

# **Cancer Surveillance and Access to Care in Rural America**

Jan M. Eberth, PhD

Whitney E. Zahnd, PhD

Peiyin Hung, PhD

February 4, 2020



# Rural and Minority Health Research Center

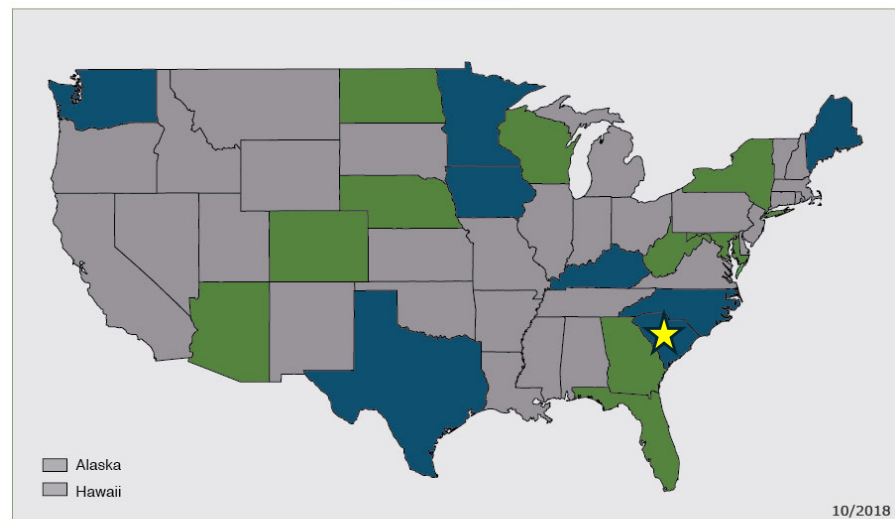
*Our mission is to illuminate and address the problems experienced by rural and minority populations in order to guide research, policy, and related advocacy.*

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**FORHP-Funded Rural Health Research Center States**  
1998-2018



\*There are two Research Centers in Iowa

■ Location of currently funded research centers  
■ Location of previously funded research centers

# Agenda

- Context for the Webinar
- Background Information
- Residential Proximity to Cancer Care in Rural America
- Challenges and Opportunities of Cancer Surveillance Datasets for Rural Cancer Research
- Implications and Key Takeaways

# Cancer Environmental Scan

- **Rationale:** Persistent rural-urban disparities in cancer mortality raise concerns about access to and underutilization of state-of-the-art cancer care, as well as inadequate care coordination. Fewer providers in rural areas may hinder access to preventive, diagnostic, and treatment services.
- **Approach:** The Rural Colon and Cervical Cancer Environmental Scan (RCCC) used mixed methods to identify opportunities for improving screening uptake, follow-up of abnormal screening, and timeliness and quality of cancer treatment received among rural residents in SC.

# Cancer Environmental Scan



To provide a geospatial assessment of the cancer care workforce and burden in South Carolina



Identify existing initiatives (and associated gaps) targeting cancer prevention and control in rural counties



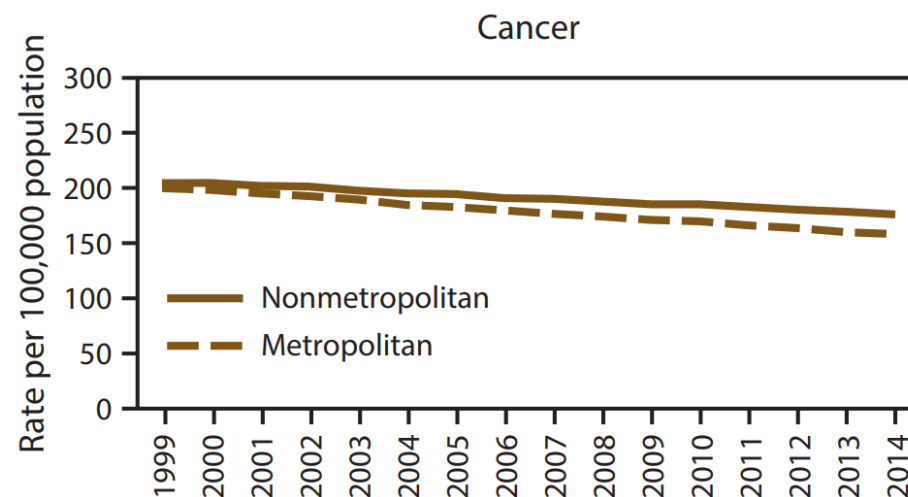
Determine barriers and facilitators to implementation of evidence-based and promising cancer prevention and control interventions among rural safety net providers



Describe care coordination and structural barriers impacting rural patients' cancer care experience and outcomes

