Welcome!

American Cancer Society Cancer Action Network℠

Welcome to Washington!

American Cancer Society Cancer Action Network℠

Rural Health Care Challenges in the Northwest

American Cancer Society Cancer Action Network℠

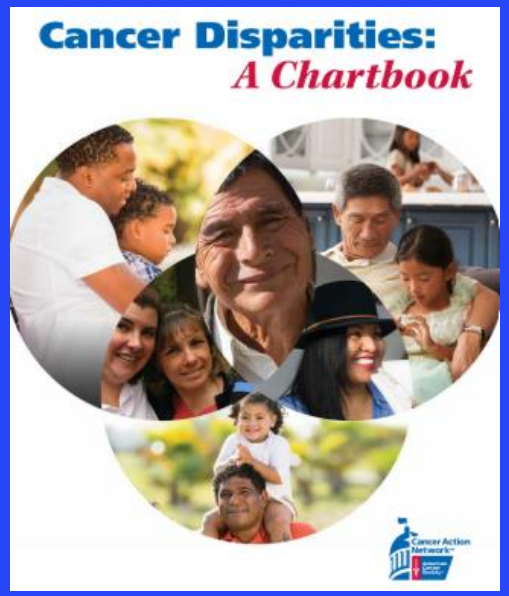
Cancer Disparities: An ACS CAN Chartbook

American Cancer Society Cancer Action Network℠

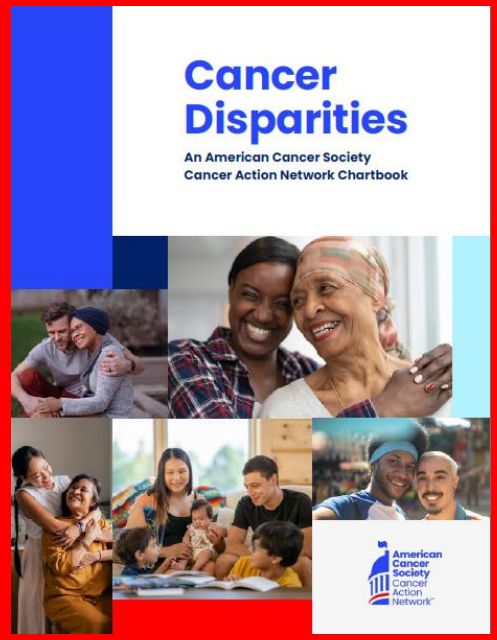
October 17, 2026

Background

2018



2026



Background

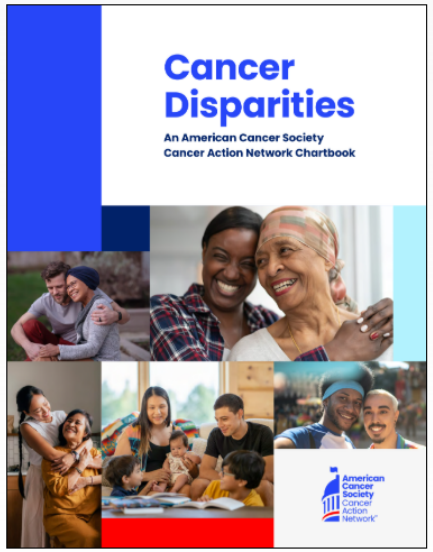
Available at www.fightcancer.org/chartbook

Cancer Disparities: An American Cancer Society Cancer Action Network Chartbook

April 16, 2026

Cancer impacts everyone, but it doesn't impact everyone equally. For the American Cancer Society (ACS) and its advocacy affiliate, the American Cancer Society Cancer Action Network (ACS CAN), health equity means everyone has a fair and just opportunity to prevent, detect, treat, and survive cancer – regardless of income, race, sexual orientation, gender identity, disability status, or where they live. ACS CAN advocates for evidence-based policies that reduce the cancer burden for everyone and is making cancer a top priority for public officials and candidates at the federal, state and local levels.

In 2018, ACS CAN released its inaugural Cancer Disparities: A Chartbook which illustrated the scope of cancer disparities across the cancer continuum in the United States, along with the evidence-based policy recommendations at the local, state and federal levels that seek to reduce these disparities. As ACS CAN continues in its commitment to advance health equity, this updated ACS CAN chartbook examines cancer disparities across different populations, shows how certain communities are uniquely burdened by cancer, and highlights the policies that can address these inequalities as we continue in our advocacy to end cancer as we know it, for everyone. This ACS CAN chartbook provides cancer-specific data related to disparities in cancer prevention, screening, and early detection; disparities in incidence mortality and survival; as well as disparities in access to coverage experienced by historically marginalized communities. Additionally, some of the maps included in this chartbook are interactive and can be further explored via the provided links.



rtbook (PDF)

New Report Examines Gaps in Cancer Prevention, Treatment and Survivorship

CHARTBOOK OFFERS PUBLIC POLICY RECOMMENDATIONS TO ADDRESS CANCER DISPARITIES

April 16, 2026

WASHINGTON, DC – APRIL 16, 2026 – The American Cancer Society Cancer Action Network (ACS CAN) released a new report today showing the scope of cancer disparities in the United States and recommended local, state and federal policies that can help reduce them. *Cancer Disparities: An American Cancer Society Cancer Action Network Chartbook* examines disparities in cancer screening, prevention and early detection, disparities in cancer incidence, mortality and survival, as well as disparities in access to health coverage.

The chartbook includes cancer-specific data on communities disproportionately affected by cancer, including American Indian and Alaskan Native (AIAN) people, Asian, Asian American, Native Hawaiian and Pacific Islander people (AANHPI), Black people, Hispanic/Latino people, Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ+) people, people with disabilities and people who live in rural areas. The chartbook outlines cancer disparities across these communities, serves as a resource to better understand the unique burden of cancer and provides evidence-based policy recommendations to reduce these disparities.

"Cancer is a disease that affects everyone but not equally," said Lisa A. Lacasse, president of ACS CAN. "Many barriers can impact a person's ability to prevent, detect, treat and survive cancer, including limited access to high quality, affordable health care and geographic location. Addressing these barriers is critical to reducing cancer disparities, improving health outcomes and saving more lives."

Background



Inform policymakers on cancer disparities across different communities



Highlight American Cancer Society data



Resource to ACS CAN & partners

Background

- Disparities in Black Communities
- Disparities in Hispanic/Latino Communities
- Disparities in Asian, Asian American, Native Hawaiian and Pacific Islander (AANHPI) Communities
- Disparities in American Indian and Alaska Native (AIAN) Communities
- Disparities in Lesbian, Gay, Bisexual, Transgender and Queer/Questioning (LGBTQ+) Communities
- Disparities in Rural Communities
- Disparities in Disability Communities

