

Bridging Cancer Care Gaps in Rural America: A CALL TO ACTION

Jill Rhodes, PharmD, CSP, BCOP, FHOPA
St. Matthews Specialty & Community
Pharmacy / University of Louisville
James Graham Brown Cancer Center
Louisville, KY
jillrhodes@stmatthewsrx.com

KENTUCKY HEMATOLOGY/ONCOLOGY
PHARMACY SYMPOSIUM 2020

Disclosures

- Jill Rhodes
 - Appointed Member, Vice President, Kentucky Board of Pharmacy, term 2018 - 2021
 - Received honorarium as advisory board member for Pfizer Oncology

Learning Objectives

- Define the rural cancer gap
- Identify the unmet needs of patients with cancer
- Discuss the opportunities and barriers in the provision of pharmacy cancer care
- Recognize oncology related patient outreach and advocacy opportunities for both pharmacists and patients
- Describe resources available for pharmacists and patients for cancer support in Kentucky

Audience Poll

Which of the following do you consider the most important gap in cancer care?

- A. Geographic access / transportation hardship
- B. Racial discrimination
- C. Socioeconomic disadvantage
- D. Genetic testing / counseling
- E. Limitation in health information technology / exchange
- F. Referral and access to hospice
- G. Shortage of providers / specialists

Defining the Rural Cancer Care Gap

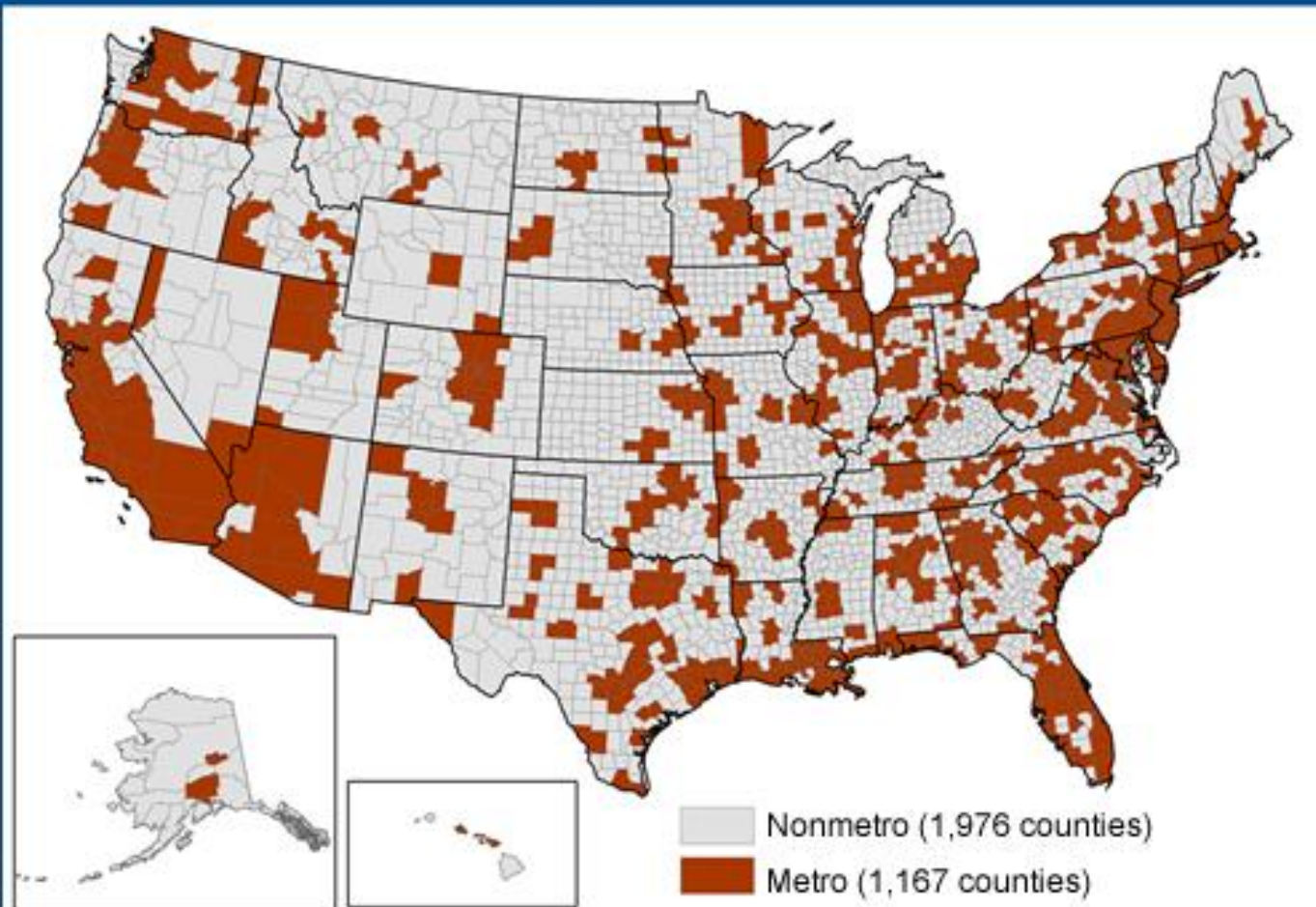
- What defines Rural?
 - RUCC
 - Rural urban continuum codes
 - Not a one size fits all concept
 - Carefully weigh the pros / cons of rural definitions
- Gaps
 - ↓ in health care providers / access to local specialists
 - Poorer quality of care?
 - Lack of genetic testing and counseling services
 - ↓ opportunity for clinical trials
 - Geographic and timing constraints
 - Less technologic access
 - Hospice