# Background: Rural Cancer Care

- Healthy People 2020 objectives: to decrease cancer mortality to **161.4** deaths per 100,000 population
- As of 2015, this objective has been met in metropolitan counties.
  - **157.8** cancer deaths per 100,000
- Yet, rural communities have been left behind.
  - **180.4** cancer deaths per 100,000

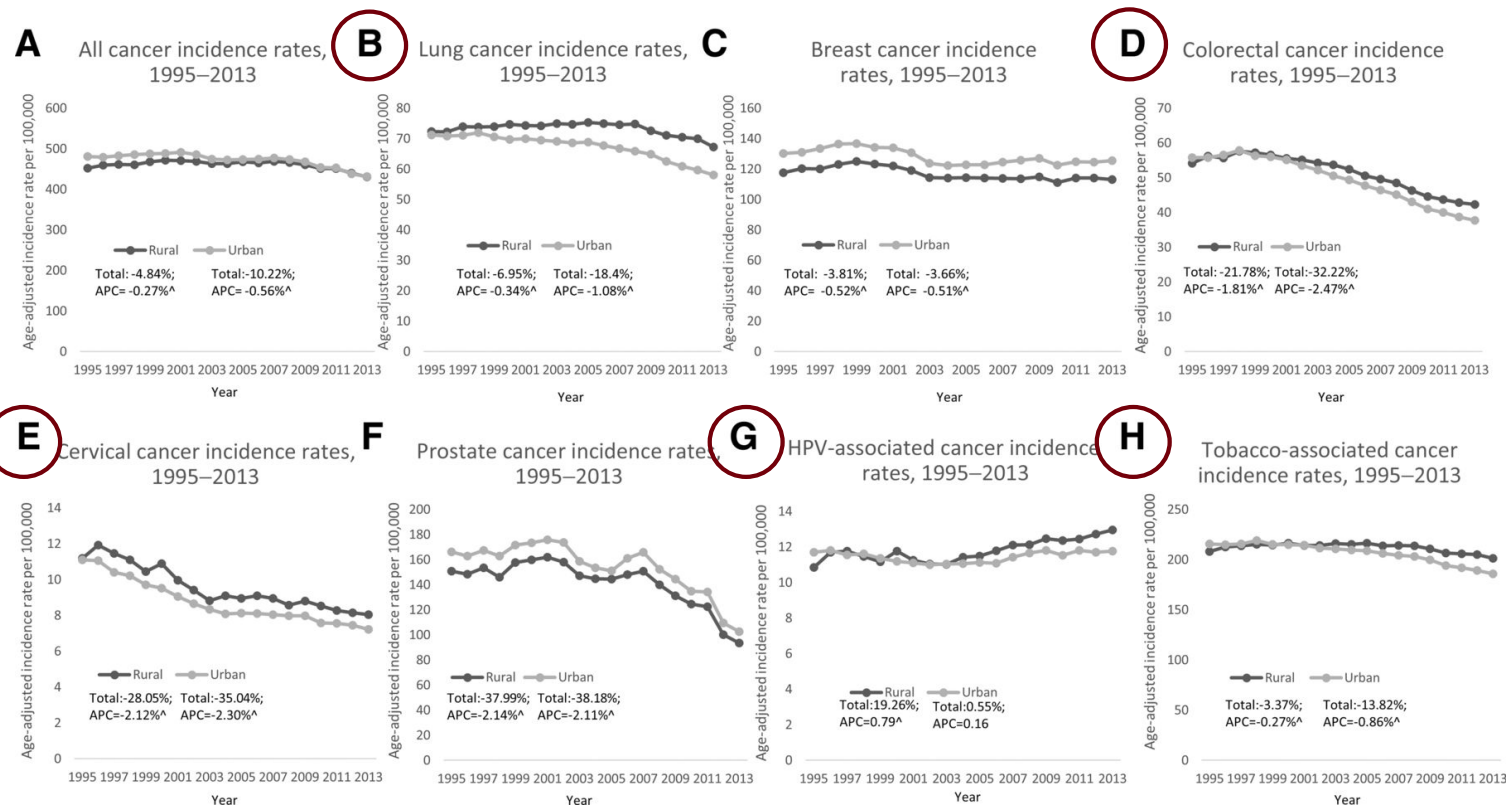


Source: Henley et al. *MMWR Surv Summ.* 2017;66(14):1-13.

# Background: Rural Cancer Care

Prevention opportunities:

Rural populations had higher incidence of tobacco-associated, HPV-associated, and colorectal cancer.



Source: Zahnd et al. CEBP. 2018; 27(11):1265-74.