Background

Disparities in Cancer Incidence, Mortality and Survival

Disparities in Access to Coverage

Disparities in Cancer Prevention, Screening and Early Detection



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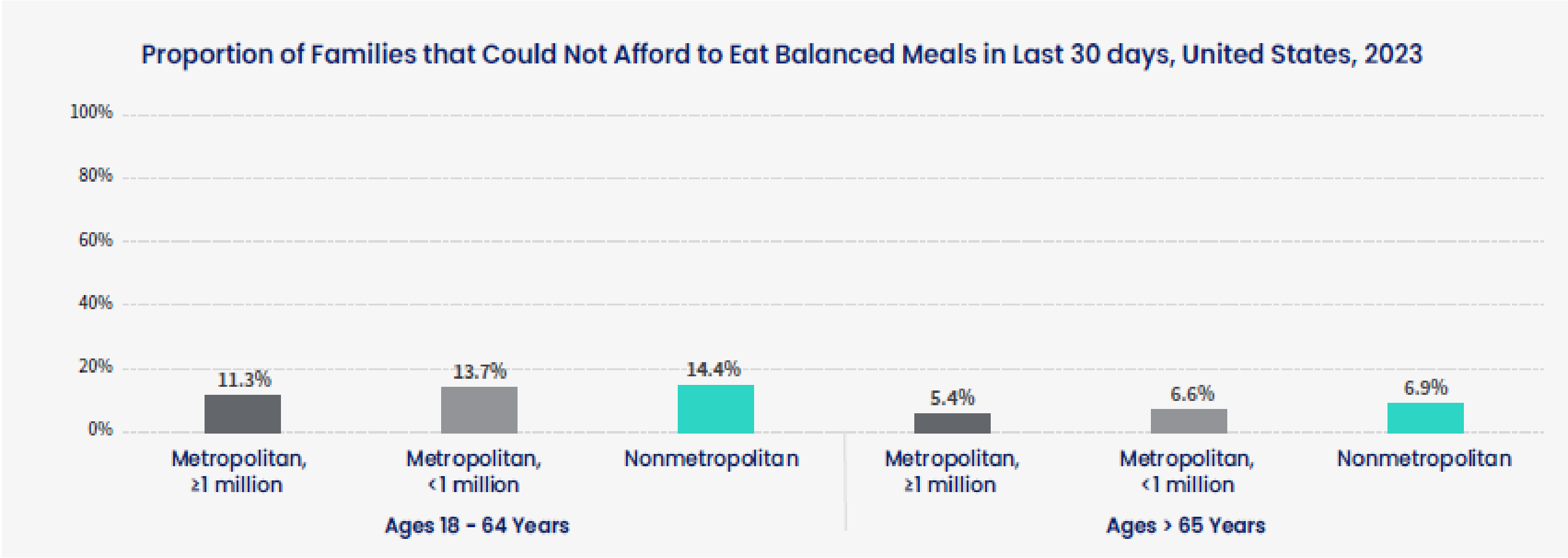
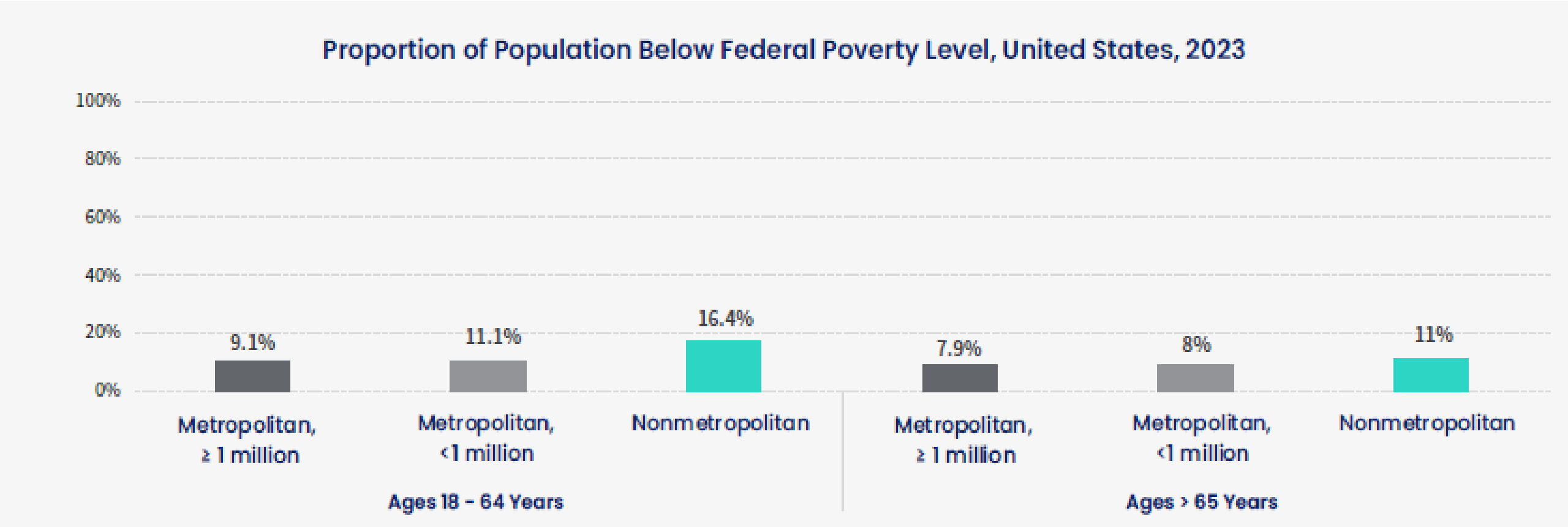
Disparities in Rural Communities