<https://www.ers.usda.gov/topics/rural-economy-population/rural-classifications/> Accessed 8.21.2020

https://www.cadca.org/sites/default/files/CADCA_Rural%20Cancer%20Publication.pdf. Accessed 8.21.2020

Defining the Rural Cancer Care Gap

Metro and nonmetro counties, 2013



Source: USDA, Economic Research Service using data from the U.S. Census Bureau.

<https://www.ers.usda.gov/topics/rural-economy-population/rural-classifications/>

Last updated: Wednesday, October 23, 2019. accessed 8.20.2020

ARS Question

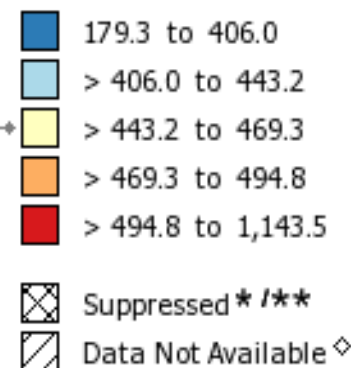
The mortality rate of individuals affected by cancer who live in rural communities is _____ compared to metropolitan communities.

- A. Higher
- B. Lower
- C. Similar
- D. Unknown

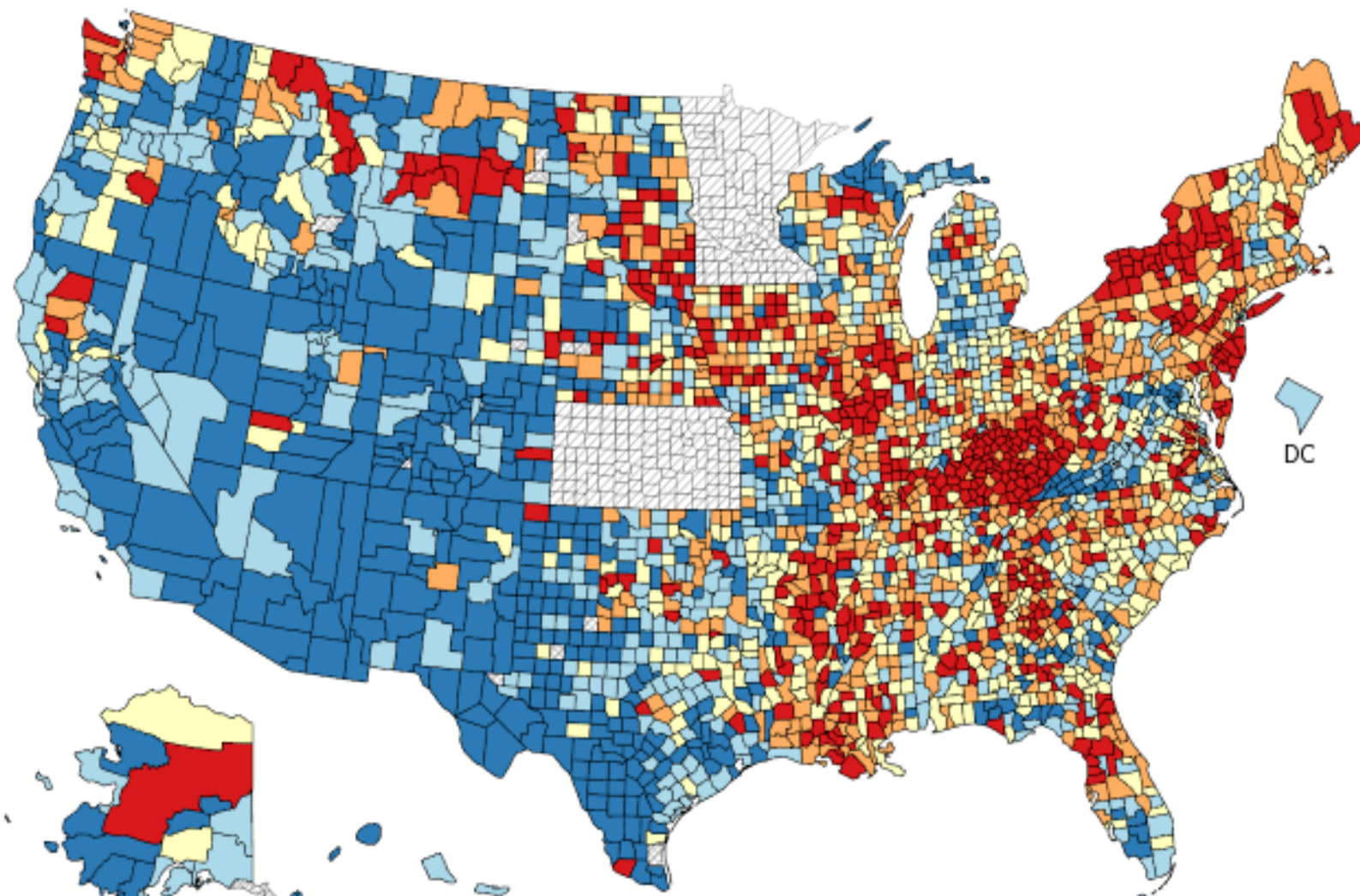
Incidence Rates[†] for United States by County
All Cancer Sites, 2013 - 2017
All Races (includes Hispanic), Both Sexes, All Ages

Age-Adjusted
Annual Incidence Rate
(Cases per 100,000)

[Quantile Interval](#)



US (SEER + NPCR)
Rate (95% C.I.)
448.7 (448.4 - 449.0)



Disparity in the Rural Cancer Population (1/4)

- Geographical location
 - 15 - 19% (46 – 59 million) of all Americans live in rural America
 - Higher rates of new cancers and greater risk of dying from cancer of the lung, colon and cervix
 - Higher all-cause cancer death rate 180 v. 156/100,000 individuals **KY* 194.8**
 - Differences in death rates between rural and urban areas are increasing over time

<https://www.cdc.gov/media/releases/2017/p0706-rural-cancer-deaths.html>. accessed 8.20.2020

