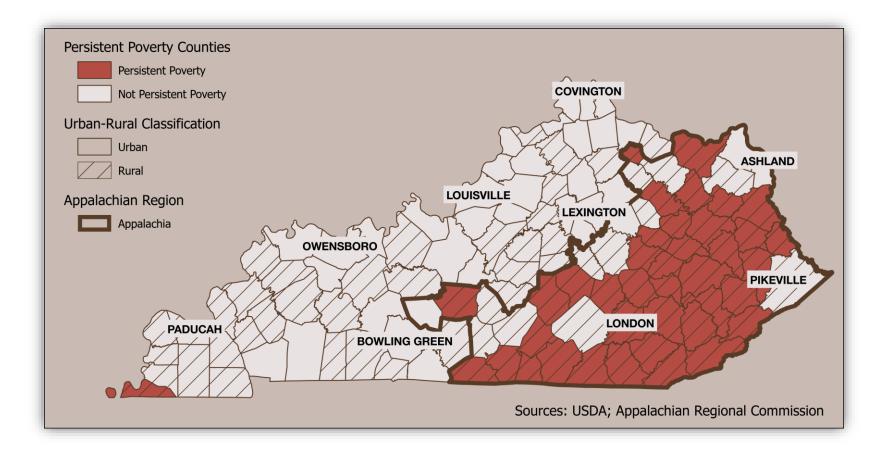
SURPRISE: Type your idea

GAPS: Type your idea

ACTION: Type your idea

Social Determinants of Health in Kentucky

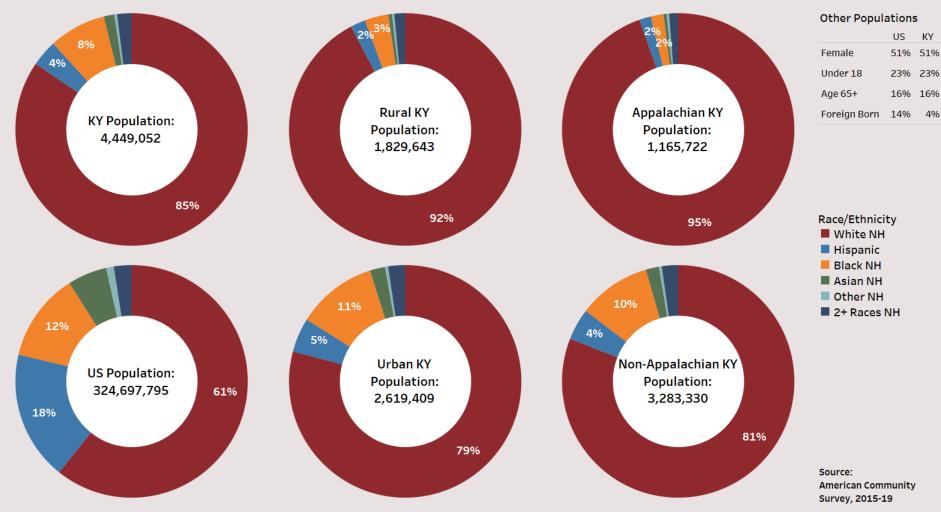
Geography and Persistent Poverty



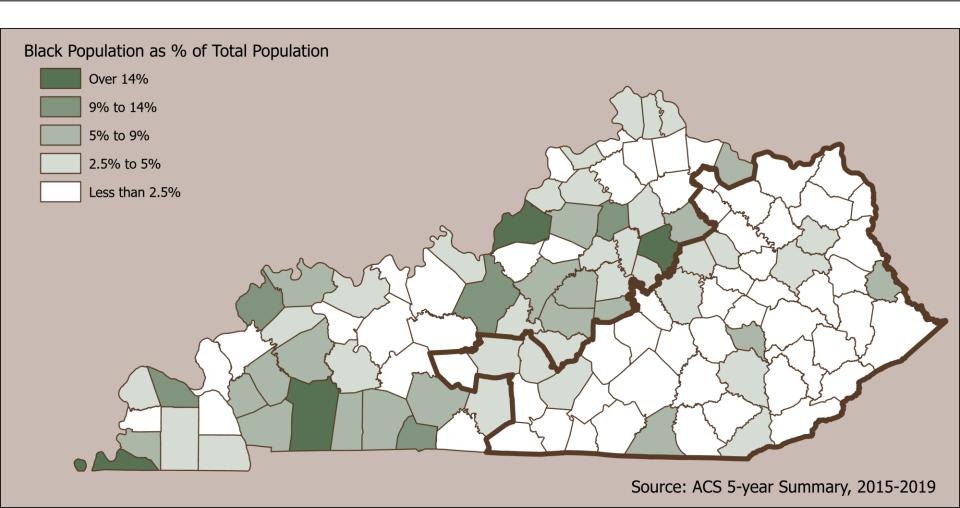
Persistent Poverty: Counties in which 20 percent or more of their populations were living in poverty based on the 1980, 1990, and 2000 decennial censuses and 2007-11 estimates