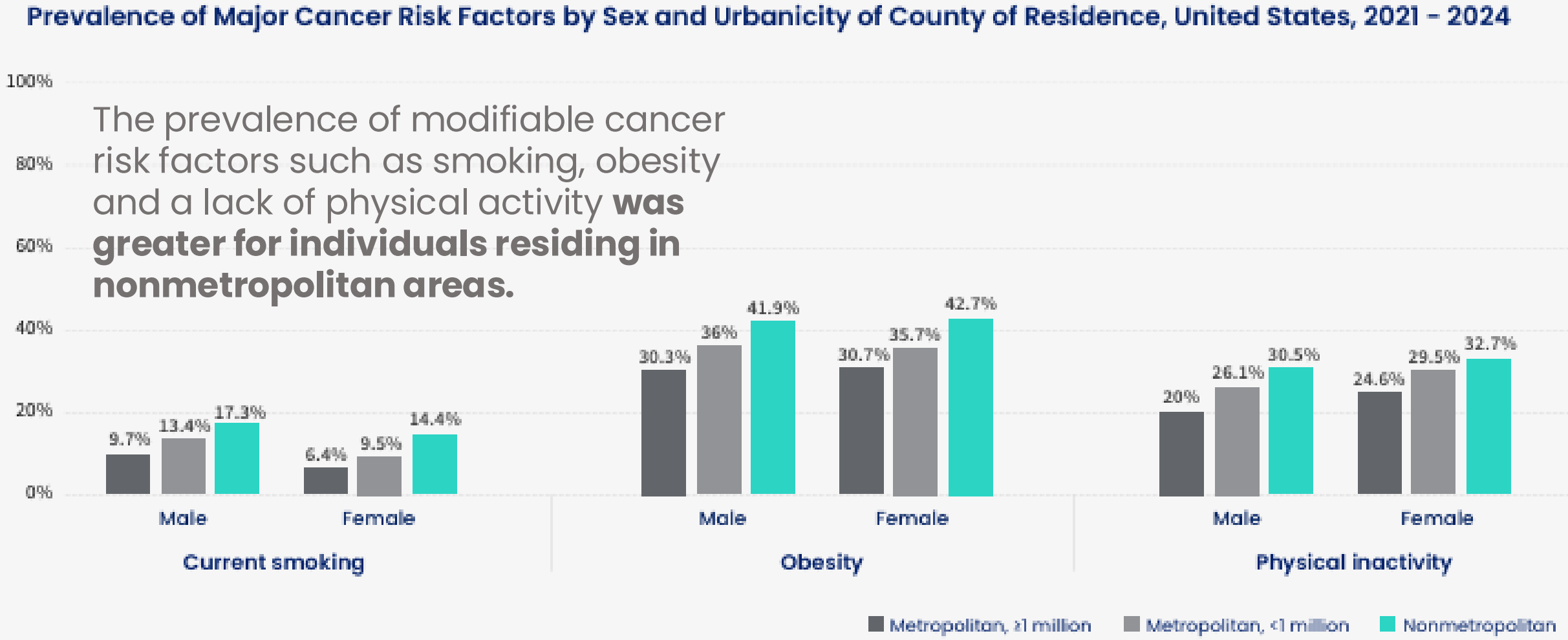
Disparities in Cancer Risk Factors



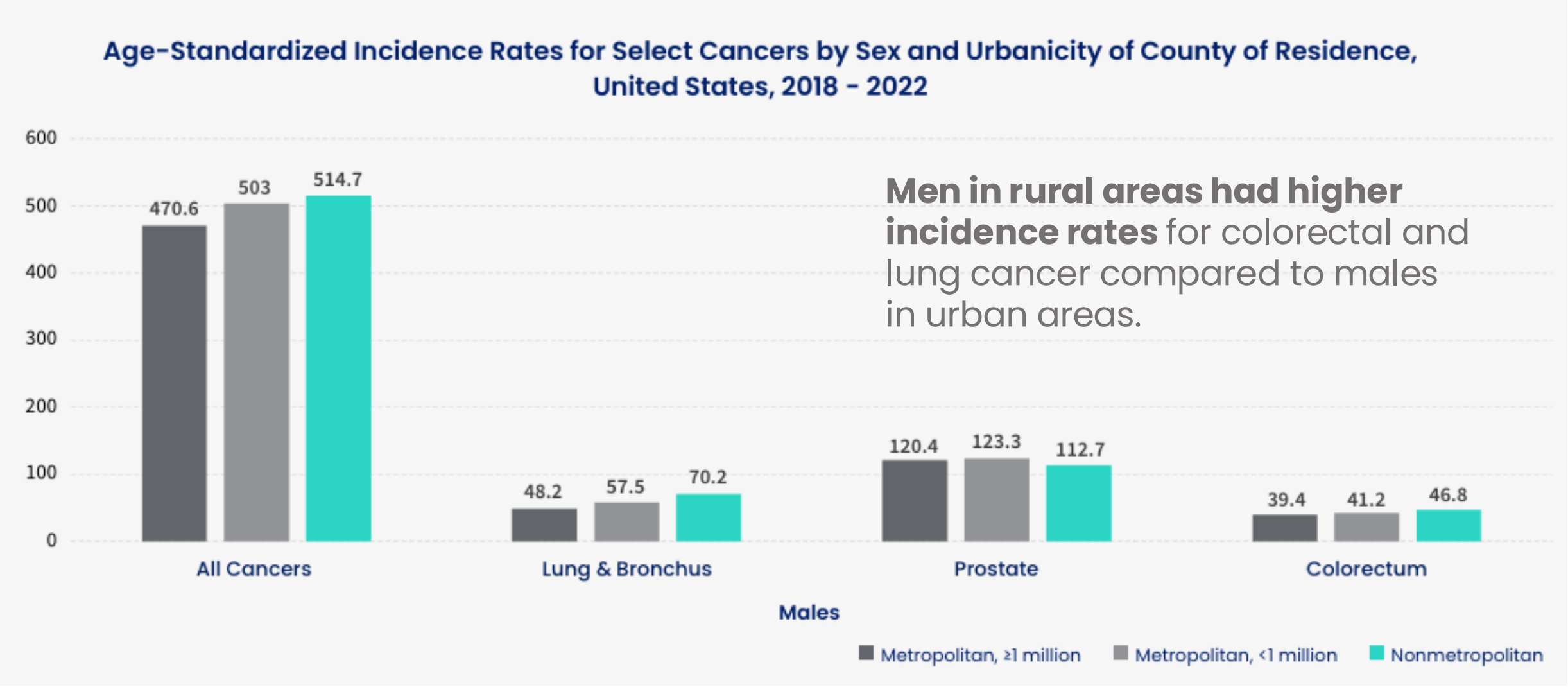
Disparities in Cancer Risk Factors



Disparities in Cancer Risk Factors

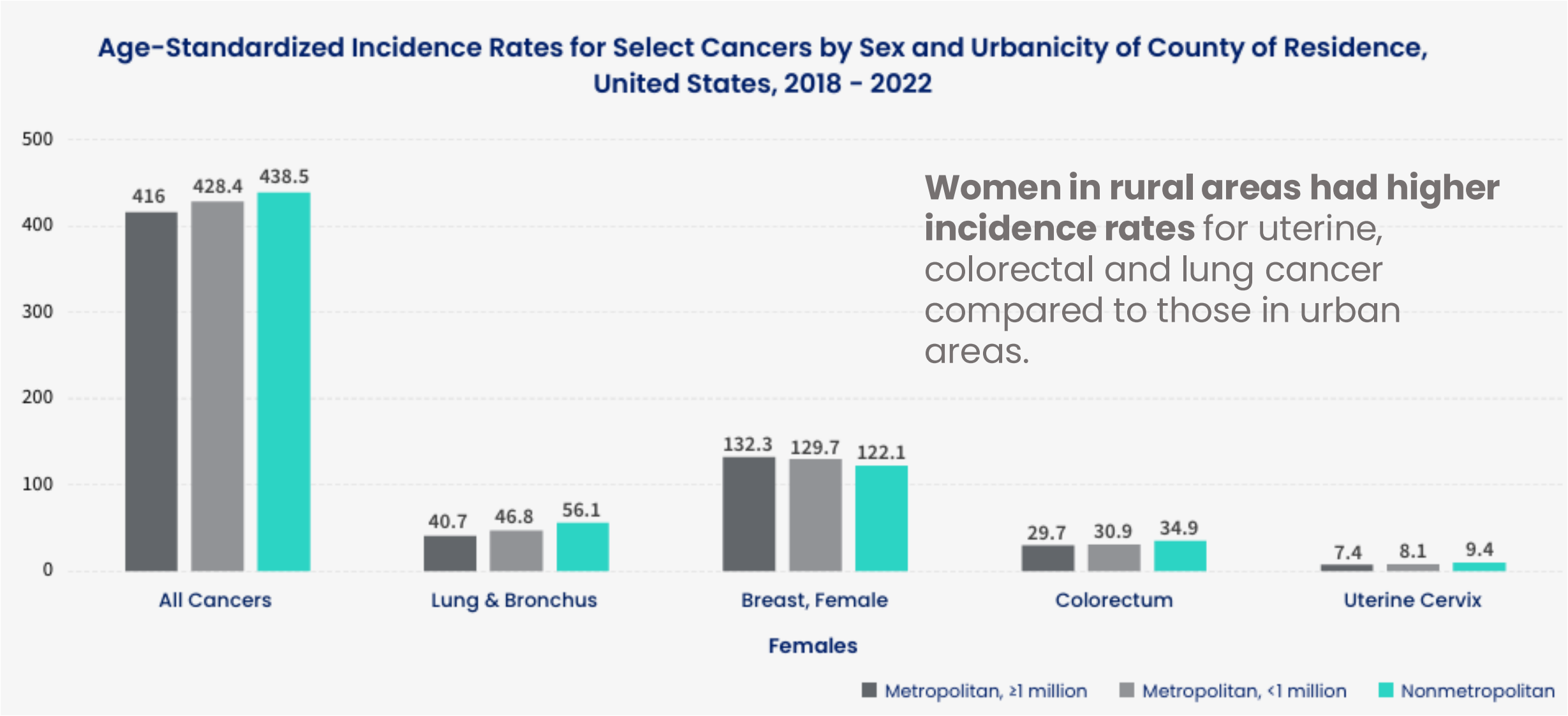


Disparities in Cancer Incidence, Mortality and Survival in Rural Communities



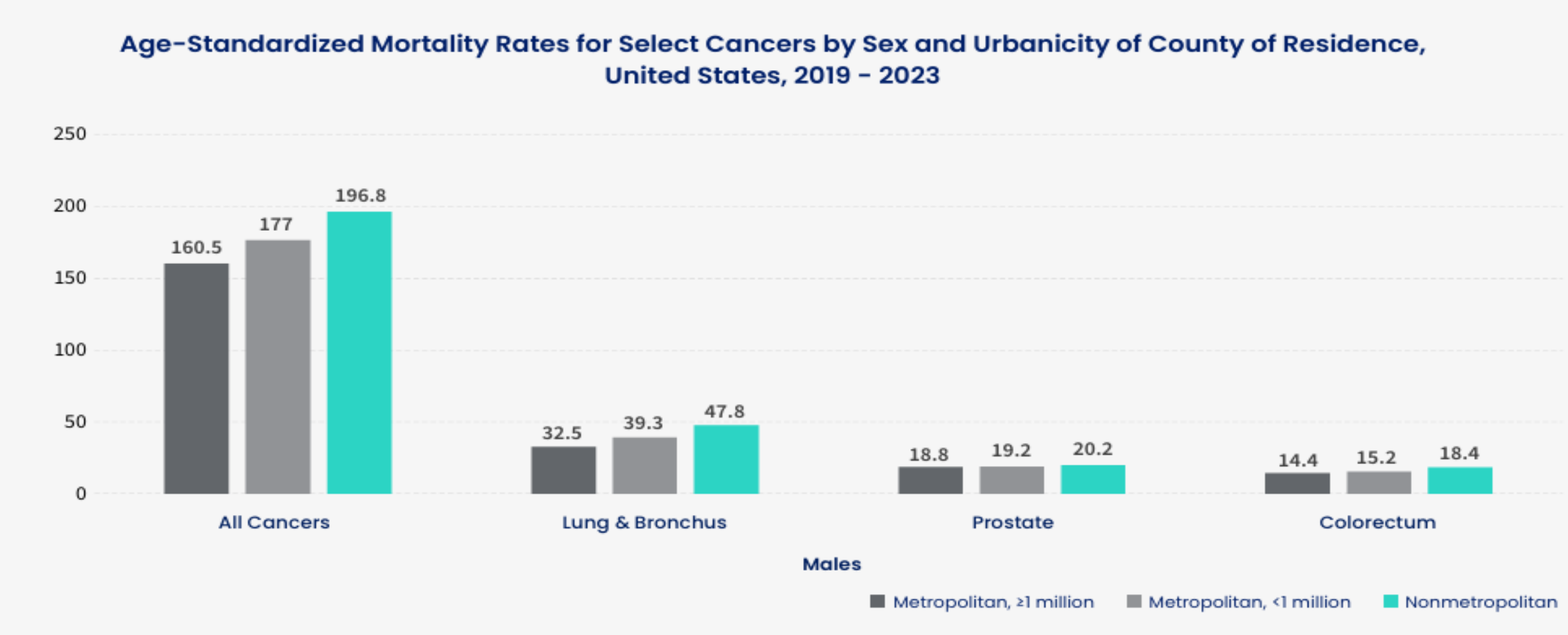