https://www.cdc.gov/mmwr/volumes/66/ss/ss6614a1.htm?s_cid=ss6614a1_w. accessed 8.20.2020

Disparity in the Rural Cancer Population (2/4)

- Race and ethnicity
 - Compared to non-Hispanic whites, more minorities living in rural areas are younger, reported their health as fair or poor, have more obesity, and that they were unable to see a physician in the past 12 months because of cost
 - Minorities less likely to have a personal health care provider

Disparity in the Rural Cancer Population (3/4)

- Genetic testing and counseling
 - Supply and Demand Imbalance
 - Clinical genetic counselor workforce is concentrated in large cities
 - The 30 largest cities hold 13% of the nation's population but 29% of the nation's genetic counselors
 - Estimated shortage of 1,879 genetic counselors
 - Barriers
 - Low levels of appropriate referrals
 - Geographical travel distance
 - Lack of clinical geneticists
 - Limited genetic counselor workforce
- KRS 304.17A-259 became effective 1/1/2020

Disparity in the Rural Cancer Population (4/4)

- Seidler, et al
 - Distribution of clinical trial sites per person was highly clustered around urban centers
- Unger, et al
 - 36,995 patients with cancer in SWOG (southwest oncology group) studies over 26 years
 - Primary endpoint
 - Determine if a difference in survival outcomes after 5 years exists between study patients with cancer in rural v. urban areas
 - Outcome
 - No statistically significant differences for survival *except* adjuvant-stage ER / PR–negative breast cancer