Demographic Characteristics

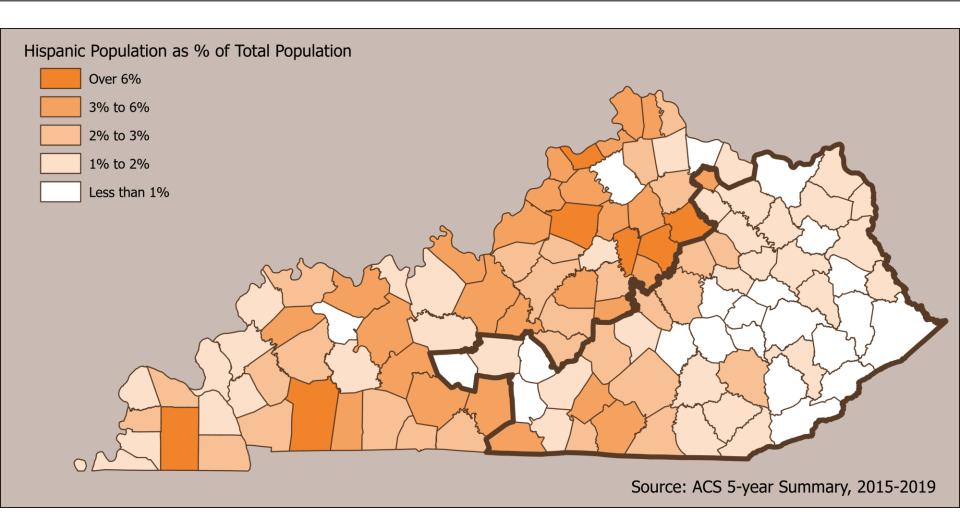
Kentucky Demographic Profile



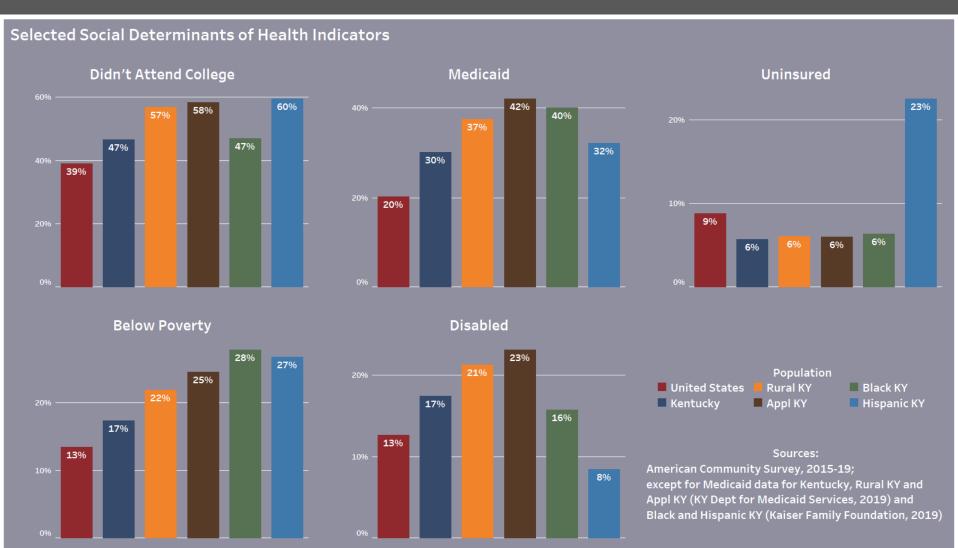
Black Population Distribution in KY



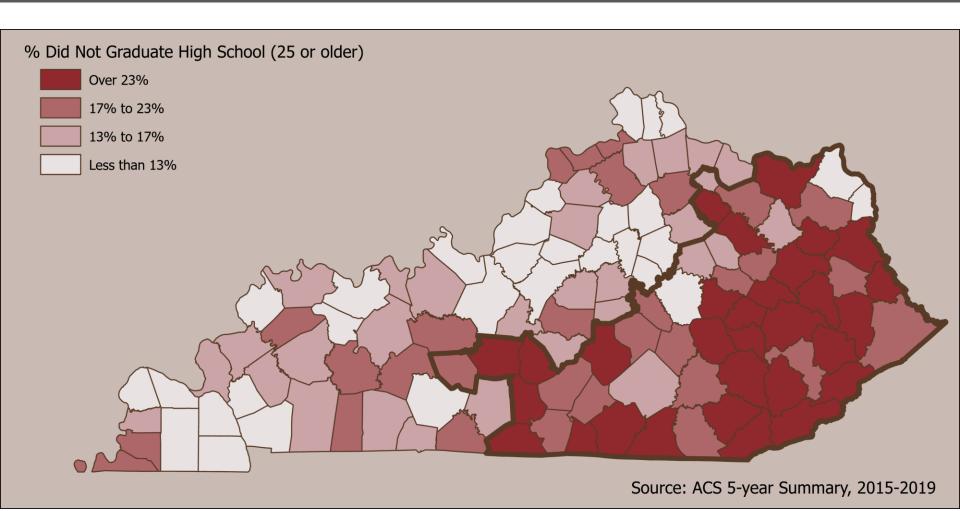
Hispanic Population Distribution in KY



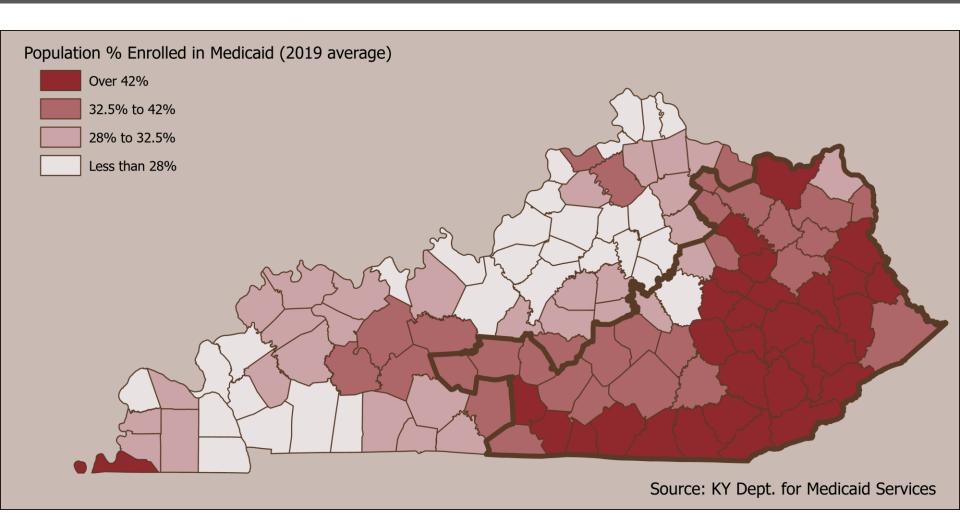
Social Determinants of Health



Social Determinants of Health: Education



Social Determinants of Health: Medicaid



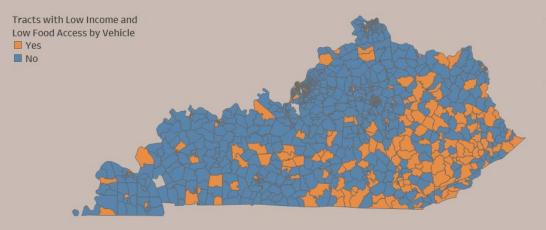
Focus Groups: Health Insurance

- "Now that the ACA has taken effect... those used to be through Medicaid or a sliding scale place, and now most people have insurance can go kind of anywhere."
- "Right, so well, I think, even people that have insurance the deductibles are so high on a lot of them that there are people that will not do. I mean there's a few things on this list that are now because of the ACA you can get screened once a year, and you don't have to pay for it."

Food Access in Kentucky

Food Access and Health in Kentucky

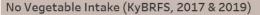
Food Deserts (USDA, 2019)

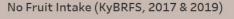


<u>Low income tract</u>: 20% of households below the poverty line, or the median family income is less than 80% of the state median family income.

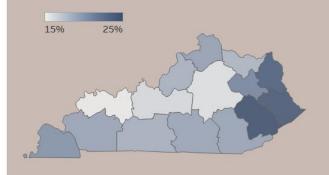
Low food access by vehicle tract: at least 100 households with no vehicle and > 0.5 miles from the nearest supermarket, or 500 residents (or 33% of residents, whichever is smaller) living > 20 miles from the nearest supermarket.

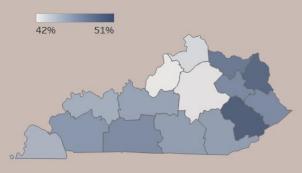
Highlighted tracts satisfy both conditions above.

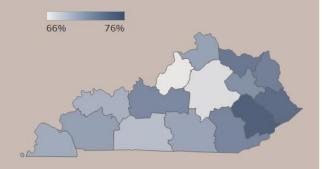




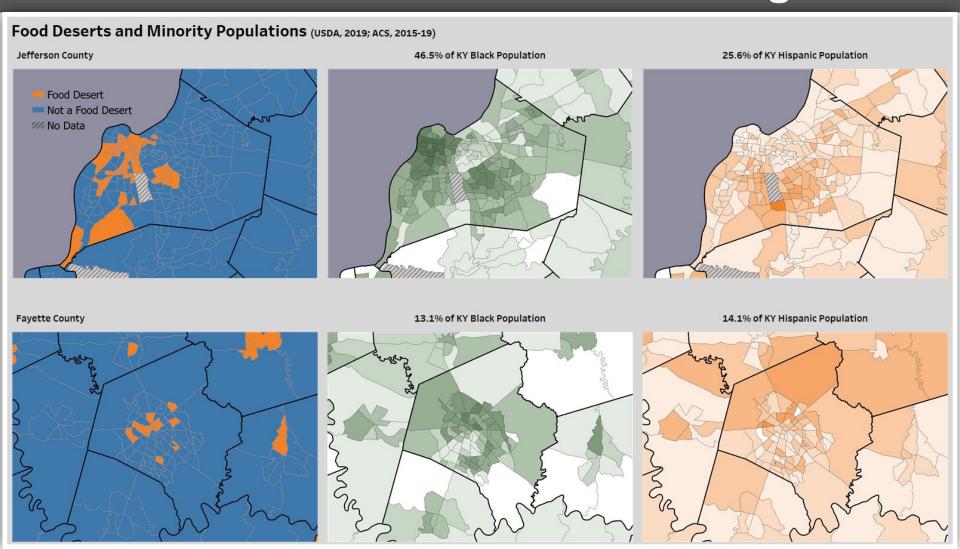
Unhealthy Weight (KyBRFS, 2016-19)



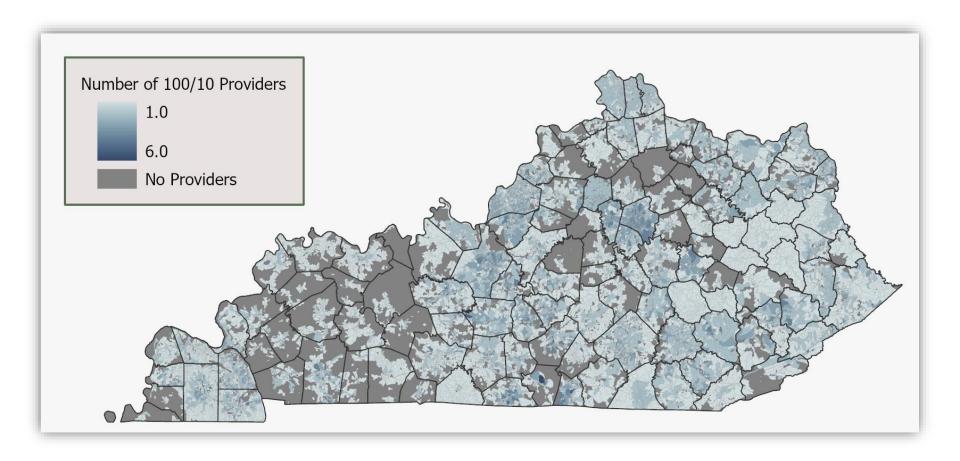




Food Access in Louisville and Lexington

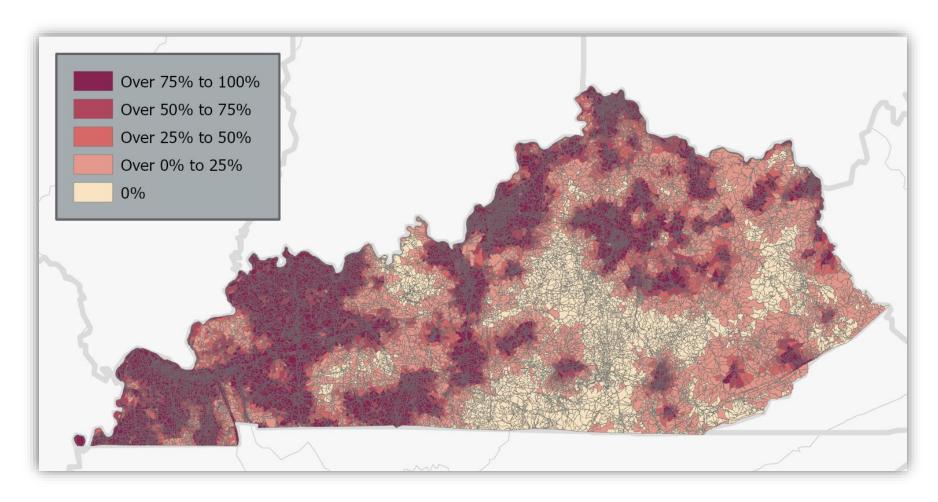


Map of High-Speed Internet Coverage (min. 100/10)



Source: FCC, June 2020

Map of 5G Coverage by Census Block



Source: FCC, June 2020

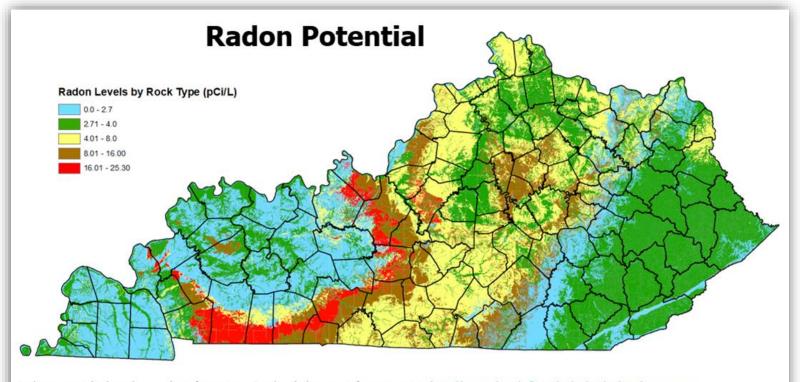
Cancer-related Environmental Contaminants

| Contaminant | Cancers associated with exposure | | | | |
|---------------------|--|--|--|--|--|
| Arsenic | Bladder cancer Skin cancer Liver cancer Kidney cancer Digestive tract cancer | | | | |
| Asbestos | MesotheliomaLung cancerCancer of the LarynxOvary cancer | | | | |
| Benzene | Leukemia and other blood disorders | | | | |
| Dioxins | Non-Hodgkin lymphoma | | | | |
| Formaldehyde | Myeloid leukemia Cancer of the paranasal sinuses, nasal cavity, and nasopharynx | | | | |
| Herbicides | Non-Hodgkin lymphomaSoft-tissue sarcomas | | | | |

| Contaminant | Cancers associated with exposure | | | | | |
|-------------------|--|--|--|--|--|--|
| Lead | Lung cancerStomach cancerUrinary-bladder cancer | | | | | |
| Pesticides | Brain cancer Prostate cancer Kidney cancer Leukemia | | | | | |
| PFAS | Kidney cancer Testicular cancer | | | | | |
| Radon | Lung cancer | | | | | |
| Tobacco Smoke | Lung cancer Breast cancer Leukemia Lymphoma Brain tumors Nasal sinus cavity cancer Nasopharyngeal cancer Bladder cancer | | | | | |
| Diesel Exhaust | Lung cancer | | | | | |

Source: UK-CARES

Map of Geological Radon Potential in Kentucky



Radon potential is based on geologic formations. For detailed county information visit: http://www.uky.edu/breathe/radon/radon-data-county. EPA suggested radon action level is 4.0 pCi/L or greater; World Health Organization suggested radon action level is 2.7 pCi/L.