Men in rural areas had higher incidence rates for colorectal and lung cancer compared to males in urban areas.

Disparities in Cancer Incidence, Mortality and Survival in Rural Communities

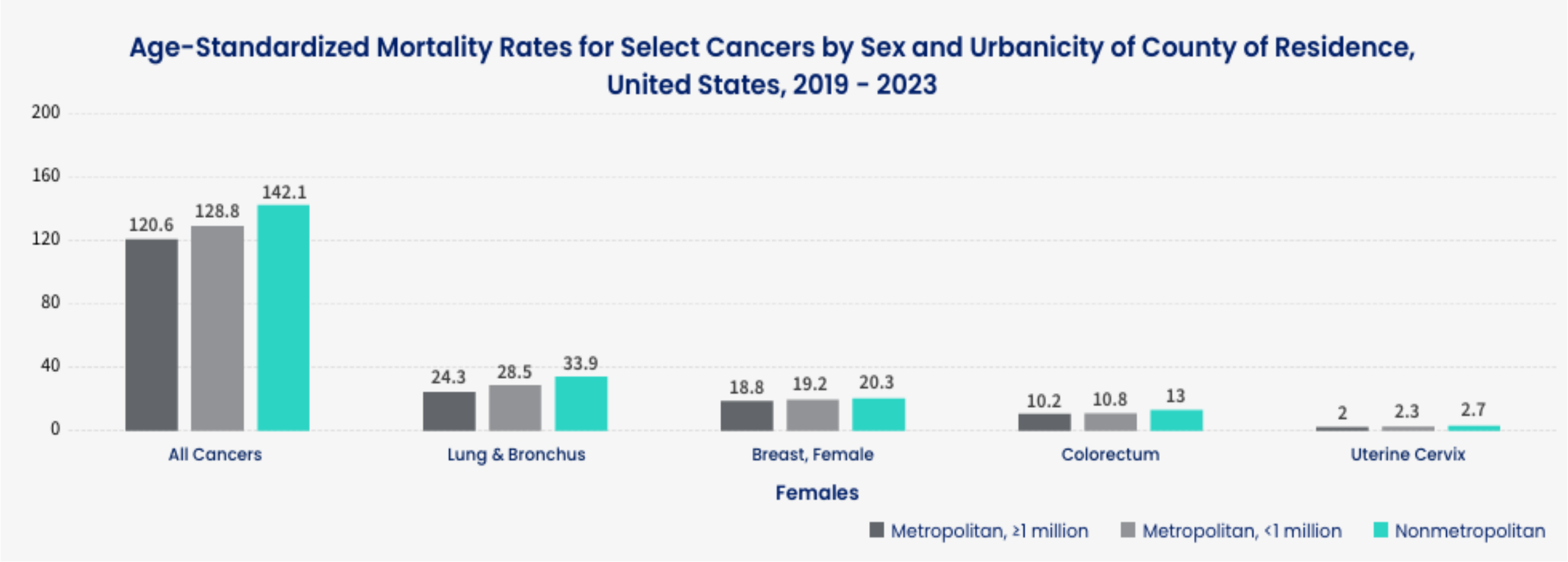


Women in rural areas had higher incidence rates for uterine, colorectal and lung cancer compared to those in urban areas.