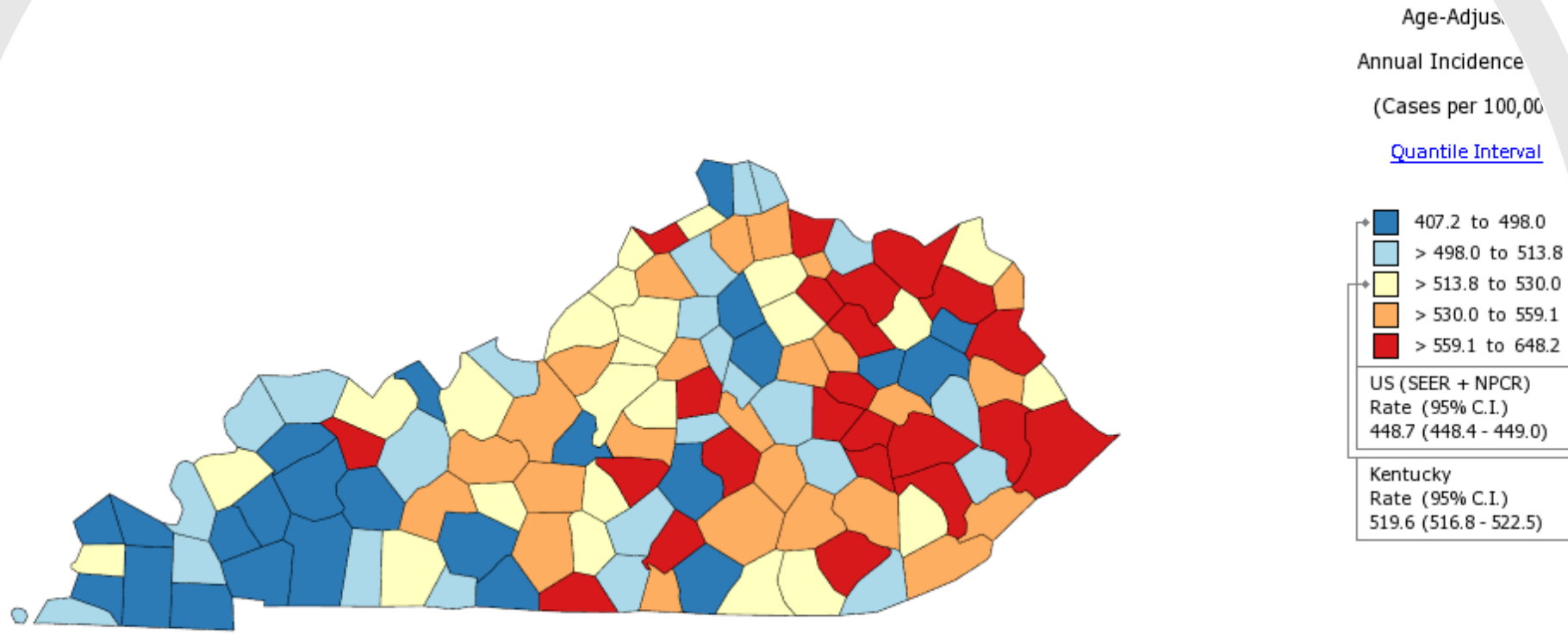
Unger J, et al. JAMA Netw Open 2018;1(4):e1811235; Seidler E, et al. Clin. Invest. 2014;4(4),373–380

*Cancers included: leukemia, lymphoma, lung, colorectal, ovarian, prostate, breast sarcoma, myeloma

The *Healthy People 2020* target death rate (161.4 deaths per 100,000 persons) for all cancers combined was met overall and in most sociodemographic groups

Annual Report to the Nation 2020
seer.cancer.gov

Incidence Rates[†] for Kentucky by County
All Cancer Sites, 2013 - 2017
All Races (includes Hispanic), Both Sexes, All Ages



[registries](#) may provide more current or more local data.

The State Cancer Profiles Web Site may differ from statistics reported by the State Cancer Registries ([for more information](#)).

Incidence rates (cases per 100,000 population per year) are age-adjusted to the [2000 US standard population](#) (19 age groups: <1, 1-4, 5-9, ... , 80-84, ...). Rates are for invasive cancer only (except for bladder which is invasive and in situ) or unless otherwise specified. Rates calculated using age-specific cancer counts for denominators are based on Census populations as modified by NCI. The [1969-2017 US Population Data](#) File is used for age-specific incidence rates.