# Background: Rural Cancer Care



## EXAMINING RURAL CANCER PREVENTION AND CONTROL EFFORTS

POLICY BRIEF AND RECOMMENDATIONS TO THE SECRETARY

AUGUST 2019

Rural cancer control was one of several topics the National Advisory Committee on Rural Health and Human Services focused on in 2019. Policy recommendations from the meeting included:

1. Combine federal funding to implement and evaluate a rural patient navigation program
2. Increase funding for NCI's Rural Cancer Control Program and related partnerships
3. Implement a national educational campaign to provide cancer related info to rural providers
4. Educate rural providers to use Medicare codes to enhance cancer care coordination
5. Require the assessment of rural-urban disparities and related goals and objectives in state cancer control plans

Source: <https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/rural/publications/2019-Cancer-Control.pdf>



# **Residential Proximity To Colorectal And Cervical Cancer Care Providers**

Hung P, Deng S, Zahnd WE, Adams SA, Olatosi B, Crouch EL, Eberth JM. Geographic Disparities in Residential Proximity to Colorectal and Cervical Cancer Providers. Cancer. Nov 8. doi: 10.1002/cncr.32594. [Epub ahead of print].

# Why Colorectal and Cervical Cancer?

- Rural communities have higher mortality from colorectal and cervical cancers than their urban peers.
- The Healthy People 2020 objectives for colorectal and cervical cancer mortality have been met in large urban counties but not in rural.
- Rural patients are less likely to receive state-of-the-art treatments, despite improvements in preventive and treatment opportunities for colorectal & cervical cancers.

References: Henley et al, 2017; Zahnd et al, 2018

# Concerns about Access to Cancer Care

- About **20%** of Americans live in rural communities, but only about **7%** of oncologists practice in rural communities.
- Nearly all National Cancer Institute/NCI-designated cancer centers are in urban communities.
- Travel burden may:
  - Hinder opportunities to access effective diagnoses and treatments among rural patients.
  - Lead to poor adherence to cancer treatments and a bad prognosis.
- Maldistribution of cancer care providers may exacerbate cancer health disparities in vulnerable communities.

References: Henley et al, 2017; Kirkwood et al, 2018; NCI website:  
<https://www.cancer.gov/research/nci-role/cancer-centers/find>

# Study Objectives

- Examine the driving distance from each residential area to the nearest cancer care provider across the United States
- Identify community-level factors associated with driving distance to each type of colorectal and cervical cancer care providers
- Use South Carolina data to investigate the relationship between travel times to cancer care facilities and cancer outcomes

# Data Sources

Data	Key Identifier	Variables
2012-2016 American Community Survey estimates	Zip Code Tabulation Area (ZCTA)	Number of residents, sociodemographic mix, educational attainment, poverty level
2018 Physician Compare data	Practice locations of physicians converted to latitude and longitude coordinates	Primary and secondary specialty designations including: colorectal surgeons, general surgeons, gynecologic oncologists, medical oncologists, radiation oncologists, and surgical oncologists.

**Settings:** Residential ZCTAs in 48 contiguous states and Washington DC.

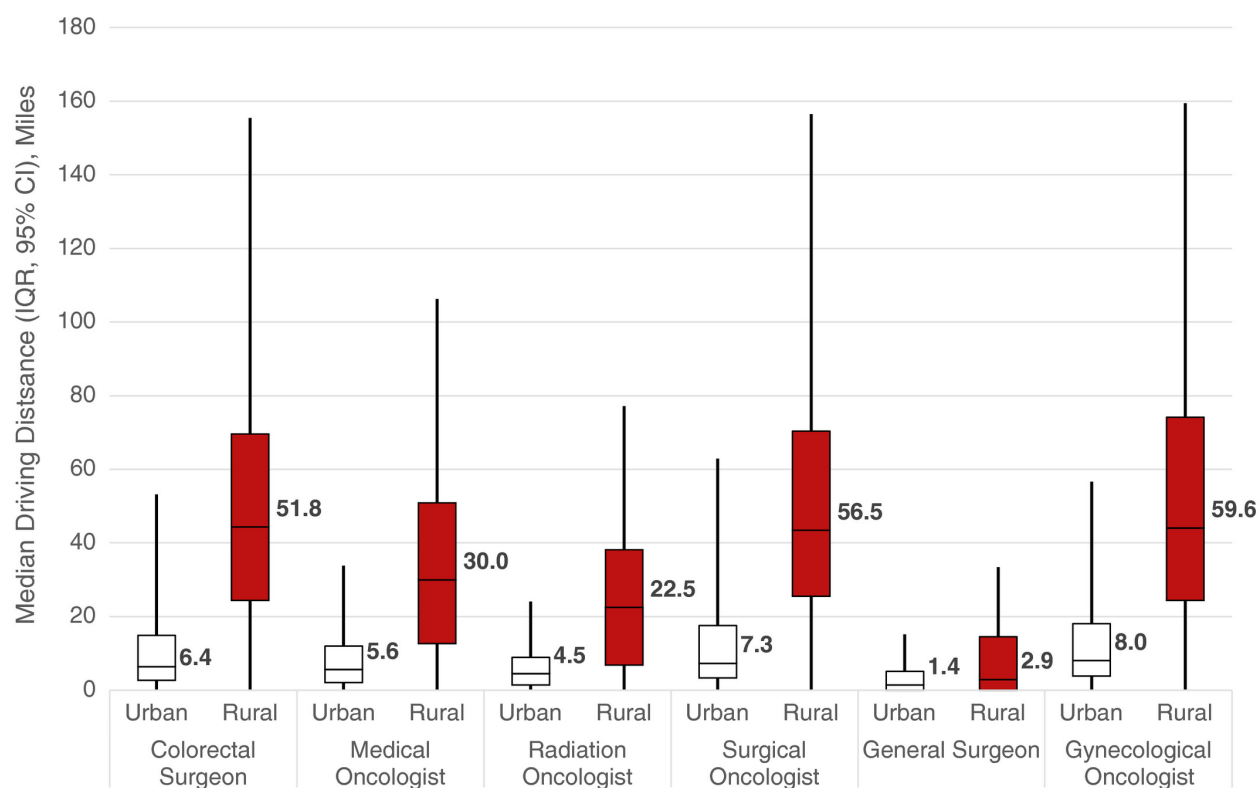
- Rural: 11,526 ZCTAs
- Urban: 21,340 ZCTAs