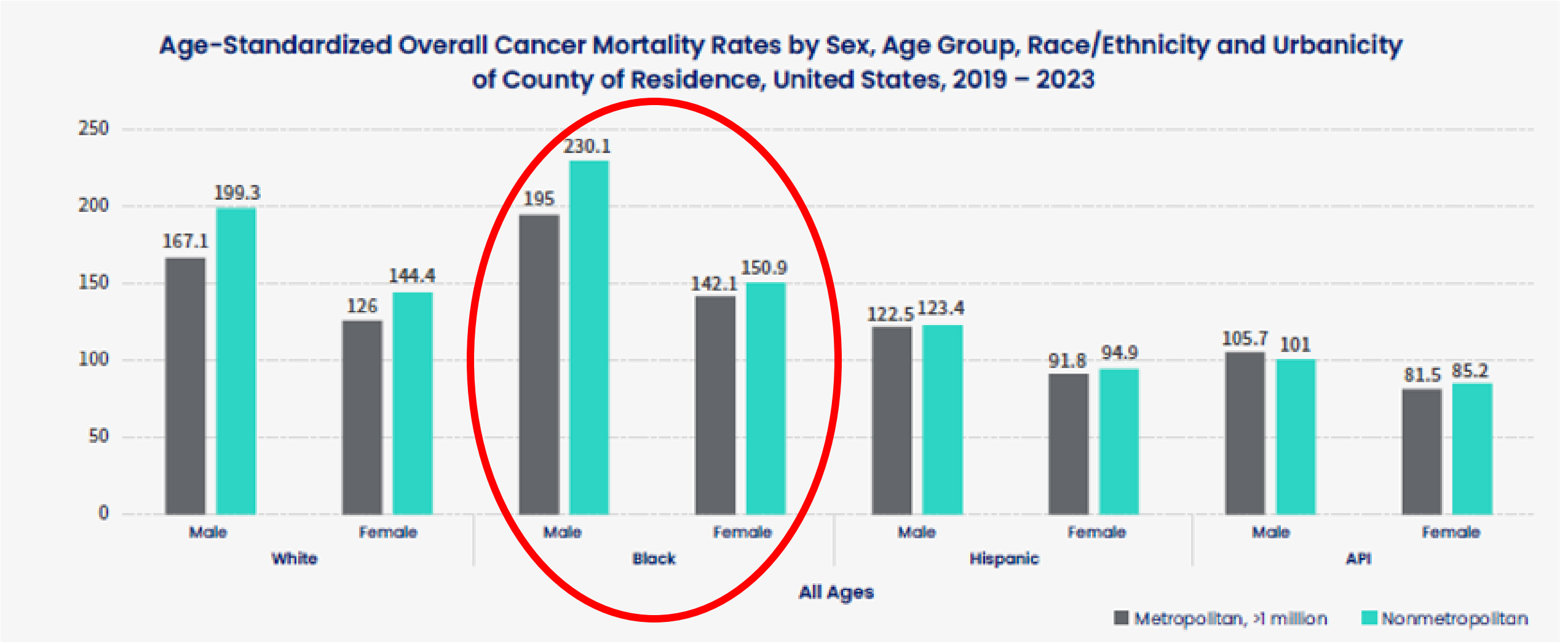
Disparities in Cancer Incidence, Mortality and Survival in Rural Communities



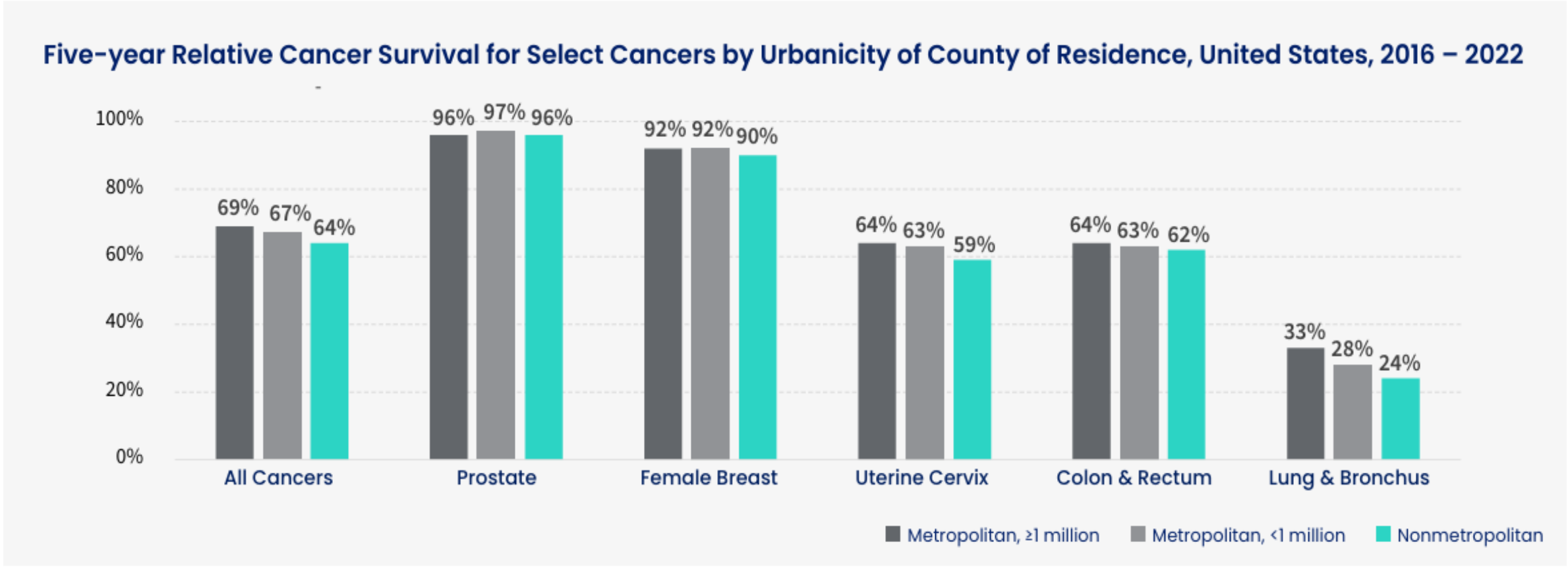
Disparities in Cancer Incidence, Mortality and Survival in Rural Communities