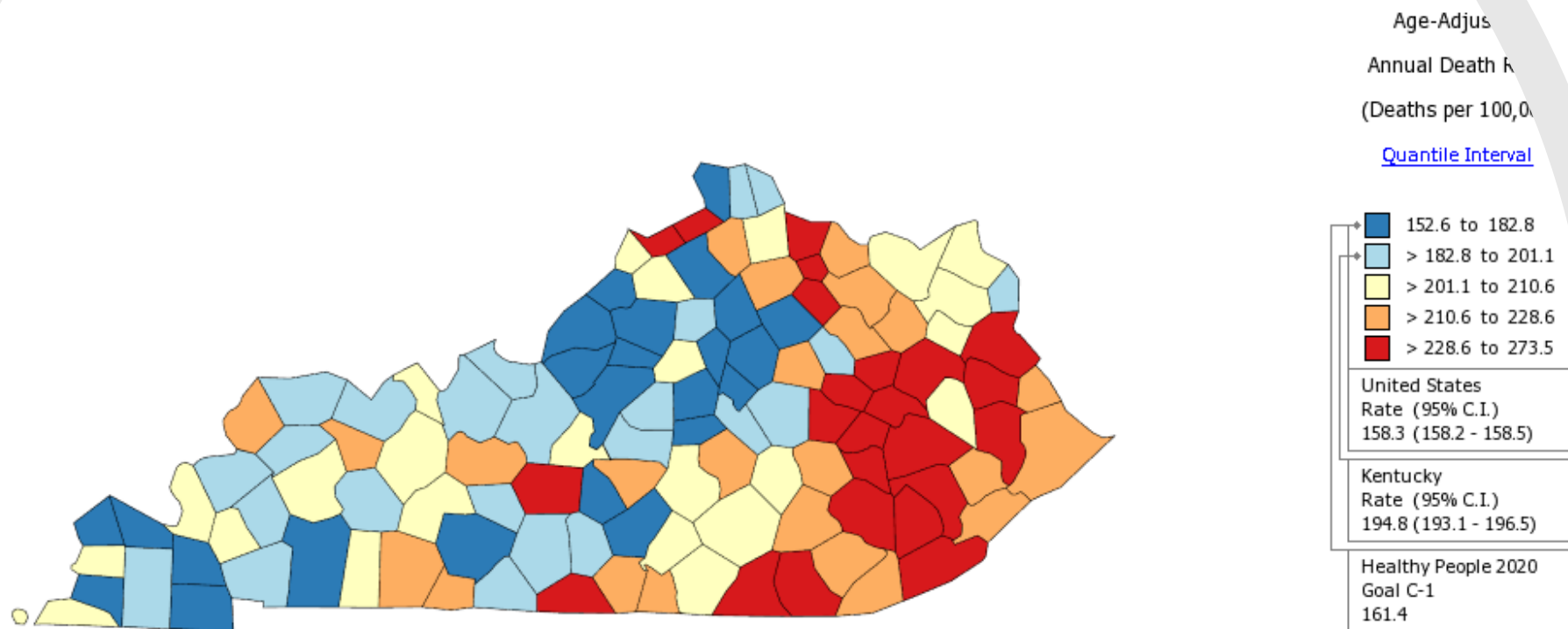
Incidence rates are for cancers classified as malignant based on ICD-O-3. For more information see [malignant.html](#)

Incidence rates do not include data from Puerto Rico

Death Rates for Kentucky by County

All Cancer Sites, 2013 - 2017

All Races (includes Hispanic), Both Sexes, All Ages



[Cancer Registries](#) may provide more current or more local data.

Data presented on the State Cancer Profiles Web Site may differ from statistics reported by the State Cancer Registries ([for more information](#)).

This data provided by the [National Vital Statistics System](#) public use data file. Death rates calculated by the National Cancer Institute using death rates (deaths per 100,000 population per year) are age-adjusted to the [2000 US standard population](#) (19 age groups: <1, 1-4, 5-9, ...).

The Healthy People 2020 goals are based on rates adjusted using different methods but the differences should be minimal.

Counts for denominators are based on the Census [1969-2017 US Population Data](#) File as modified by NCI.

Goal C-1 : Reduce the overall cancer death rate to 161.4.

Objectives provided by the [Centers for Disease Control and Prevention](#).