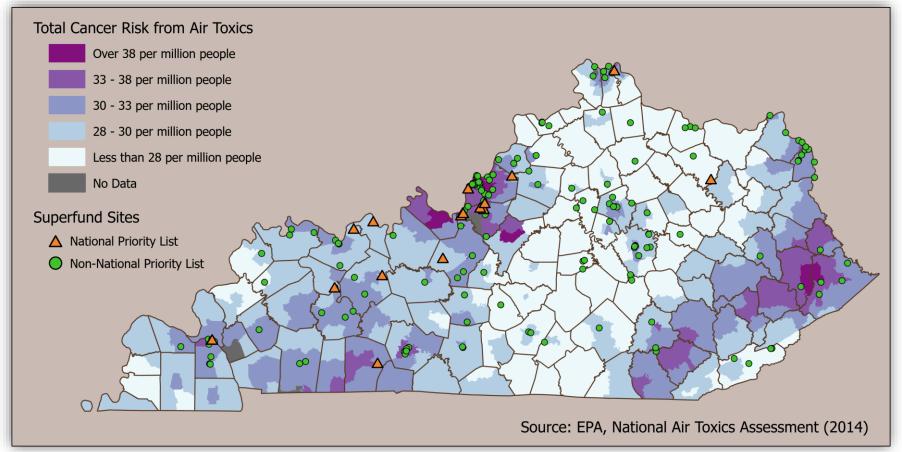






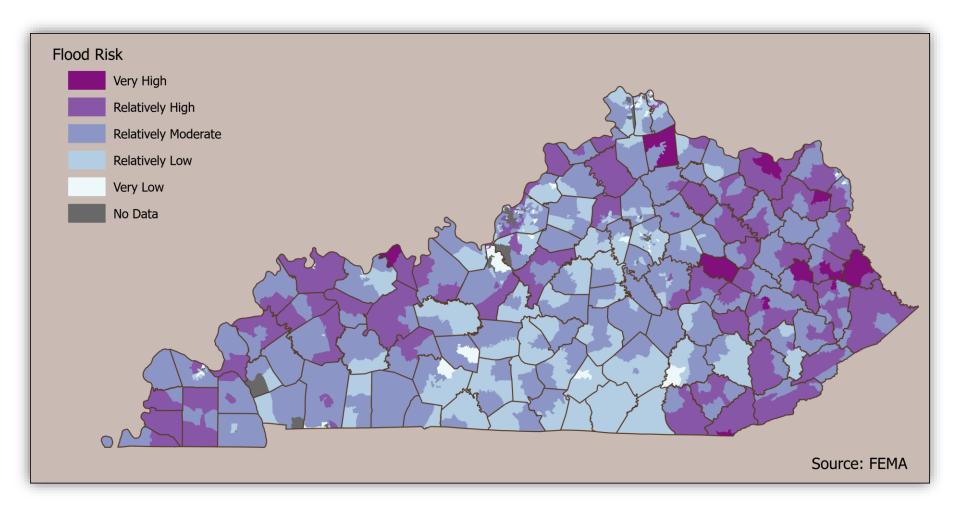
Map of Air Toxics and Superfund Sites in Kentucky

Contaminants commonly found at Superfund sites: Asbestos, Dioxin, Lead, Radiation

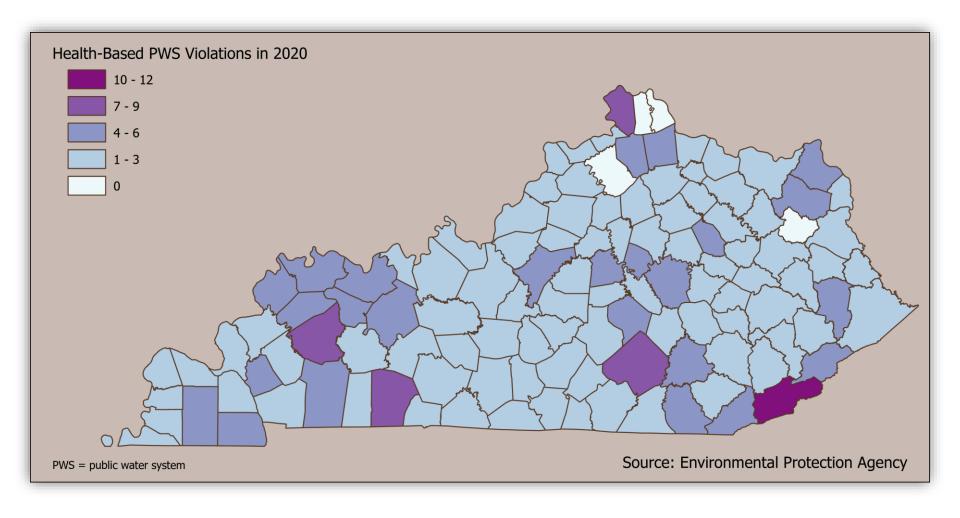


"Superfund Sites" are contaminated due to hazardous waste being dumped, left out in the open, or otherwise improperly managed. Sites include manufacturing facilities, processing plants, landfills and mining sites.

Map of Flood Risk in Kentucky



Map of Safe Drinking Water Violations in Kentucky



Focus Groups: Environmental Exposures

• "I know there's a lot of **controversy** and stuff like that, on the environment, and you know us living in Eastern Kentucky where **there's mining and logging** and things like that... **take the politics out** of it, and you know just **give us information and let us then decide**."

• "One thing that concerns me is the pollution from all the industries in the West [KY], and I know so many people who grew up with me who have developed cancer over the years. I know that since there's not as much chemical manufacturing going on anymore, that it must be reduced some, but it does seriously concern me what's in the air."

Focus Groups: Environmental Exposures

• "We could definitely have a **bigger presence** of that [awareness of environmental pollutants] in my specific area, especially with **how much agriculture** we do have in the area, and **the runoff from that can cause a lot more issues than I think most of our residents are aware of.**"

More data on attitudes about environmental exposures in Eastern KY: UK-CARES Community Environmental Health Assessment https://ukcares.med.uky.edu/ceha

Discussion: Social Determinants of Health

Share your thoughts and ideas about:

- 1. SURPRISES and new insights from the data
- 2. GAPS in data for future attention
- 3. ACTION opportunities suggested by the data

Make notes to share out loud during discussion, or share your ideas in the chat box in this format to label the type of idea:

SURPRISE: Type your idea

GAPS: Type your idea

ACTION: Type your idea

Overall Burden of Cancer in Kentucky versus U.S.

Top 10 Cancer Rate Comparisons

(KCR and SEER, 2014-18)

| | | US | KY | Rural KY | Appl KY | Black KY |
|-----------------------------------|-----------------------------|-------|--------|----------|---------|----------|
| | All Sites | 438.3 | 513.8† | 523.9† | 534.3† | 481.8† |
| | Female Breast | 127.4 | 127.3 | 118.5‡ | 117.9‡ | 128.0 |
| ok) | Prostate (males only) | 108.3 | 103.6‡ | 95.3‡ | 90.9‡ | 157.3† |
| er 10 | Lung and Bronchus | 49.3 | 88.1† | 97.8† | 104.3† | 82.3† |
| ate (p | Colon and Rectum | 37.5 | 47.7† | 51.7† | 54.3† | 49.2† |
| Age-Adj Incidence Rate (per 100k) | Melanoma of the Skin | 23.6 | 27.9† | 28.1† | 26.2† | 1.4‡ |
| | Corpus Uteri (females only) | 26.3 | 27.0 | 29.1† | 32.2† | 24.9 |
| -Adj I | Urinary Bladder | 18.6 | 22.2† | 22.8† | 22.6† | 11.0‡ |
| Age | Kidney and Renal Pelvis | 16.1 | 20.9† | 21.2† | 21.5† | 23.1† |
| | Non-Hodgkin Lymphoma | 19.1 | 19.6 | 19.5 | 19.7 | 14.7‡ |
| | Leukemia | 13.8 | 15.8† | 16.1† | 15.9† | 13.1 |

| | | US | KY | Rural KY | Appl KY | Black KY |
|-----------------------------------|-----------------------|-------|--------|----------|---------|----------|
| ok) | All Sites | 147.5 | 189.3† | 205.8† | 213.5† | 186.7† |
| | Lung and Bronchus | 32.9 | 59.9† | 69.0† | 73.2† | 52.6† |
| | Female Breast | 19.9 | 20.8 | 21.3† | 22.8† | 25.6† |
| er 10 | Prostate (males only) | 19.6 | 19.1 | 19.4 | 19.0 | 34.0† |
| Age-Adj Mortality Rate (per 100k) | Colon and Rectum | 13.1 | 16.4† | 18.4† | 19.1† | 19.5† |
| lity R | Pancreas | 10.8 | 11.5† | 11.1 | 11.1 | 13.1† |
| Morta | Leukemia | 6.0 | 6.9† | 7.2† | 7.2† | 5.4 |
| -Adj I | Liver and IBD | 7.1 | 6.8 | 6.7 | 6.8 | 8.5† |
| Age | Ovary (females only) | 6.8 | 6.3 | 6.3 | 6.6 | 4.7‡ |
| | Non-Hodgkin Lymphoma | 5.3 | 6.0† | 6.1† | 5.8 | 4.0‡ |
| | Urinary Bladder | 4.1 | 4.9† | 5.0† | 4.7† | 3.3 |

Group Comparisons:

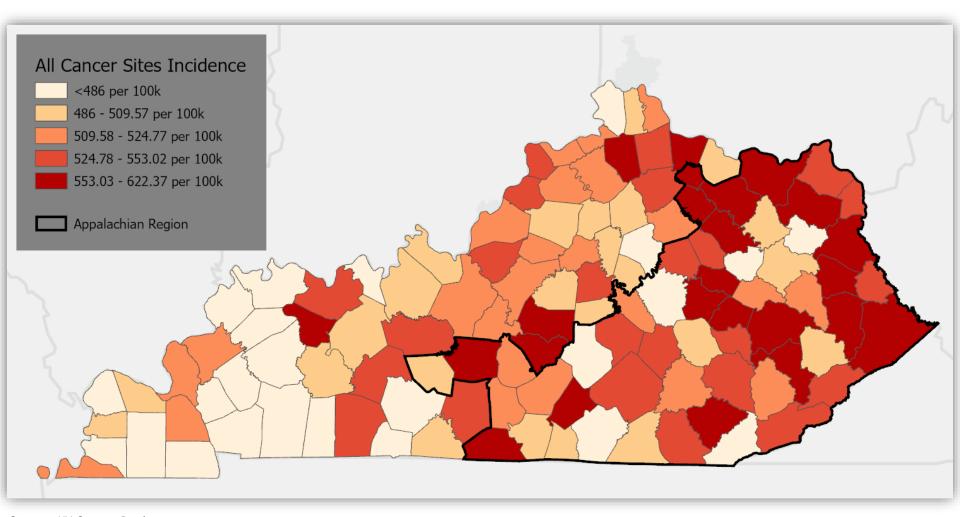
(1) Kentucky/Rest of SEER, all sex & race; (2) Rural KY/Urban KY, all sex & race; (3) Appalachian KY/Non-Appalachian KY, all sex & race; (4) Black KY/White KY, all sex