# Measures

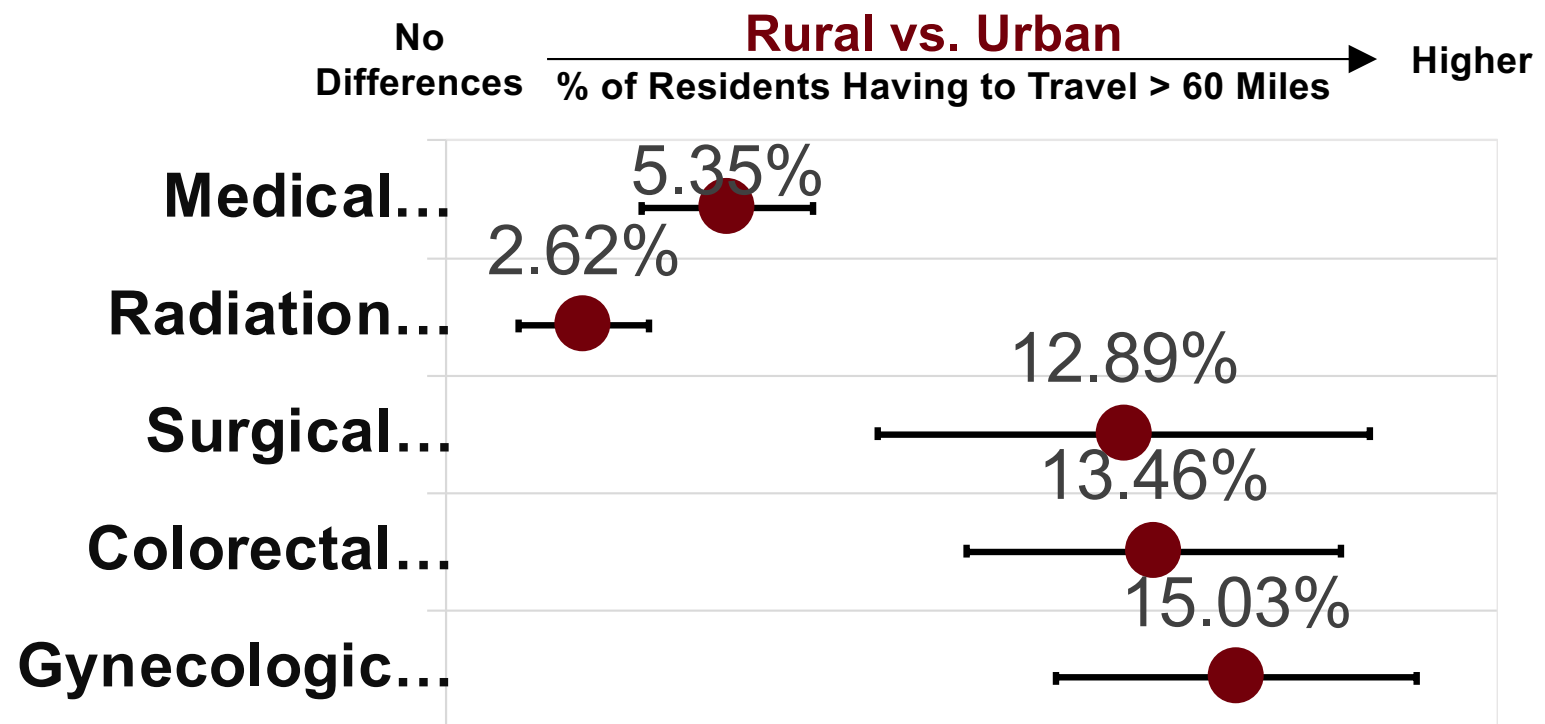
- **Primary outcomes:** One-way road miles from each residential ZCTA centroid to the nearest cancer care physician(s) by specialty
  - **Secondary outcome:** whether residents in a ZCTA have to travel > 60 miles to reach the nearest cancer care physician
- **Independent variables:**