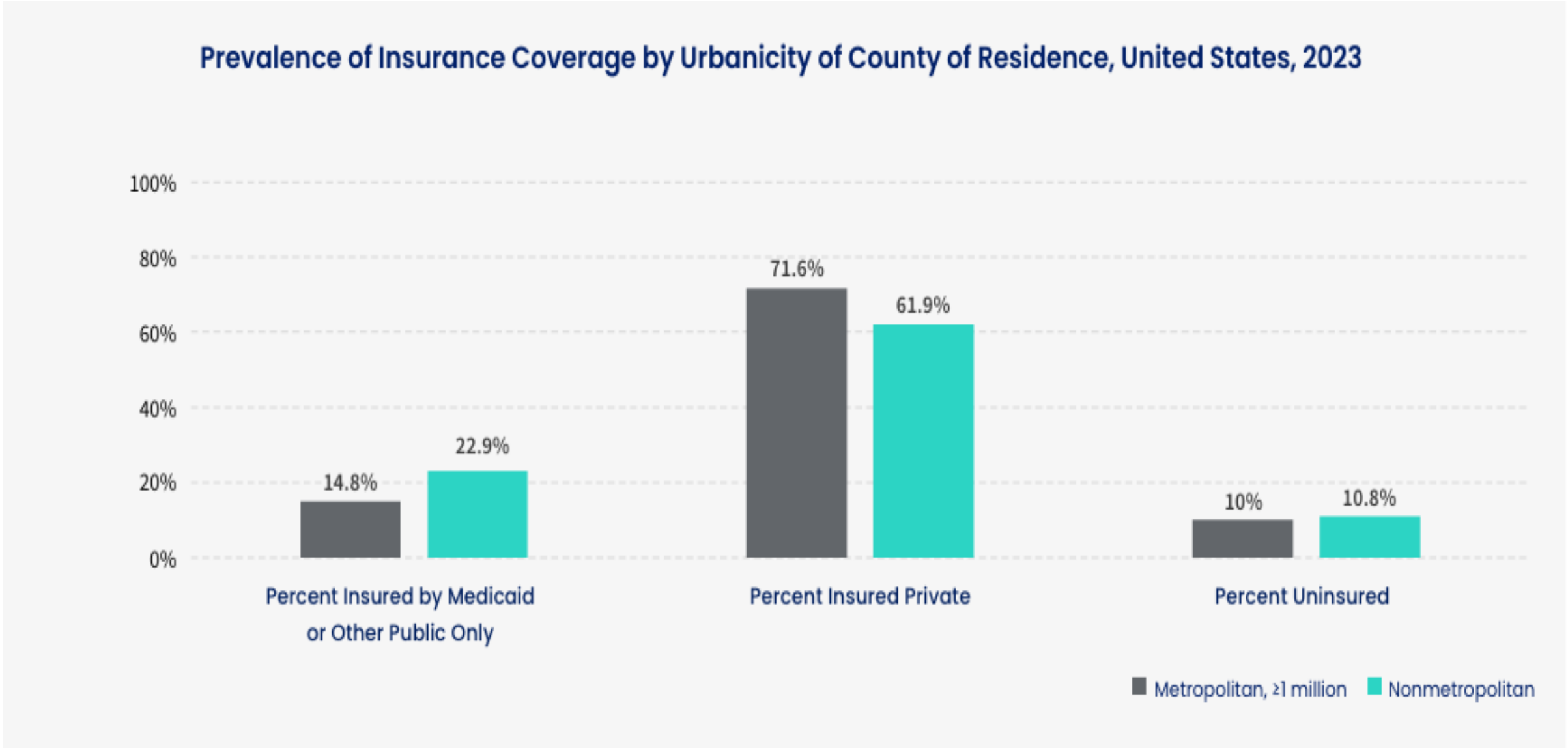
Disparities in Cancer Incidence, Mortality and Survival in Rural Communities



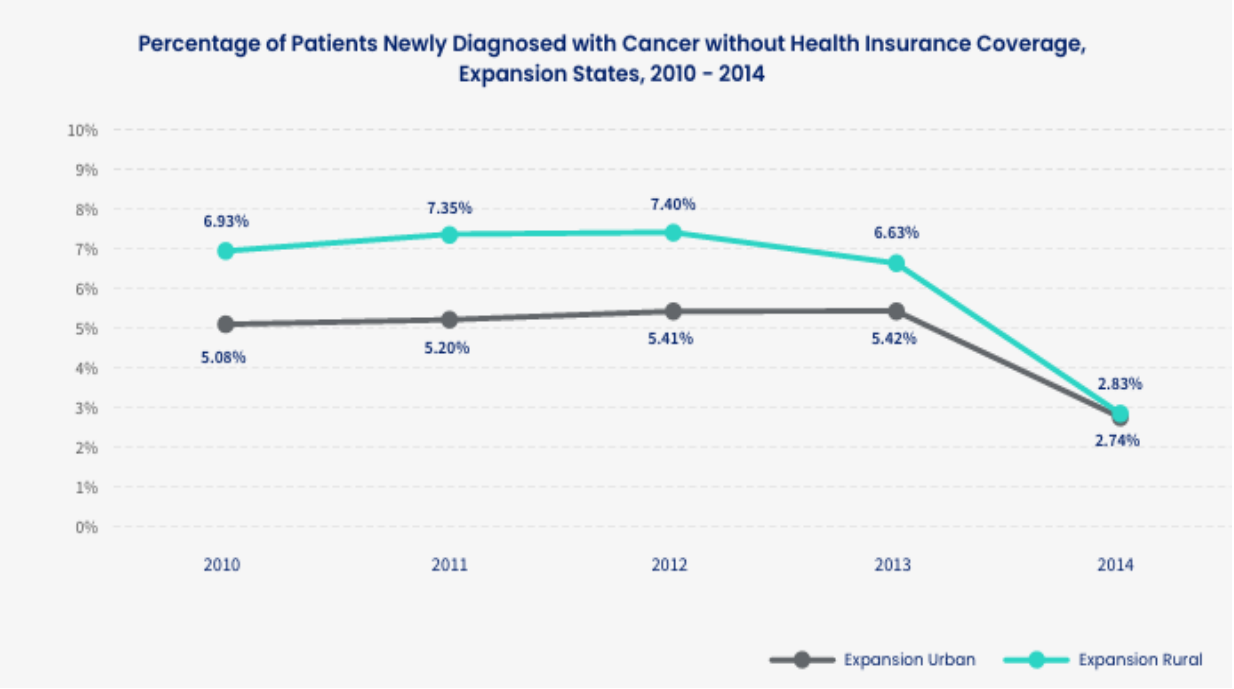
Disparities in Cancer Incidence, Mortality and Survival in Rural Communities