Significance vs comparison group:

Significantly higher rate than comparison Significantly lower rate than comparison

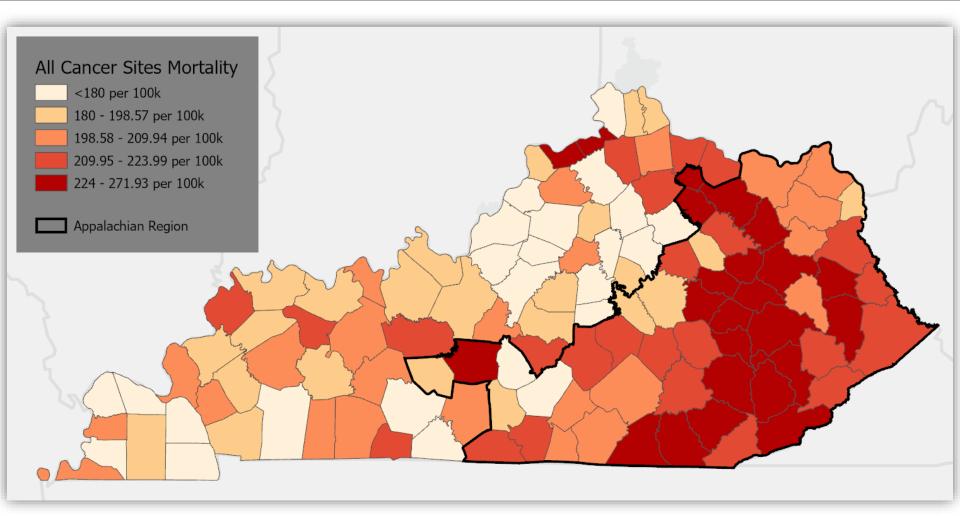
Significance vs all sex, all race US rates:

All Site Cancer Incidence, 2014-2018



Source: KY Cancer Registry

All Site Cancer Mortality, 2014-2018



Source: KY Cancer Registry

Discussion: Overall Cancer Burden & Disparities

Share your thoughts and ideas about:

- 1. SURPRISES and new insights from the data
- 2. GAPS in data for future attention
- 3. ACTION opportunities suggested by the data

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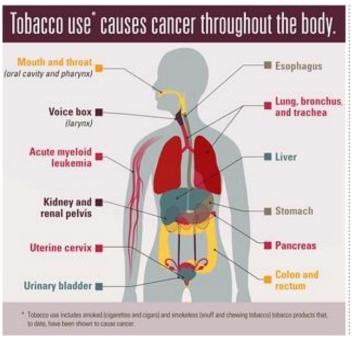
SURPRISE: Type your idea

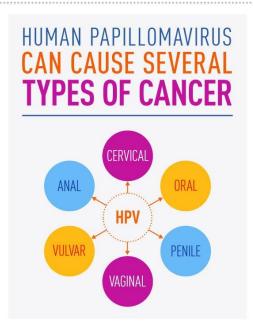
GAPS: Type your idea

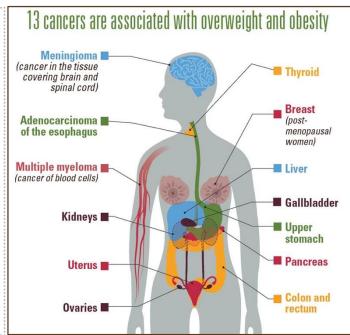
ACTION: Type your idea

Cancers Linked to Evidence-Based Risk Reduction Behaviors

Tobacco, HPV and Obesity Related Cancers



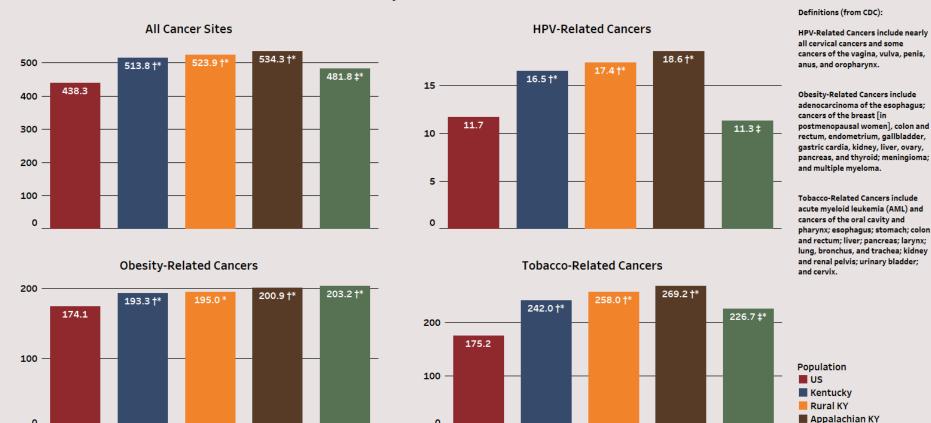




Sources: CDC and NCI

Risk Factor Related Cancer Incidence

All Site and Risk Factor Related Cancer Incidence in Kentucky



Group Comparisons

(1) Kentucky/Rest of SEER, all sex & race; (2) Rural KY/Urban KY, all sex & race; (3) Appalachian KY/Non-Appalachian KY, all sex & race; (4) Black KY/White KY, all sex

Significance vs all sex, all race US rates:

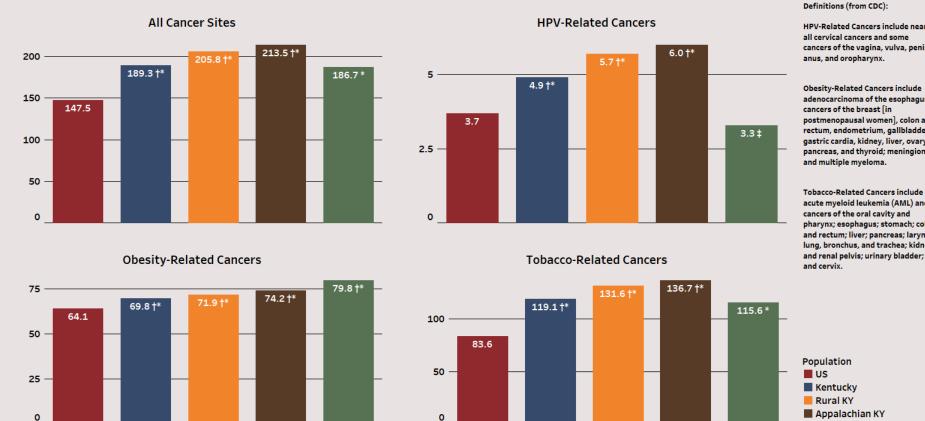
* = Significantly higher than all sex/all race US

Sources: KCR and SEER, 2014-18

Black KY

Risk Factor Related Cancer Mortality

All Site and Risk Factor Related Cancer Mortality in Kentucky



(1) Kentucky/Rest of SEER, all sex & race; (2) Rural KY/Urban KY, all sex & race; (3) Appalachian KY/Non-Appalachian KY, all sex & race; (4) Black KY/White KY, all sex

Significance vs all sex, all race US rates:

† = Significantly higher than comparison group ‡ = Significantly lower than comparison group

* = Significantly higher than all sex/all race US

HPV-Related Cancers include nearly cancers of the vagina, vulva, penis,

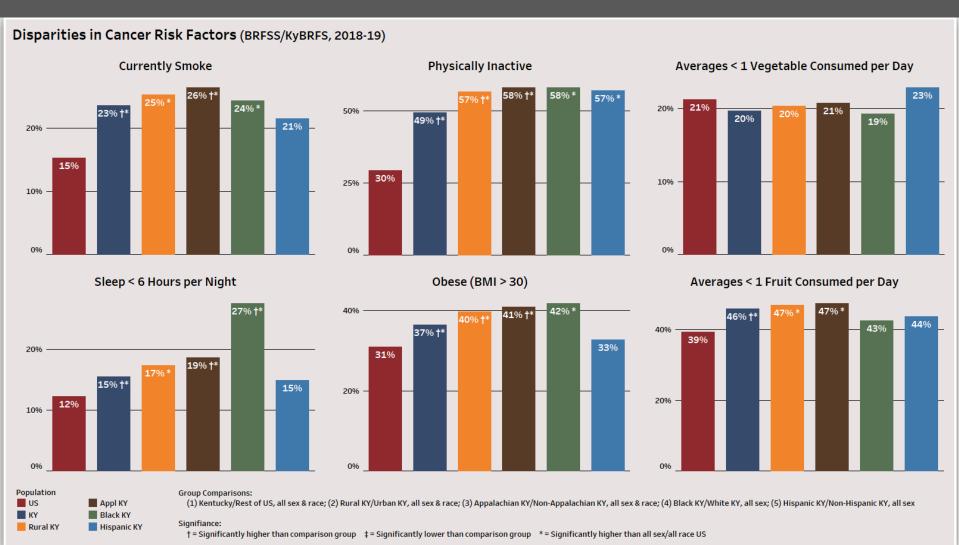
Obesity-Related Cancers include adenocarcinoma of the esophagus; postmenopausal women], colon and rectum, endometrium, gallbladder, gastric cardia, kidney, liver, ovary, pancreas, and thyroid; meningioma;

acute myeloid leukemia (AML) and pharynx; esophagus; stomach; colon and rectum; liver; pancreas; larynx; lung, bronchus, and trachea; kidney and renal pelvis; urinary bladder;