Geography	ZCTA rurality (rural vs. urban), census region
Sociodemographic mix	Age, race/ethnicity
Socioeconomic mix	% in poverty, educational attainment

## Rural-Urban Differences in Travel Distances to the Nearest Cancer Care Providers



# Rural-Urban Differences (95% CI) in % Having to Travel >60 Miles to the Nearest Cancer Care Provider(s) by Specialty





# Communities with Greater Travel Burden

- Higher residents in poverty (<200% of the Federal Poverty Level)
- Higher % of residents classified as American Indian/Alaska Native
- Located in the South and West regions of the U.S.

# **Travel Burdens and Colorectal Cancer Outcomes in South Carolina**

A retrospective cohort analysis of patients diagnosed with invasive colorectal cancer during 2001-2016, using linked South Carolina Central Cancer Registry data

# Study Objectives

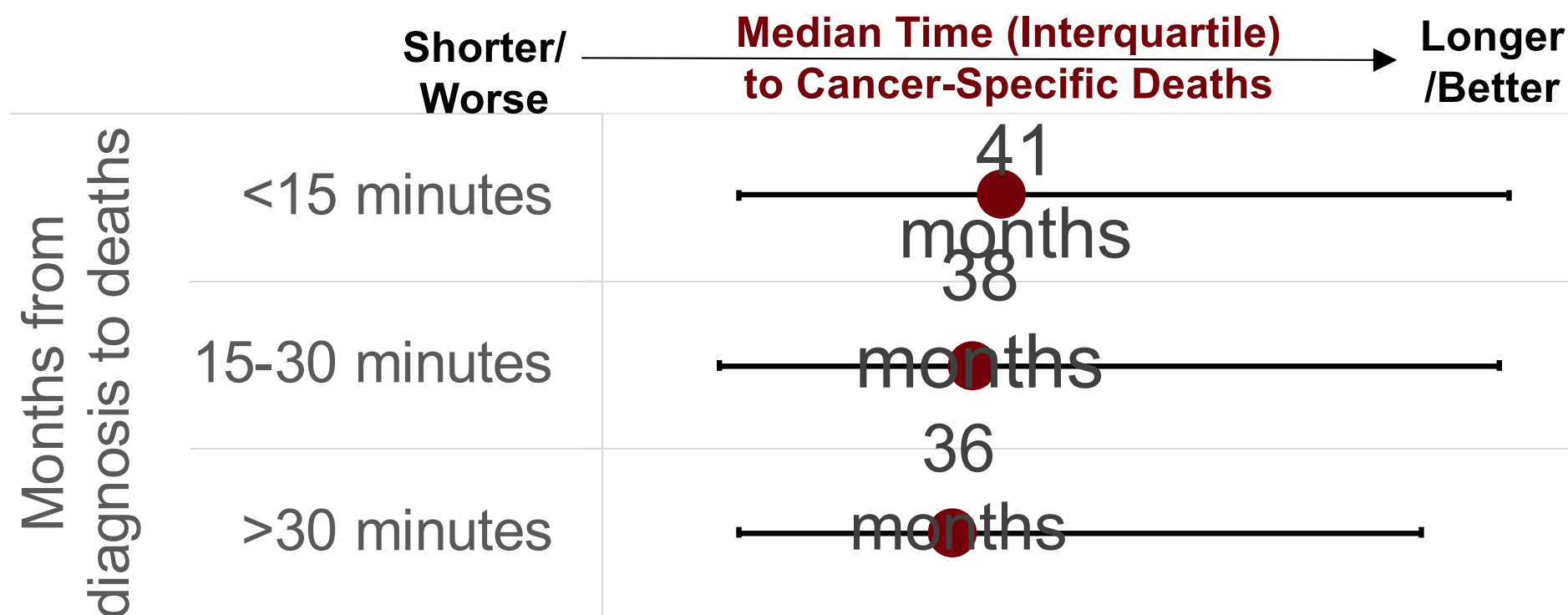
To investigate the relationship between driving times to the treating cancer facilities and survival and days to cancer treatment initiation among patients diagnosed with colorectal cancer in South Carolina.