This does not include data from Puerto Rico

Cancer Disparity in Kentucky

- Compared to the US average
 - ↑ white population, % **below poverty** (1.5x), % rural living (2x)
 - ↓ black and minority population, **high school** / college degree
 - ↑ *smoking*
 - *2nd highest US smoking rate*
 - ↑ *obesity rate*
 - *5th highest obesity rate; ~69% adults have BMI ≥ 25*
 - ↑ *mortality*
 - *In African Americans and Appalachian Kentuckians*
- Appalachia compared to KY
 - ↑ white population, % **below poverty** (2.5x), % rural living (4x)
 - ↓ minority population, **high school** / college degree

Kentucky's Cancer Burden – The Big Four

Cancer Type	U.S. Incidence Rate Ranking	U.S. Mortality Rate Ranking	Difference in Mortality Rate (KY v. U.S.)
Lung	1	1	50.2%
Colon	1	5	16.8%
Breast	35	18	3.2%
Cervical	1	7	26.1%

*US Cancer Statistics, 2008 - 2012

Kentucky Cancer Consortium Cancer Action Plan. https://ftp.cdc.gov/pub/Publications/Cancer/ccp/kentucky_ccc_plan-508.pdf. Accessed 8.21.2020

Adapted from McDowell, J. Tucker, T. Kentucky Cancer Consortium Webinar. Posted 6.1.2020. M CCP Word Press Admin. <https://www.kycancerc.org/2020/06/01/kcc-webinar-cancer-data-in-the-commonwealth/> Accessed 8.21.2020

Concerning Trends from 2000-2017: Widening Gaps of Cancer Disparity in Kentucky

- LUNG cancer
 - Growing gap in incidence and mortality rates in Appalachia subgroup
 - Appalachians are not experiencing the decline in incidence and mortality observed in non-Appalachians
 - Rise in incidence in Appalachian women
- BREAST cancer
 - Higher incidence of triple negative breast cancer in African Americans
 - Higher mortality in African American and growing gap in Appalachians
- COLON cancer
 - Growing gap in incidence and mortality rates in Appalachia subgroup
 - Incidence in African Americans has dropped and gap is closing and no difference in mortality
- CERVICAL cancer
 - 51.7% KY women diagnosed with late stage cancer
 - HPV vaccination rate well below national average
 - 13.3% males 13-17yo
 - 37.5% females 13-17yo

Kentucky Cancer Consortium Cancer Action Plan. https://ftp.cdc.gov/pub/Publications/Cancer/ccckentucky_ccc_plan-508.pdf.

Adapted from McDowell, J. Tucker, T. Kentucky Cancer Consortium Webinar. Posted 6.1.2020. MCCP Word Press Admin.

<https://www.kycancerc.org/2020/06/01/kcc-webinar-cancer-data-in-the-commonwealth/> Accessed 8.21.2020

More Gaps in Cancer Care?

- **WHAT** are the other areas that we are not fulfilling for patients with cancer?
- **WHERE** are the resources that assist pharmacists in meeting the needs of patients?
- **WHY** are we not utilizing the resources that are available?

ARS Question

What percent of patients / caregivers that you counseled over the past month did you refer to a patient outreach organization for information and/or support?

- A. 0%
- B. 1-25%
- C. 25-50%
- D. 50-75%
- E. 75-100%

What Patients Want and Need

Oncology professionals and patient requests for cancer support services

- 1,180 completed surveys by physicians, nurses and social workers in oncology practice (ASCO, ONS, AOSW)
- 94% of patients asked about cancer-related support services

Most common inquiries	Other inquiries identifying unmet needs
Education about cancer (72%)	Alternative medication
Support groups (65%)	Transportation
Hospice referral (52%)	Lodging during treatment
Financial aid, nutrition, pain (> 40%)	
Counseling, home care, insurance (> 30%)	

ARS Question

How often do you inform the patient whether the treatment they will receive is curative versus non-curative when performing cancer treatment counseling?

- A. Always
- B. Sometimes
- C. Never

Gap 1: Patient / Caregiver Education and Comprehension of Treatment

Patient and Caregiver Understanding of Treatment Intent

- Study of caregiver knowledge of patients with advanced cancer
 - 48% knew treatment was non-curative
 - 27% were unsure of treatment intent
 - 25% believed treatment was curative
- Study of patient's knowledge with advanced cancer
 - 46% knew treatment was non-curative
 - 29% believed treatment was curative

ARS Question

How often do you initiate counseling and recommend physical activity for cancer patients?