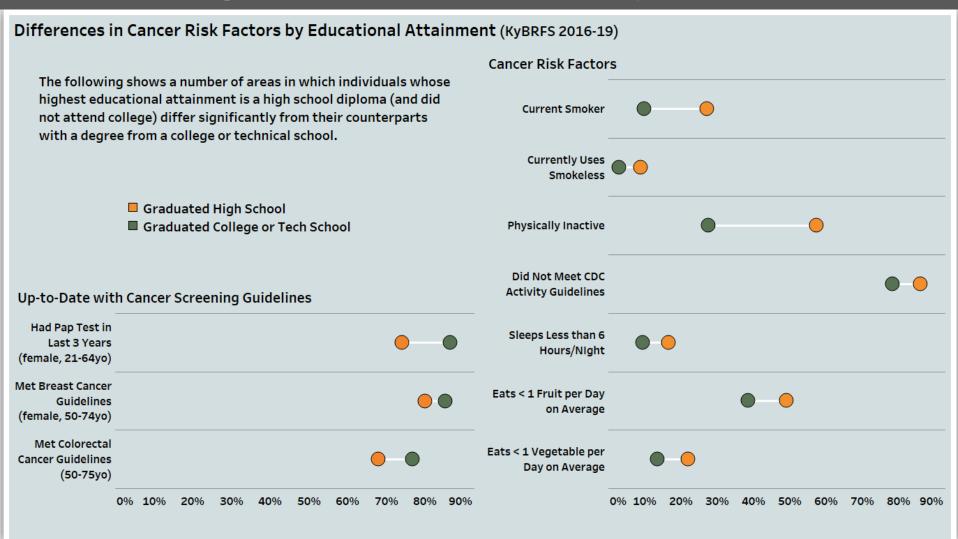
Black KY

Sources: KCR and SEER, 2014-18

Behavioral Risk Factors



Screening and Risk Factors by Education



Focus Groups: Risk Reduction - Tobacco Use

• "My husband still smokes heavily, and he knows all the risk and he still does it because he's addicted to it. I think that preventing it from happening [in the first place] is definitely a concern. I know in my area, my dad and mama did, their uncle did, their grandpa did. [When I] ask, they say, "well, I started smoking at seven when I got a cigarette from my grandpa," and it's just old family mentality circles."

Focus Groups: Risk Reduction – Tobacco Use

- "I just don't see as many people smoking as I used to, so I feel like these education programs and things that are out there are helping... and, of course, then you've got the vaping and stuff now. When it first started, you know, it was like so it was supposed to be so much safer and everything, but now, people are learning it's not and it can be even more dangerous, so I think, maybe a focus some on that part."
- "The Health Department does cessation tobacco cessation, and it's sort of a catch 22 that Extension Offices teach farmers, how to grow bigger and better tobacco and grow lots of crops and we're trying to teach people to be healthy."

Focus Groups: Risk Reduction – Diet

- "It's expensive eating healthy. I know my family we try to invite a lot of fresh fruits and vegetables, and my husband just commented to me the other day is like this is expensive."
- "I'm probably exposed in some way to watch this [nutrition] stuff through my church. We have a food pantry... and one of our members is a doctor with U of L and she brings in nurses and things like that to see people who come visit food pantry."

Focus Groups: Risk Reduction – Physical Activity

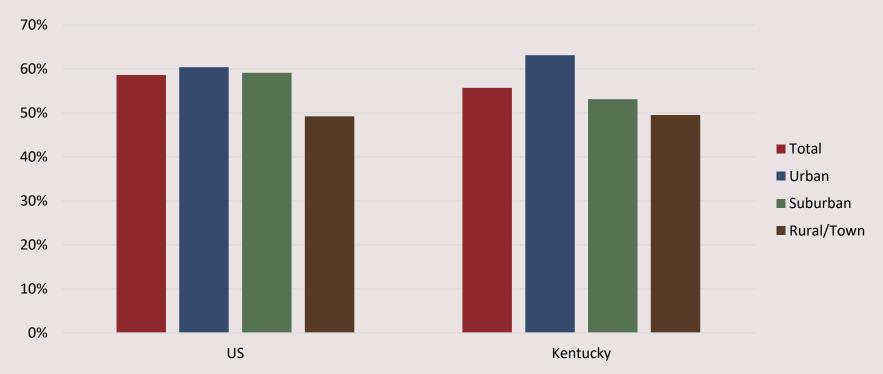
- "Not everybody can afford the go to gym or not every everybody has access to transportation to get to trails."
- "And a lot of small towns are getting into that [walking paths] and building bike paths and making it a tourism thing, but then it's good for your health and people get out."

Focus Groups: Risk Reduction – Physical Activity

• "There was like a group of ladies that came together, and they would walk on their lunch... then they get on Facebook and talk about how far they walked and how they failed so then sometimes that might motivate you that you want to go down there and walk. But I think that that program was pretty successful for a little while and then everything just kind of fizzles out."

HPV Vaccination

Up-to-Date with HPV Vaccination (All Doses), Ages 13-17, 2020



Source: National Interview Survey-Teen
Urban=MSA (Metropolitan Statistical Area), Central City; Suburban=MSA, non-Central City; Rural/Town=Non-MSA

Data on racial/ethnic differences are not available for Kentucky.

Nationally, Black and Hispanic adolescents have higher HPV vaccination than Whites.

Focus Groups: Risk Reduction – HPV Vaccine

"The only time I've ever seen anything about the HPV vaccine is at the Health Department."

 "I wonder how serious the throat cancer is because of HPV. I wasn't really familiar with that, but I just lost a friend who had, I don't know if it had anything to do with HPV, but she died of throat cancer. She wasn't a smoker."

Focus Groups: Risk Reduction – HPV Vaccine

• "The Latino community, generally speaking, when parents bring their daughters to their appointments and the doctor starts talking about the HPV vaccination, the doctors also start talking about if the teen's been sexually active and that doesn't click so well... perhaps there is there is a deep cultural and religious background, but many moms are like 'I don't see the need for that vaccination, because my daughter is not sexually active."

Focus Groups: Risk Reduction – Sun Exposure

- "I've also never had my family doctor say anything to me about sunscreen. I mean I went to a dermatologist, and she did. That was the first time someone was like you should really be using moisturizer with sunscreen in it, so that's a little disappointing. I feel like you don't hear anything until something is bad."
- "Especially African Americans, you think, 'Oh, we don't really need those,' but we need to just as much as everybody else does, you know. We can go get the skin cancer as well, and there's not enough information about that."

Focus Groups: Risk Reduction – Stress & Alcohol

• "When they get stress, they should be able to think of another option. They could go take a walk or, you know, go and do some other chores, maybe they can go talk to a friend, or go and sit somewhere and maybe do some type of exercises instead of resorting to having a smoke, you know, regardless if it's cigarettes or drugs or having a drink, so it's good to have some form of coping skills to help you with the stress."

 "I actually am ignorant to the fact that drinking could have an effect, you know, could cause cancer. I did not know that myself, and there's a lot of people here that drink. I mean if they didn't smoke, they do drink."

Focus Groups: Risk Reduction – Attitudes

- "To not eat well or not exercise, but if they were raised in that environment, I think those are those are those types of habits are really hard to break so education and ways to help implement new habits, I think, would be necessary."
- "It's about people feeling attacked, so I think it just really goes back to messaging, and I think in my years, people always want to know why, like what's your motivation for doing it, so I think the better you can communicate that."

Discussion: Risk Reduction

Share your thoughts and ideas about:

- 1. SURPRISES and new insights from the data
- 2. GAPS in data for future attention
- 3. ACTION opportunities suggested by the data

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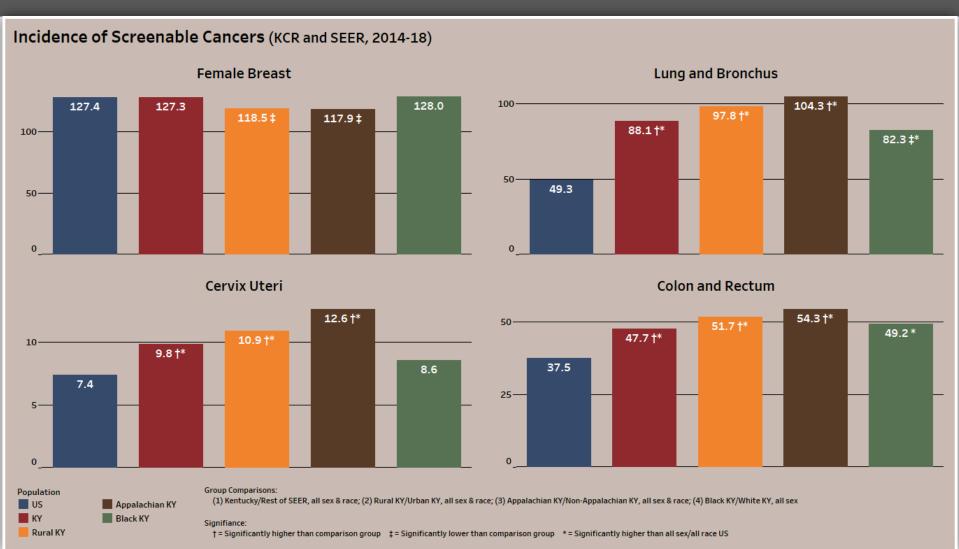
SURPRISE: Type your idea