# Methods

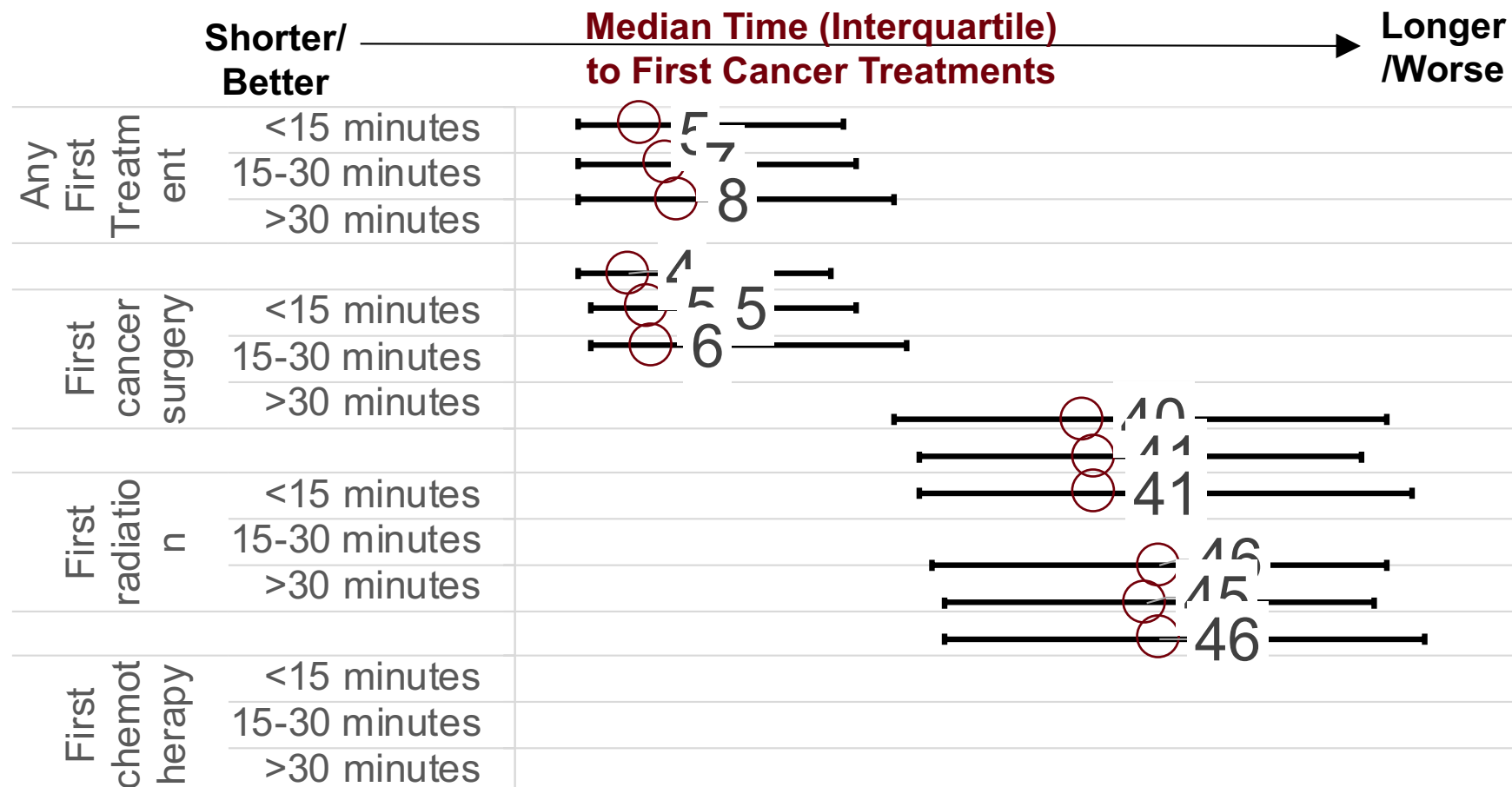
- **Design:** A retrospective cohort analysis of 25,651 patients diagnosed with invasive colorectal cancer during 2001-2016
- **Data sources:**

Dataset	Information
South Carolina Central Cancer Registry	Patient residence location, dates of cancer diagnosis, treatment, and mortality (if any), first cancer provider identifier
American Hospital Association Annual Survey	Attributes of hospital-based cancer care facilities
National Provider Identifier Registry	Attributes of office-based cancer care providers

# Time to Cancer-Specific Mortality by Drive Time



# Days to Cancer-Specific Treatment by Drive Time



# **Maldistribution of Cancer Care Specialists**

**Those most in need face highest travel burdens.**

- Rural residents face substantial travel burdens to cancer specialists and colorectal/cervical cancer surgeons.
- Rural communities with higher % of American Indian/Alaska Natives and/or with higher % of residents in poverty had disproportionate barriers to accessing cancer care specialists.