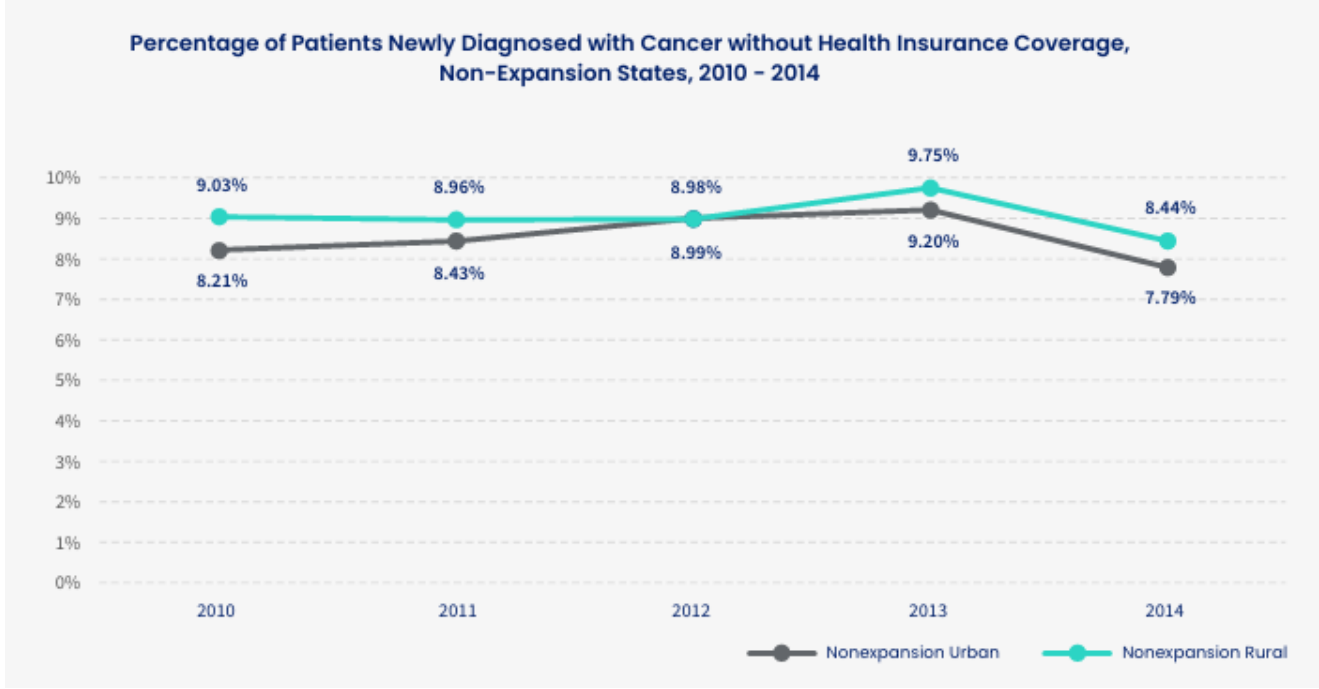


Disparities in Access to Coverage in Rural Communities



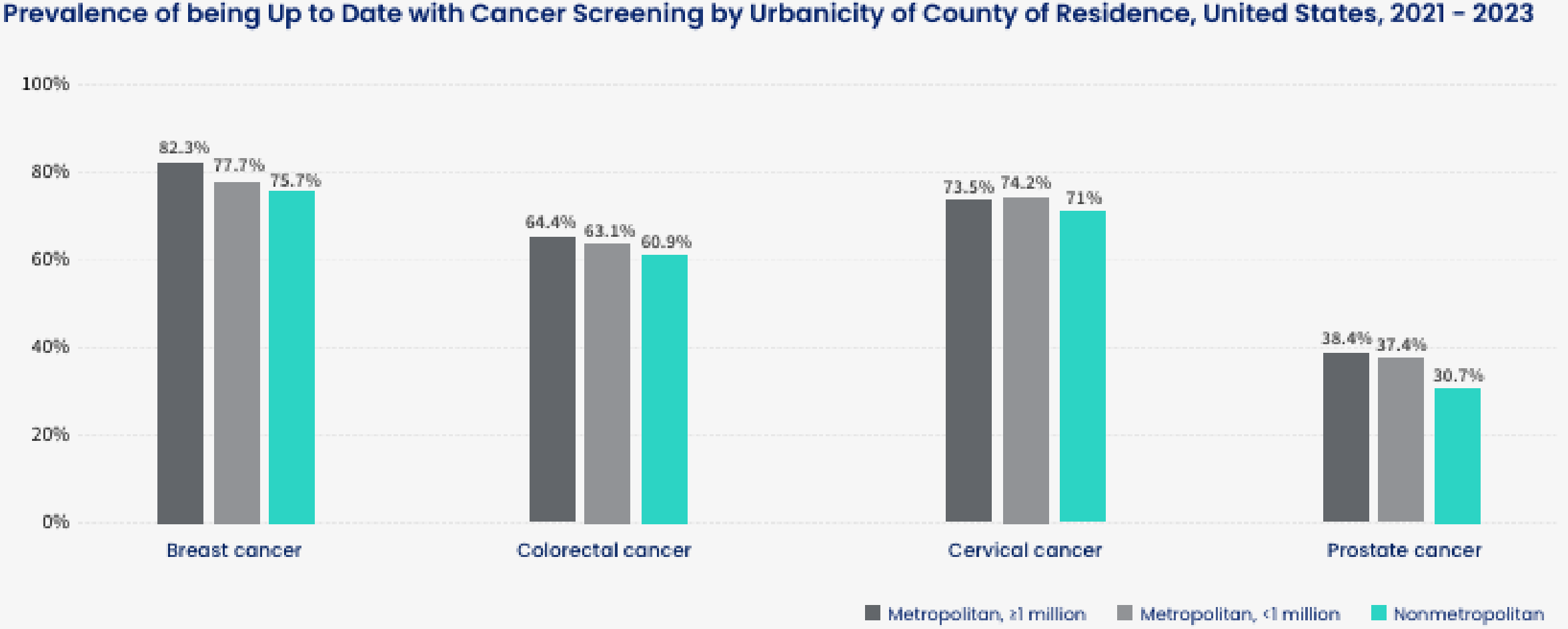
Disparities in Access to Coverage in Rural Communities





Following the implementation of Medicaid expansion under the Affordable Care Act in 2014, rural-urban **health insurance coverage disparities decreased in expansion states** among individuals aged 18-64 years newly diagnosed with cancer, but not in non-expansion states.

Disparities in Cancer Prevention, Screening, and Early Detection in Rural Communities





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Policy Recommendations

Policy Recommendations to Address Disparities in Cancer Incidence, Mortality and Survival

- **Timely accurate demographic data collection** and publication is essential to advance health equity
- Increasing access to **patient navigation services**
- Protecting and sustaining **cancer registry funding**

Policy Recommendations to Address Disparities in Access to Care

- **Protecting Medicaid coverage and expanding Medicaid** in the remaining states that have not done so
- Safeguarding access to care through **insurance protections**
- Ensuring access to **care without discrimination**
- Ensuring health **insurance plan network adequacy** for affordable and equitable cancer care
- Expanding access to **comprehensive affordable cancer care to the uninsured**
- Increasing access to quality cancer care for marginalized people through **telehealth service and telemedicine**
- Addressing and preventing **medical debt**

Policy Recommendations to Address Disparities in Cancer Prevention, Screening and Early Detection

- Protecting and increasing **colorectal cancer screening and control program funding**
- Ensuring Congress passes the **Prostate-Specific Antigen (PSA) Screening for High-Risk Insured Men (HIM) Act**
- Protecting and increasing funding for the lifesaving **National Breast and Cervical Cancer Early Detection Program (NBCCEDP)**
- **Eliminating cost sharing** for cancer screening and all follow-up tests
- Increasing access to and update of **evidence-based vaccines** that protect against cancer-causing viruses, treat cancer, and safeguard cancer patients and their families by maximizing community immunity

Policy Recommendations to Address Disparities in Cancer Prevention, Screening and Early Detection Continued

- Ensuring **physical accessibility of transportation, products and services** that individuals need to access routine preventive services and cancer screenings
- **Eliminating tobacco use** to address health disparities
- Supporting **access to affordable, nutritious food**

Policy Recommendations to Address Research Disparities

- Improving access to a **skilled and inclusive cancer workforce**
- Reducing barriers to **participating in clinical trials**
- Enforcing statutorily required **clinical trial diversity plans** at FDA
- Expanding community **clinical trial infrastructure**