GAPS: Type your idea

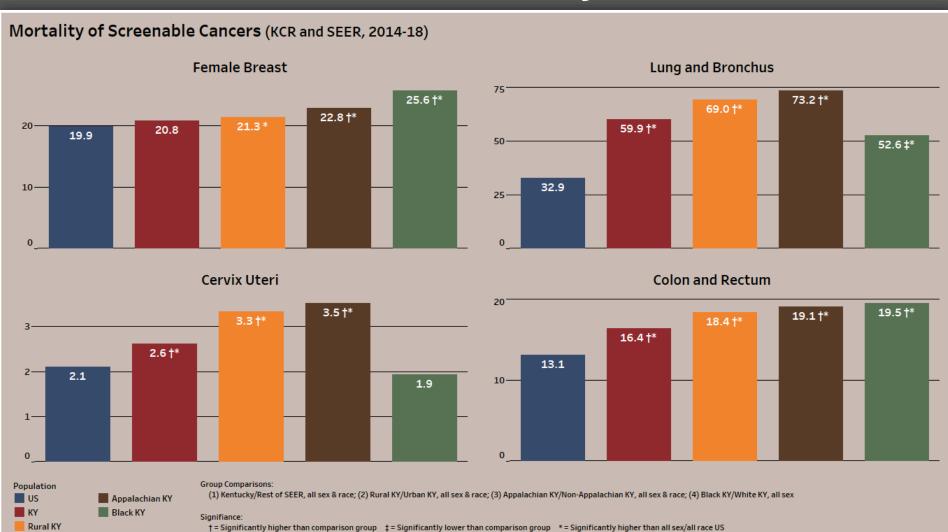
ACTION: Type your idea

Cancers with Evidence-Based Screening Guidelines

Screenable Cancer Incidence

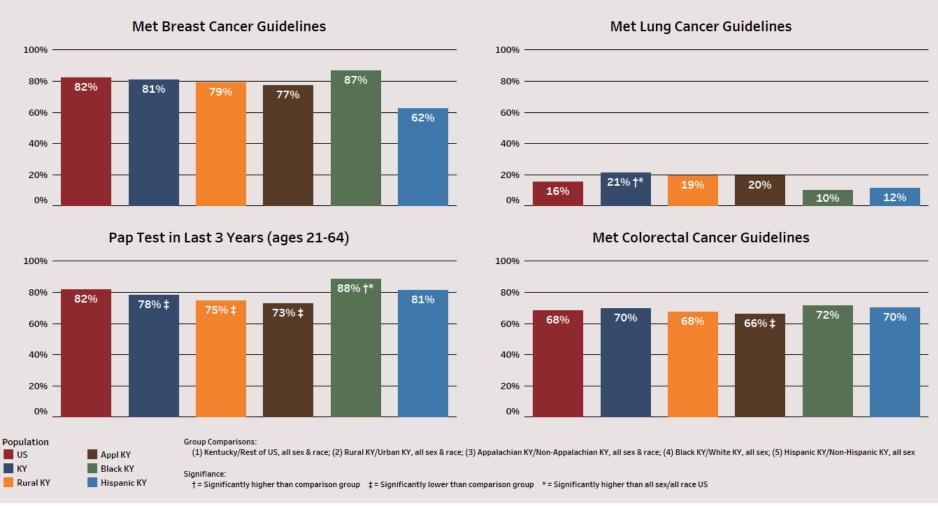


Screenable Cancer Mortality



Cancer Screening Rates

Disparities in Cancer Screenings (BRFSS/KyBRFS, 2016-19)



Screenable Cancer Stage Rates and Survival

Kentucky Data on Stages of Screenable Cancers

Percent Late Stage Diagnosis for Screenable Cancers (KCR, 2014-18)

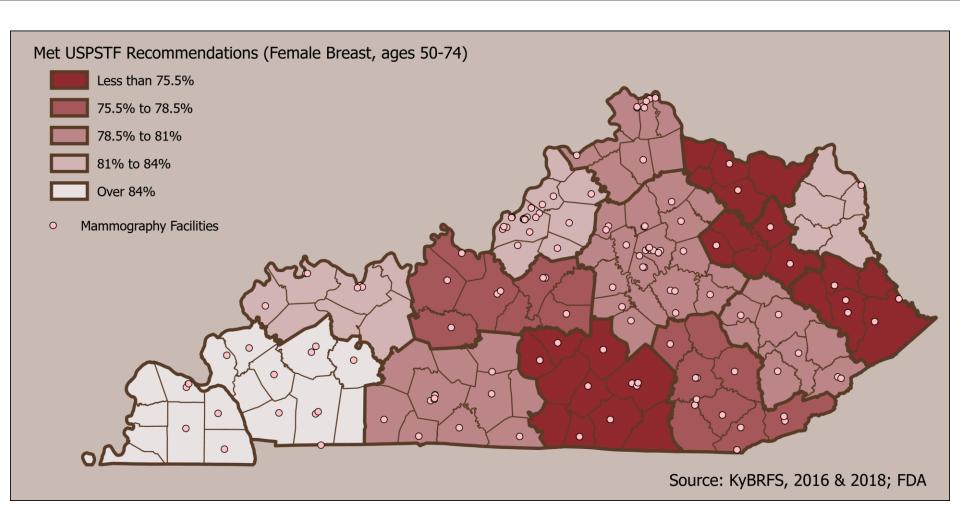
| | Kentucky | Rural KY | Urban KY | Аррі КҮ | Non-Appi KY | Віаск КҮ | White KY |
|-------------------|----------|----------|----------|---------|-------------|----------|----------|
| Lung and Bronchus | 77.3% | 78.3% | 76.4% | 78.9% | 76.5% | 78.9% | 77.2% |
| Colon and Rectum | 42.4% | 42.3% | 42.6% | 43.9% | 41.8% | 42.8% | 42.7% |
| Cervix Uteri | 41.8% | 44.7% | 39.4% | 44.3% | 40.5% | 41.0% | 42.1% |
| Female Breast | 25.8% | 27.1% | 24.9% | 28.2% | 24.9% | 28.8% | 25.5% |
| | | | | | | | |

| Relative Survival for Screenable Cancers by Stage (SEER, 2012-18) | | | | | | | |
|---|---------------------|-----------------------|----------------------|--|--|--|--|
| | Early Stage (local) | Late Stage (regional) | Late Stage (distant) | | | | |
| Lung and Bronchus | 54.5% | 30.8% | 5.1% | | | | |
| Colon and Rectum | 90.1% | 72.8% | 13.6% | | | | |
| Cervix Uteri | 92.1% | 58.3% | 13.9% | | | | |
| Female Breast | 99.7% | 84.1% | 27.7% | | | | |
| | | | | | | | |

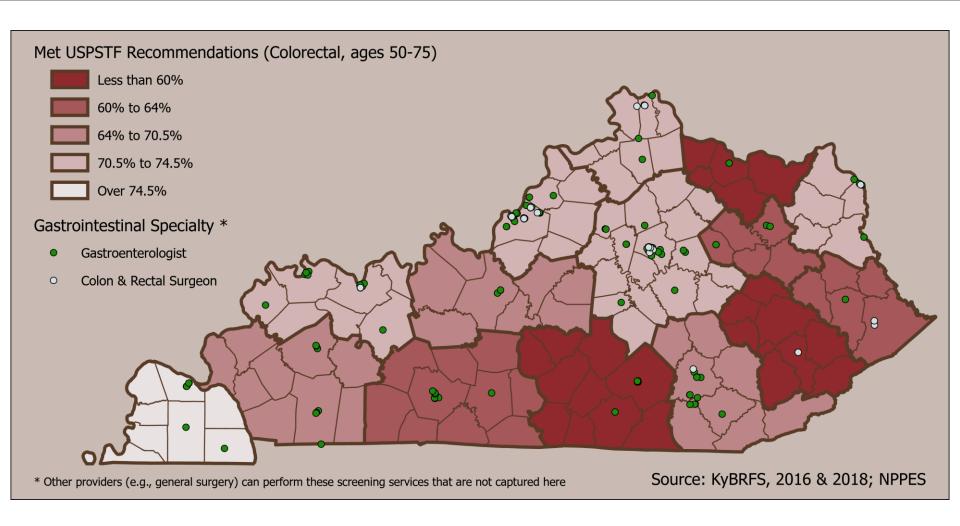
Risk Increase by Stage of Diagnosis (SEER, 2012-18)

| Nisk mereuse by stuge of Blughosis (SEEK, 2012-10) | | | | | | | | | |
|--|---|--|---|--|--|--|--|--|--|
| Lung and Bronchus | Colon and Rectum | Cervix Uteri | Female Breast | | | | | | |
| 1.5 times more likely to die within 5-years | 2.7 times more likely to die within 5-years | 5.3 times more likely to die within 5-years | 53.0 times more likely to die within 5-years | | | | | | |
| with a regional vs a local diagnosis | with a regional vs a local diagnosis | with a regional vs a local diagnosis | with a regional vs a local diagnosis | | | | | | |
| 2.1 times more likely to die within 5-years | 8.7 times more likely to die within 5-years | 10.9 times more likely to die within 5-years | 241.0 times more likely to die within 5-years | | | | | | |
| with a distint vs a local diagnosis | with a distint vs a local diagnosis | with a distint vs a local diagnosis | with a distint vs a local diagnosis | | | | | | |

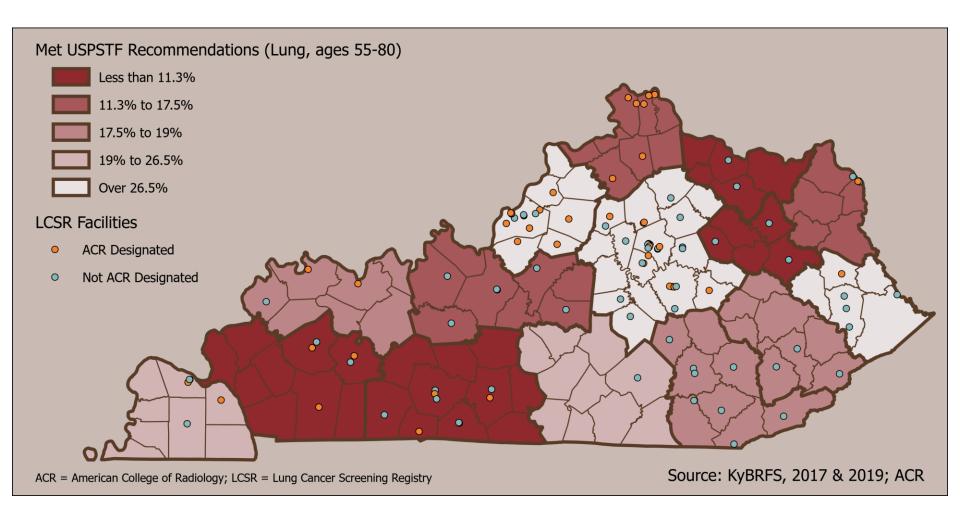
Breast Cancer Screening Locations



Colorectal Cancer Screening Locations



Lung Cancer Screening Locations



Focus Groups: Cancer Screening Access

- "There's a lot of older folks here, and there's a lot of lower income people who don't have cars so they're not able, you know to drive, you know, to go 30 minutes out a way to go to it."
- "Another issue is that even people that have insurance and then all the things [she] said, like people that work all the time that are working two jobs or they don't have someone to watch their kids. They don't have transportation. That's a big problem here, we don't have public transit."

Focus Groups: Cancer Screening Access

- "The CT scans for the lung [cancer]. I guess I didn't know that they actually did that. I don't know if there's a time for that or what, but I have a family history for that to happen."
- "You know, I do think some people were just not especially some of our older seniors – they weren't going out [because of COVID], and it was recommended that they not go out. Well, you can't do screenings on teleconference. I definitely think that it has had some impact."

Focus Groups: Cancer Screening Access

 "I think it was a mammogram screening. It was on the mobile clinic, so I think that's a really good idea that they had as they came up with, and you know, it's able to go around and meet the people where they are with the mobile clinic."