# Travel Burden Matters!

For colorectal cancer patients in South Carolina, driving time to an actual treatment provider was associated with:

- Prolonged time to treatment initiation
- Shorter time to cancer-related death



# Policy Implications

- Need to mitigate potential negative consequences due to long travel distances.
- Multifaceted solutions to target underserved and low-income communities and provide affordable travel options to repeated outpatient cancer care
  - Tele-oncology approaches
  - Home-based or local hospital chemotherapy
  - Cancer care delivery training for home health aides, nurses and physician assistants

# **Challenges of Using Nationally Representative Surveys To Study Rural Cancer Control**

Zahnd WE, Askelson N, Vanderpool RC, Stradtman L, Edward J, Farris PE, Petermann V, Eberth JM. Challenges of using nationally representative, population-based surveys to assess rural cancer disparities. *Prev Med.* 2019;129(S):105812.

# Importance of Cancer Surveillance Data

- Helps us understand and monitor the burden of cancer in the United States to guide public health/clinical planning
  - Healthy People 2020/2030 objectives (National)
  - Comprehensive Cancer Control Planning (State)
  - Community Health Needs Assessment and other assessments (Local)
- Informs federal and state programming
  - National Breast and Cervical Cancer Early Detection Program
  - Colorectal Cancer Control Program

Source: Ryerson et al. *Preventing Chronic Disease*. 2017.

# Cancer Surveillance Data Sets

- Population-Based Surveys
  - Health Information National Trends Survey (HINTS)
  - Behavioral Risk Factor Surveillance System (BRFSS)
  - National Health Interview Survey (NHIS)
  - Medical Expenditure Panel Survey (MEPS)
- Population-Based Cancer Surveillance Data
  - Surveillance Epidemiology and End Results (SEER)
- Clinical Surveillance Data
  - National Cancer Database (NCDB)

# Health Information National Trends Survey (HINTS)

- Population-based survey administered by NCI—  
administered since 2003 with multiple iterations released  
including 2019 data released in January 2020
  - Focused on cancer communications, caregiving, screening, risk  
perception, and cancer-related health behaviors
- Includes rural-urban continuum codes, Census region,  
Appalachia designation, and Delta designation (in 2019  
data only) in the public use dataset
  - RUCA codes are available upon request
  - Processes in place to request linkage of contextual variables
- Strengths
  - Full continuum of RUCC codes across iterations
  - Important regional designations included
  - Covers a lot of cancer-related areas
- Weaknesses
  - Small rural sample sizes, especially for cancer survivors



# Behavioral Risk Factor Surveillance System (BRFSS)

- A nationally representative, population-based CDC survey administered by states since 1984
- Includes questions on cancer-related health behaviors and screening
  - Optional modules related to cancer survivorship, HPV vaccination, and lung cancer screening
- MSA/non-MSA for those who participated by landline since 2011, but considerable “missingness” in recent years (e.g. 57.4% in 2017)
  - NEW: Rural-urban variable now available in 2018 BRFSS
- Strengths
  - Large overall sample size
  - Ability to look at state level data (i.e., flexibility in examining rural-urban variables may be available through individual states)
- Weaknesses
  - Limitations in examining rural-urban status in publicly available data until 2018 data released
  - Even with 2018 data, there are limitations in grouping rural and urban—dichotomous or “three group” rural variable



# National Health Interview Survey (NHIS)

- A nationally representative CDC-sponsored survey that has been administered since 1957
  - Broad health focus, but includes questions on cancer screening, cancer-relevant health behaviors, genetic testing, family history, cancer risk, and cancer survivorship
- Rural-urban variables are only available at research data centers (RDCs) throughout the U.S. (~\$3000)
- Strengths
  - Wide range of cancer-relevant variables
- Weaknesses
  - RDCs may be difficult to access due to cost and distance
  - Not appropriate for state-level analyses



# Medical Expenditure Panel Survey (MEPS)

- The Medical Expenditure Panel Survey (MEPS) has been administered by AHRQ since 1996
- The sample is drawn from among NHIS participants
- Cancer-relevant questions on health behaviors, screening and cost of care
- Experiences with Cancer Supplement (2011 and 2016) on issues related to financial burden of cancer and related survivorship areas
- Strengths
  - Availability of financial related cancer data
- Weaknesses
  - Rural metric (as of 2013) only available at RDCs





# Surveillance Epidemiology and End Results (SEER)

- SEER 18-collection of NCI funded cancer registries representing ~35% of the US population
  - Data on demographics and cancer and treatment characteristics
- SEER 21 data, includes NY, MA, and ID
  - Strengths
    - Population-based
    - Can link contextual data
    - SEER-Medicare data options
    - Overrepresents rural minority populations
- Weaknesses
  - Underrepresents rural overall and regionally
  - Disproportionate regional representation
  - May overestimate rural cancer burden

	U.S. rural population	SEER 18 rural population
Total population	11.8%	18.8%
Census Region		
Northeast	10.1%	2.3%
Midwest	32.9%	16.8%
South	42.8%	52.9%
West	14.2%	29.2%

Source: Zahnd WE, et al. *Cancer Epidemiol Biomarkers Prev.* 2018.