- A. Always
- B. Sometimes
- C. Rarely
- D. Never

Gap 2: Physical Activity Promotion

Physical Activity (PA) Promotion

- Oncology care providers perspectives on exercise promotion in those diagnosed with cancer
 - Survey administered to oncology care providers (n=120)
 - 80% were unaware of any exercise guidelines in cancer and self reported poor knowledge on when, how, and which patients to refer to an exercise program
 - Over 80% of providers agreed that exercise counseling should be a part of care
 - Barriers included: Poor knowledge, lack of time for discussion, and safety concerns for the patient
 - Interventions: Education to oncology care providers and guidance on assessment for exercise safety

Gap 3: Awareness of Cancer Support Services

Healthcare professional's awareness of cancer support services

- 1,241 questionnaires collected from physicians, nurses, social workers in oncology practice
- Most common organizations patients were referred to:
 - American Cancer Society (83%), National Cancer Institute (55%), Leukemia & Lymphoma Society (42%)
- > 70% were aware of the services but < 60% recommended them or thought these services were helpful to patients
- Potential improvement: Developing a directory of resources, improve collaboration among agencies, increasing staff, targeting specific services in specific areas

Gap 4: Addressing Survivorship

There are many unmet needs in our patient population!!

- Cancer Survivorship: NEJM 2018;379:2438-50
 - Talks about identifying unmet needs in health disparities among cancer survivors and the need for increased efforts in wellness promotion for both survivors and caregivers
- ASCO Core Curriculum for Cancer Survivorship Education
 - Importance of survivors and the financial burdens of caregivers

Numerous publications on unmet social needs:

- Emotional, physical, financial, practical, spiritual, etc....
 - Wang T, et al. BMC Palliative Care 2018;17:96. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review

What are Organizations Doing to Better Understand?

Cancer Support Community 2017 Cancer Experience Registry
(>12,000 people: Survivors, patients, and caregivers-over 45 cancer types)

Quality of Life	53% are worried about the future and what lies ahead
Treatment Decision Making	93% rated QOL as a very important factor when weighing treatment options
Side effect and symptom management	Only 52% received guidance on long term side effects of treatment and 1 in 5 did not receive information on short term side effects
Clinical Trials	77% believed that insurance would not cover clinical trial costs
Financial Impact	73% did not talk about costs of treatment with a member of their care team

https://www.cancersupportcommunity.org/sites/default/files/uploads/our-research/2017_Report/registry_report_final.pdf

Patient Outreach for Pharmacists

1. Not just advocacy/drug costs....Thinking Beyond Co-Pay Assistance!
2. Providing education beyond drug information
 - Local support meetings, webinars, you-tube videos
3. Making or providing tools/resources for patients, caregivers, and pharmacists
 - Hotline, survivor/caregiver links, educational documents
4. Expanding our scope of involvement
 - Engagement in our communities, states, nationally
5. Navigating the needs of our patients
 - What are the unmet needs of your patient?

Kentucky Action Plan: The Pharmacist's Role

Pharmacists assist in controlling cancer in Kentucky

- Access to Preventative Care
 - Obesity Counseling
 - Screening referrals for preventable cancers
 - Lung, Cervical, Breast, Colorectal
 - Smoking Cessation
 - Vaccination
 - Improve HPV vaccination rates
 - *The United States Department of Health & Human Services (HHS) Office of the Secretary issued the "Third Amendment to Declaration Under the Public Readiness and Emergency Preparedness Act [(PREP Act)] for Medical Countermeasures Against COVID-19" to increase access to lifesaving childhood vaccines and decrease the risk of disease outbreaks as children across the country return to daycare and school.*
 - *Pharmacists and licensed interns registered by the state board can administer, any vaccine that ACIP recommends to persons 3-18 according to standard immunization schedule (PREP Act Amendment - 8.19.2020)*

<https://www.hhs.gov/sites/default/files/third-amendment-declaration.pdf>. Accessed 8.21.2020

<https://www.hhs.gov/about/news/2020/08/19/hhs-expands-access-childhood-vaccines-during-covid-19pandemic.html>.