 "Well, you know the colon [screening], it's not so much that the procedure's horrible but the process of getting ready for the procedure is not pleasant, and I know that I'm aware of that. And even though my best friend has gone through the process, she shared it, so I'm trying to hold off."

Focus Groups: Cancer Screening Attitudes

- "Even if they do have a way, 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."
- "Some people really don't go to the doctor unless they know for a fact something is wrong with them. Sometimes I think what the Black community, there is a lack of trust with health care providers, and I think that sometimes there's a lot of fear so out of sight out of mind. Like, if I don't have anybody telling me that there's nothing wrong with me, then I don't have anything to worry about."

Discussion: Cancer Screening

Share your thoughts and ideas about:

- 1. SURPRISES and new insights from the data
- 2. GAPS in data for future attention
- 3. ACTION opportunities suggested by the data

Make notes to share out loud during discussion, or share your ideas in the chat box in this format to label the type of idea:

SURPRISE: Type your idea

GAPS: Type your idea

ACTION: Type your idea

Inherited Cancers and Precision Oncology

Focus Groups: Genetic Testing

- "I have never openly heard anybody talk about that [family history/genetics] other than in my private conversations with my doctors."
- "Even though they know that this is all prevalent in our family, they just don't want to know, so I think that's a lot for people, like my family, people don't want to know, because what you don't know won't hurt you right, which it will."

Focus Groups: Genetic Testing

• "The younger like 30 and under group, like we're much more open to like 23 and me, and like exchanging information and talking to each other about it. Whereas like my mom is over 60 and I think she's much more like 'you're sending off your DNA' and 'I don't want to know,' and I feel like maybe there's like a like a generational difference for sharing information and understanding like why it's important."

Discussion: Inherited Cancers & Precision Oncology

Share your thoughts and ideas about:

- 1. SURPRISES and new insights from the data
- 2. GAPS in data for future attention
- 3. ACTION opportunities suggested by the data

Make notes to share out loud during discussion, or share your ideas in the chat box in this format to label the type of idea:

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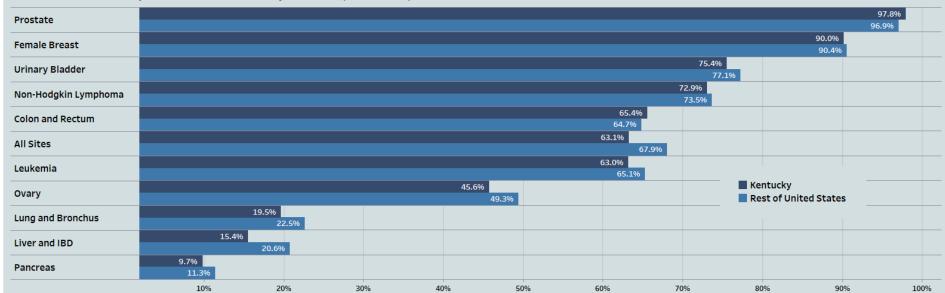
ACTION: Type your idea

Needs of Cancer Survivors in Kentucky

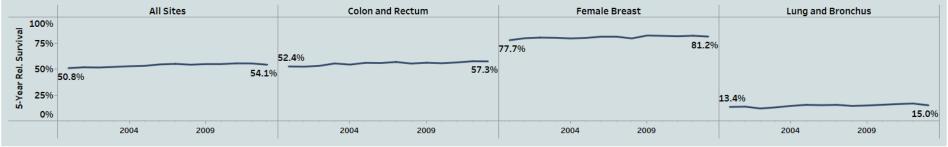
Relative Survival of Cancers

Overview of Relative Survival in Kentucky

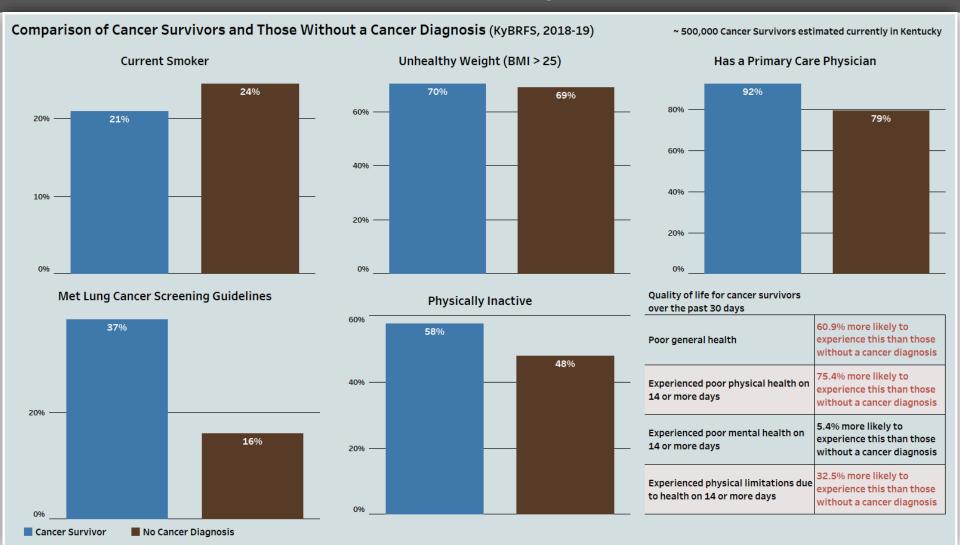
Relative Survival of Top 10 Cancers for Mortality, KY vs US (SEER 2012-18)



Relative Survival Trends for Major Cancers in KY (SEER 2000-2013)



Cancer Survivors in Kentucky



Focus Groups: Survivor Mental Health Needs

- "But the reality is there's no in-person support groups right now. I spent today trying to find a an individual therapist, and everybody's either... full up they're not taking any new patients."
- "We probably need more mental health professionals down here. Everybody needs more mental health professionals right now. When I first got a cancer diagnosis, the insurance company sent me a letter in the mail that I could talk to an oncology nurse, and I talked with her, and that was really helpful to have like a third party person not involved in like my achieving my plan and not family or friend who has any emotional investment but also not my doctor to talk to. That was a really great support."

Focus Groups: Survivor Quality of Life

- "She ended up having just about every kind of cancer you possibly have, and she was eighty-three years old... they said that she wouldn't live six months, but [she lived] two years. They put her on to some experimental drug and obviously it helped, but I don't want to die that way."
- "I think they gave her family false hope and that they did things that work, probably, for some people because they're younger. They would choose to take extraordinary measures at the end of their life, but I think they did things that probably lowered her quality of life at the end when it was inevitable that she was going to pass away."

Focus Groups: Survivor Follow-up Needs

 "Because a lot of times, especially the physical therapy or all of that [survivor supports] requires referrals and sometimes that can be a process, depending upon the type of medical insurance."

"And the other person I met with... was like 'well, I don't understand why a young pretty women like you wouldn't want to have that surgery done.' So I think that there is sort of like pressure to meet traditional gender stereotypes in reconstruction, and you know, like how you deal with that that sort of thing, and also with like fertility issues."

Focus Groups: Survivor Follow-up Needs

• "They found that she had Medicaid it's like 'oh we're sorry, this is an experimental treatment, and this isn't covered by Medicaid.' So, [we asked] how much does this cost. It will cost you about \$100,000 to get this, and it might as well have been a million dollars. I have followed the research and it has been phenomenal, and it's so sad that we live in a world that \$100,000 is worth more than an extra 10 to 15 years of my mother's life."

Discussion: Cancer Survivors

Share your thoughts and ideas about:

- 1. SURPRISES and new insights from the data
- 2. GAPS in data for future attention
- 3. ACTION opportunities suggested by the data

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Overall Reflection and Discussion

Healthy People 2030 Cancer Goals

Healthy People 2030 Cancer Goals

| Goal | HP2030 Source | US Baseline | Target | Kentucky |
|--|---------------|-------------|--------|----------|
| Reduce the overall cancer death rate (per 100k people) | NVSS | 149.1 | 122.7 | 189.3 |
| Reduce the lung cancer death rate (per 100k people) | NVSS | 34.8 | 25.1 | 59.9 |
| Reduce the female breast cancer death rate (per 100k women) | NVSS | 19.7 | 15.3 | 20.8 |
| Reduce the colorectal cancer death rate (per 100k people) | NVSS | 13.4 | 8.9 | 16.4 |
| Reduce the prostate cancer death rate (per 100k men) | NVSS | 18.8 | 16.9 | 19.1 |
| Increase the proportion of cancer survivors who are living 5 years or longer after diagnosis (%) | SEER | 64.1 | 66.2 | 63.1 |
| Increase the proportion of oral and pharyngeal cancers detected at the earliest stage (%) | SEER | 29.5 | 34.2 | 29.7 |

Kentucky currently worse than US baseline Kentucky better than US baseline, but worse than target

The NHIS isn't publicly available or representative at the state level, making a direct comparison to Healthy People cancer goals based on this source impossible. For interest of comparison, a similar measure has been provided for each using the KyBRFS from 2016 to 2019.

| Goal | HP2030 Source | KY Source | US Baseline | Target | Kentucky |
|--|---------------|-----------|-------------|--------|----------|
| Increase the proportion of adults who get screened for lung cancer (%) | NHIS | KyBRFS | 4.50 | 7.50 | 21.20 |
| Increase the proportion of females who get screened for breast cancer (%) | NHIS | KyBRFS | 72.80 | 77.10 | 80.80 |
| Increase the proportion of adults who get screened for colorectal cancer (%) | NHIS | KyBRFS | 65.20 | 74.40 | 69.90 |
| Increase the proportion of females who get screened for cervical cancer (%) \ast | NHIS | KyBRFS | 80.50 | 84.30 | 78.30 |

^{*} Kentucky value only includes percentage of women 21-64 who have not had a hysterectomy and received a Pap test

Discussion: Overall

Share your thoughts and ideas about:

- 1. SURPRISES and new insights from the data
- 2. GAPS in data for future attention
- 3. ACTION opportunities suggested by the data

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GAPS: Type your idea

ACTION: Type your idea

Next Steps

CNA Data Resources: Coming Soon



Summary Report: Key Highlights

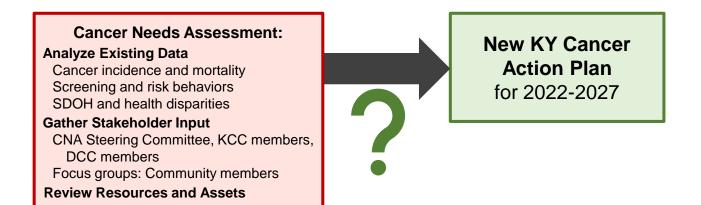


Web Portal:
Interactive Mapping
and Tables



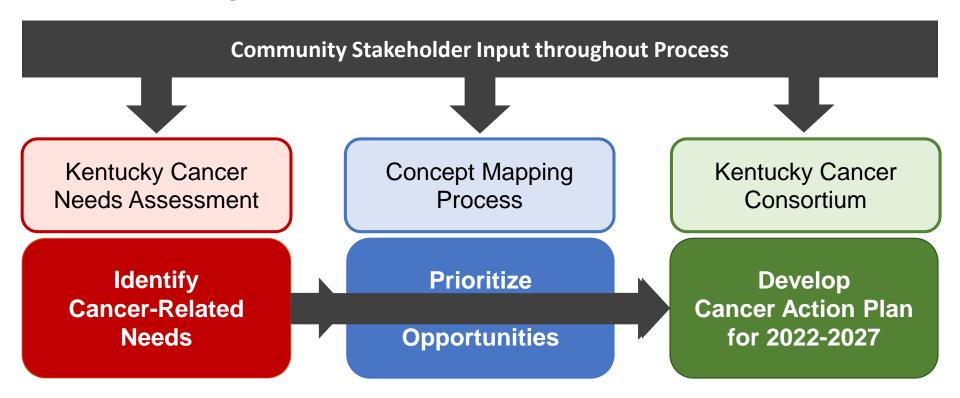
District Profiles

Lots of Data and Stakeholder Input ... Now What?