# National Cancer Database (NCDB)

- Clinical surveillance data from Commission on Cancer accredited hospitals representing ~70% of all cancer cases diagnosed in the United States
- Includes demographic, clinical, and treatment characteristics of the patient, limited data on the facility
- Strengths
  - Availability of treatment data to assess quality of care
  - Large coverage
- Weaknesses
  - Underrepresents rural hospitals and subsequently rural patients
  - Mix of geographic scale in contextual data
  - Data dictionary guidance (i.e., “metro, urban, and rural counties” for Rural-Urban Continuum Codes rather than “metro and non-metro”)



# Overarching Challenges and Potential Solutions of Surveillance Data Sets

- Challenges
  - Limited accessibility of rural-urban variables
  - Variability of defining rural across surveys
  - Inadequate or disproportionate representation of rural
- Solutions
  - Improve more ready access of geocoded data to non-federal researchers
  - Improve survey design and analysis approaches to ensure adequate rural representation
  - Increase geographic scope/rural representation in publicly available cancer surveillance data sets

# Key Takeaways

- Rural-urban disparities in spatial access to cancer care exist.
- Travel burden to reach a cancer provider was associated with worse survivorship and treatment initiation.
- Current challenges in capturing rural populations with nationwide data may hinder the opportunities to address rural cancer disparities.
  - Solutions: oversampling, data access, etc.

# Acknowledgments and Funding



**Acknowledgments:** We thank the entire RMRHC team for their support. We would also like to thank the members of the Cancer Prevention and Control Research Network Rural Cancer Workgroup for their contribution to our paper in *Preventive Medicine* (2019).


**Funding:** This study was supported by the Federal Office of Rural Health Policy (FORHP), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services under cooperative agreement [5 U1CRH30539-03-00] and the National Cancer Institute. The content is solely the responsibility of the authors and does not necessarily represent the official views of FORHP, HRSA, DHHS, or NCI.

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PREVENTING CHRONIC DISEASE  
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY

## A Bivariate Mapping Tutorial for Cancer Control Resource Allocation Decisions and Interventions

TOOLS FOR PUBLIC HEALTH PRACTICE — Volume 17 — January 2, 2020  9

Claire Biesecker, BA<sup>1</sup>; Whitney E. Zahnd, PhD<sup>1</sup>; Heather M. Brandt, PhD<sup>1,2</sup>; Swann Arp Adams, PhD<sup>1,3,4</sup>; Jan M. Eberth, PhD<sup>1,3</sup> (View author affiliations)

Suggested citation for this article: Biesecker C, Zahnd WE, Brandt HM, Adams SA, Eberth JM. A Bivariate Mapping Tutorial for Cancer Control Resource Allocation Decisions and Interventions. Prev Chronic Dis 2020;17:190254. DOI: <https://dx.doi.org/10.5888/pcd17.190254> 

PEER REVIEWED

### Abstract

Bivariate choropleth mapping is a straightforward but underused method for displaying geographic health information to use in public health decision making. Previous studies have recommended this approach for state comprehensive cancer control planning and similar efforts. In this method, 2 area-level variables of interest are mapped simultaneously, often as overlapping quantiles or by using other classification methods. Variables to be mapped may include area-level (eg, county level) measures of disease burden, health care use, access to health care services, and sociodemographic characteristics. We demonstrate how geographic information systems software, specifically ArcGIS, can be used to develop bivariate choropleth maps to inform resource allocation and public health interventions.

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##### Abstract

GIS Mapping to Inform Cancer Prevention and Control Efforts

Uses of Bivariate Choropleth Mapping in Cancer Prevention and Control

Cervical Cancer Screening Example: Public Health Programming and Surveillance Data




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Funded by the Federal Office of Rural Health Policy, Health Resources and Services Administration.

# Thanks!

**Jan Eberth, PhD**

Email:  
jmeberth@mailbox.sc.edu



@jmeberth

**Whitney Zahnd, PhD**

Email: zahnd@mailbox.sc.edu



@whitneyzahnd

**Peiyin Hung, PhD**

Email: hungp@mailbox.sc.edu



@peiyinhung



@RMHRC\_UofSC



South Carolina