Accessed 8.21.2020

Pharmacist Tools and Resources

Kentucky Cancer Resources

- Pathfinder: Directory for Kentucky cancer related resources
 - <https://netapps.louisville.edu/PathFinder/>
- Kentucky Cancer Consortium
 - www.kycancerc.org
- Kentucky Cancer Program
 - <https://www.kycancerprogram.org>
- Kentucky Cancer Plan
 - https://ftp.cdc.gov/pub/Publications/Cancer/ccc/kentucky_ccc_plan-508.pdf
- Kentucky Cancer Registry
 - <https://www.kcr.uky.edu/>

Pharmacist Tools and Resources

Vaccines

- Enroll in the state Vaccine for Children Program
- Comprehensive Clinic Assessment Software Program
 - <https://www.cdc.gov/vaccines/programs/cocasa/index.html>
- QRS codes for CDC vaccine sheets now available!
 - <https://www.vaccinesheets.com/>

Smoking Cessation

- Kentucky Tobacco Quit Line 1-800-QUIT-NOW
 - Free CE
 - <http://www.kycancerprogram.org/professional-education-and-training>

Education Sheets & Clinical Trials

- www.clinicaltrials.gov
- Pharmacy/Nursing Collaboration
 - www.oralchemoedsheets.com

Kentucky Action Plan: The Pharmacist's Role

Pharmacists assist in controlling cancer in Kentucky

- Access to Cancer Treatment and Support
 - Develop treatment plan at time of diagnosis with care team for every patient
 - Order and recommend next generation sequencing for appropriate patients
 - Educate and counsel patient on intent of treatment and benefits/risks
 - Identify eligible clinical trials
 - Refer and recommend support organizations
 - Navigate access to medication (prior authorization, formulary utilization, payer and limited distribution channels)
 - Provide copay assistance

Kentucky Action Plan: The Pharmacist's Role

Pharmacists assist in controlling cancer in Kentucky

- Pharmacist Advocacy for Patients
 - Create a patient/caregiver panel at your institution
 - Make your voice heard for them
 - Get involved with your state professional organization's legislative group
 - Call/ Visit your representative
 - Host a legislator
 - Respond to CMS when items impacting your profession are out for comment
 - Partner with patient organizations and pharmaceutical companies to make progress on like minded goals



Kentucky Action Plan: The Pharmacist's Role



Professional and Patient Advocacy Resources

ACCC – Association of Community Cancer Centers **Financial and Payer Resources**

- Patient Assistance Reimbursement Guide (updated June 2020)
- <https://www.accc-cancer.org/home/learn/publications/patient-assistance-and-reimbursement-guide>
- Financial Advocacy Network
- Financial Advocacy Services Guidelines
- Financial Advocacy Boot Camp
- Financial Advocacy Tool Kit
- <https://www.accc-cancer.org/home/learn/financial-advocacy>

Experian Payer Alerts

- Paid subscription-based notification
- <https://www.experian.com/healthcare/products/audit-payers/payer-alerts>

Professional and Patient Advocacy Resources

Medication Financial Assistance

PAN Foundation

- www.panfoundation.org

Healthwell Foundation

- www.healthwellfoundation.org

Needy Meds

- <https://www.needymeds.org/>

Good Days

- <https://mygooddays.org>

Patient Advocate Foundation
Co-pay Relief

- www.copays.org

Manufacturer Patient
Assistance Programs

Professional and Patient Advocacy Resources

Aunt Bertha - The Social Care Network

- Based on zipcode
- Links patient care resources
 - Transit, food, housing, medical supplies, legal, work and much, much more!
- www.auntbertha.com

Cancer Support Community

- > 170 locations worldwide, including 46 licensed affiliates and health care partnerships
- Help Line: 1-888-793-9355
- www.cancersupportcommunity.org

Society of Immunotherapy in Cancer Resource List

For patients

- **SITC Patient Portal**
- Patient Resource Guide
- SITC Cancer Immunotherapy connectED
- Educational videos

For professionals

- **SITC Clinician Portal**
- JITC – Journal of Immunotherapy in Cancer; annual meeting

CONTACT SITC: 1-414-271-2456; info@[sitcancer.org](mailto:info@sitcancer.org)

Novel Approaches to Cancer Care Delivery

- Mobile medical clinics
- Oral health education programs
- Lay patient navigators
- Care partnerships between local primary care providers and distant hematology/oncology specialists
- Telemedicine
- In-home infusion and cancer treatment

<https://www.ruralhealthinfo.org/topics/healthcare-access/project-examples> accessed 8.21.2020

Final Points

- Kentucky's preventable cancer burden is much higher than the national average
- Pharmacists have a unique opportunity to enhance cancer preventative health measures in the community through immunization, tobacco cessation, diet and exercise counseling and screening referrals
- Pharmacists have the skills to navigate and improve treatment for patients at diagnosis, during and after treatment
- Unmet needs in care existing that require community and multidisciplinary effort to address patient needs and improve health equity

Professional and Patient Advocacy Resources