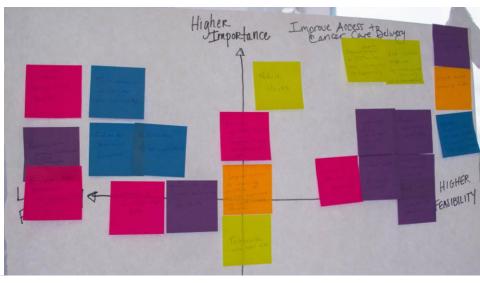
Next Steps: How CNA will be used for new CAP

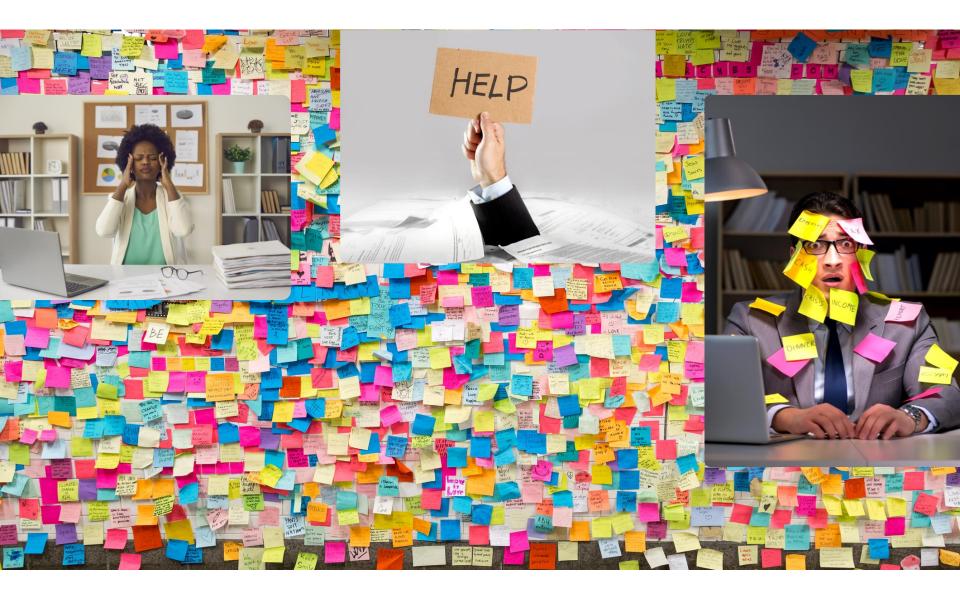












What is Concept Mapping?

1. Preparation

- Outline planning goals
- Determine participant recruitment process

2. Generation

- Brainstorming and idea generation around focal question
- *Generate list from CNA

3. Structuring

- Sorting and rating the brainstormed items
- *Stakeholder organizations and lay community members

4. Representation

 Run multi-level analysis to create concept maps

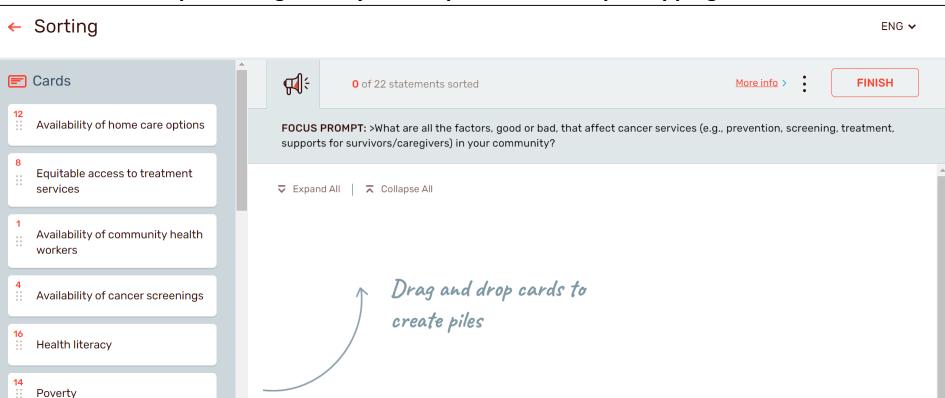
5. Interpretation

- Group discussions to understand meaning of concept maps
- *Stakeholder organizations and lay community members

6. Utilization

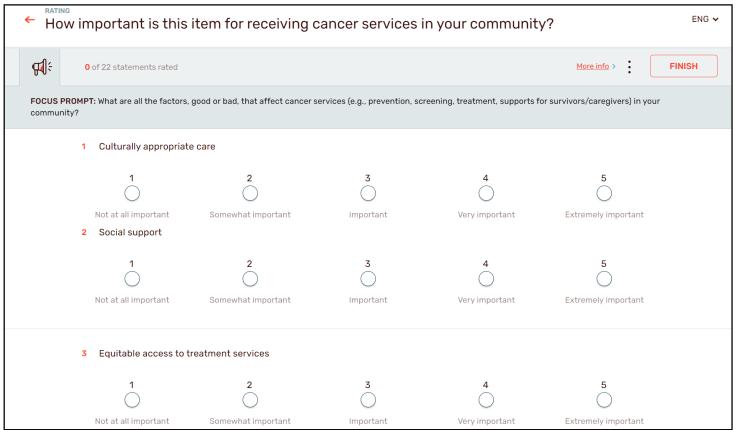
- How findings can be used to inform planning goals
- *Use results to identify priorities & objectives for CAP
- Concept mapping is "a structured process, focused on a topic or construct of interest, involving input from one or more participants, that produces an interpretable pictorial view (concept map) of their ideas and concepts and how these are interrelated" (Trochim, 1989)
- Participatory method (directly engaging stakeholders) to identify priorities

Example Sorting Activity in Groupwisdom Concept Mapping Software



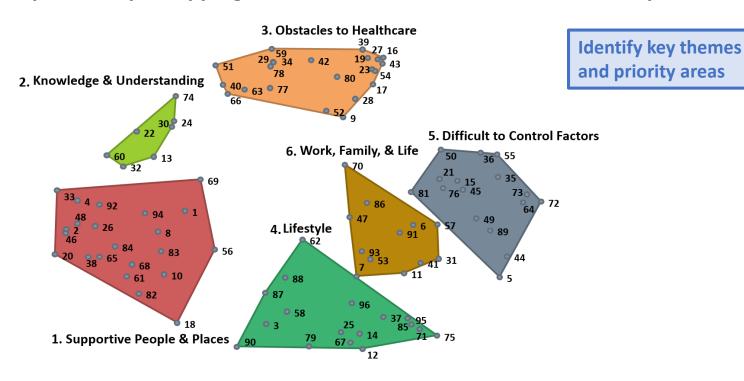
- Completely online and accessible by computer/tablet/mobile phone at any time
- Time: Total 30-60 minutes; does not have to be done in one sitting
- Provides detailed step-by-step instructions

Example Rating Scale in Groupwisdom Concept Mapping Software



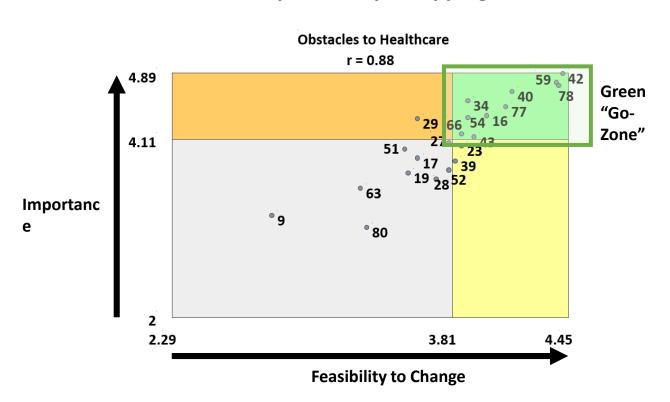
- Completely online and accessible by computer/tablet/mobile phone at any time
- Time: Total 20-30 minutes per rating (if 2 ratings: total 40-60 minutes); does not have to be done in one sitting
- Provides detailed step-by-step instructions and easy to use radio buttons

Example Concept Mapping Results: Combined Point and Cluster Map



- Created from the combination of all sorting data
- Items that are closer together were more often sorted together by participants
- Cluster analysis identifies item groups by conceptual area
- Foundation for a conceptual framework and identification of priority areas

Example Concept Mapping Results: Go-Zone Plots



- Allows for exploration within specific clusters
- Can be used to identify specific items (e.g., items in the green "Go-Zone") high across multiple rating scales or to compare different participant groups

Identify potential strategies and actions

Sample Items:

- 16. Cost of medication, even with insurance coverage
- 34. Availability of specialist doctors in the community
- 40. Going to annual doctor visits
- 42. Healthcare affordability
- 43. Insurance changes repeatedly causing changes in doctors making it hard to get appointments/plan an overall health strategy
- 54. Cost to maintain proper health screenings
- 59. Good medical insurance
- 66. Seeing a dentist regularly to address tooth decay and gum disease
- 77. Availability of women's health care services
- 78. A doctor you trust

Next Steps

- Preparing list of key findings from CNA to be used in online concept mapping tool
- Aiming to send out invitations for online concept mapping in late October
- Provide concept mapping findings to KCC Leadership Committee in December