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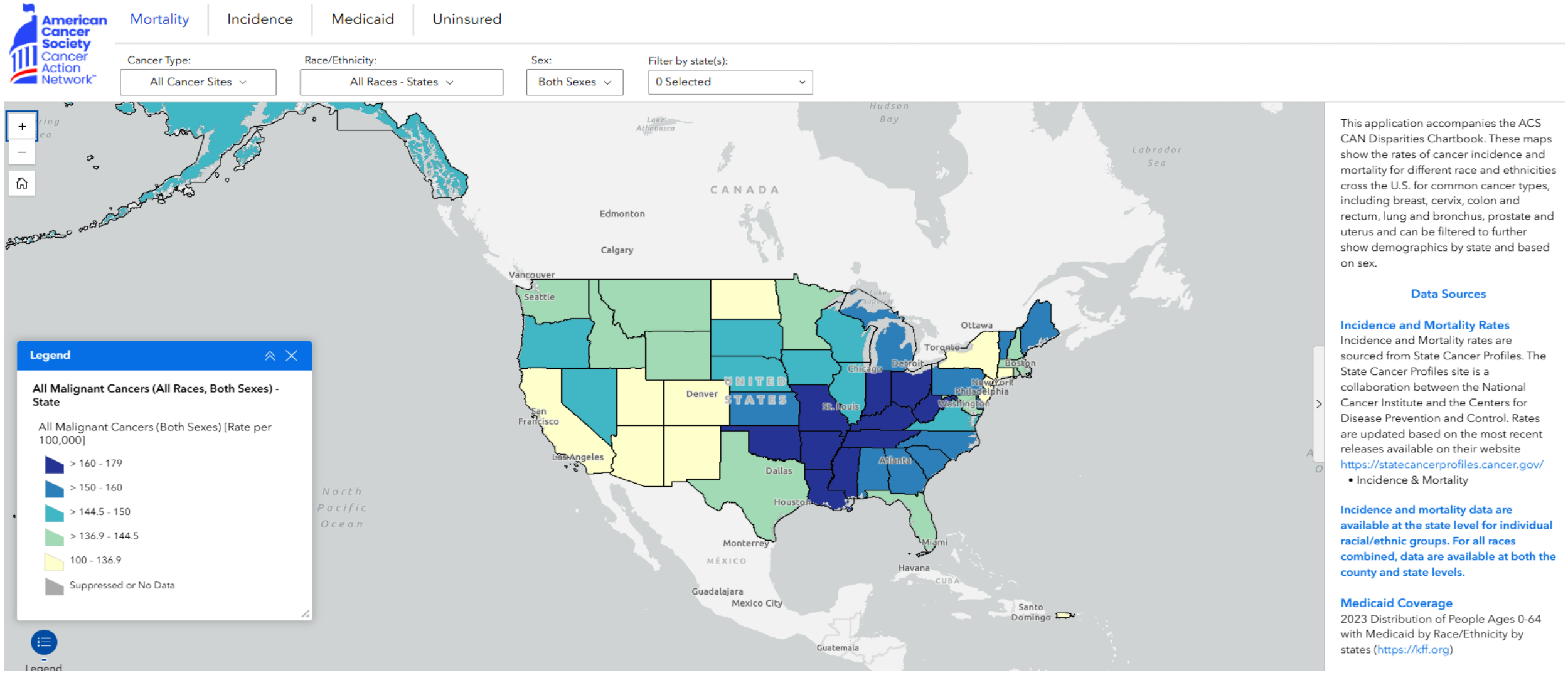
Additional Resources

Interactive Maps



This application accompanies the ACS CAN Disparities Chartbook. These maps show the rates of cancer incidence and mortality for different race and ethnicities cross the U.S. for common cancer types, including breast, cervix, colon and rectum, lung and bronchus, prostate and uterus and can be filtered to further show demographics by state and based on sex.

Data Sources

Incidence and Mortality Rates

Incidence and Mortality rates are sourced from State Cancer Profiles. The State Cancer Profiles site is a collaboration between the National Cancer Institute and the Centers for Disease Prevention and Control. Rates are updated based on the most recent releases available on their website https://statecancerprofiles.cancer.gov/

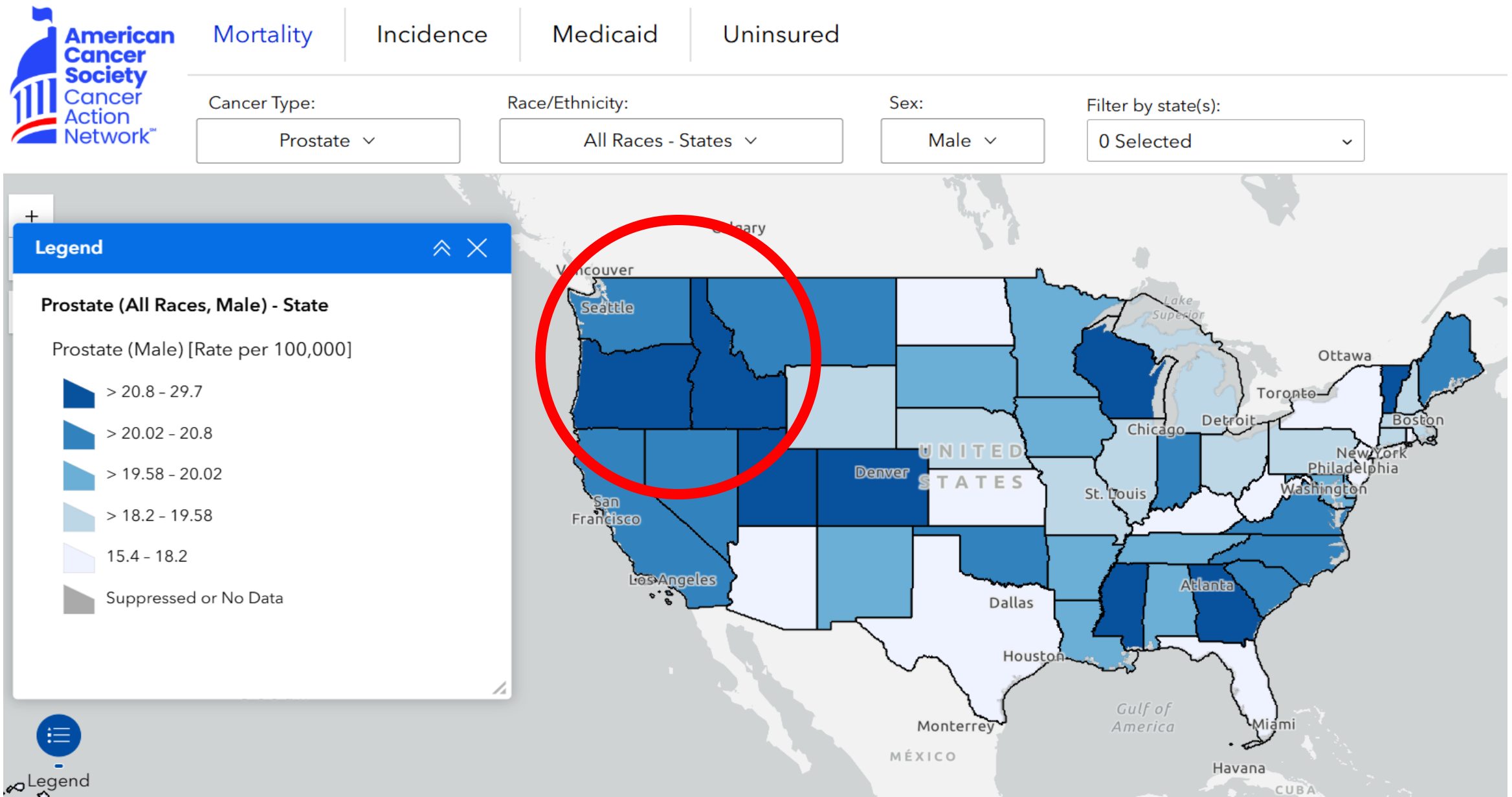
- Incidence & Mortality

Incidence and mortality data are available at the state level for individual racial/ethnic groups. For all races combined, data are available at both the county and state levels.

Medicaid Coverage

2023 Distribution of People Ages 0-64 with Medicaid by Race/Ethnicity by states (https://kff.org)

State Spotlights: Idaho, Oregon & Washington



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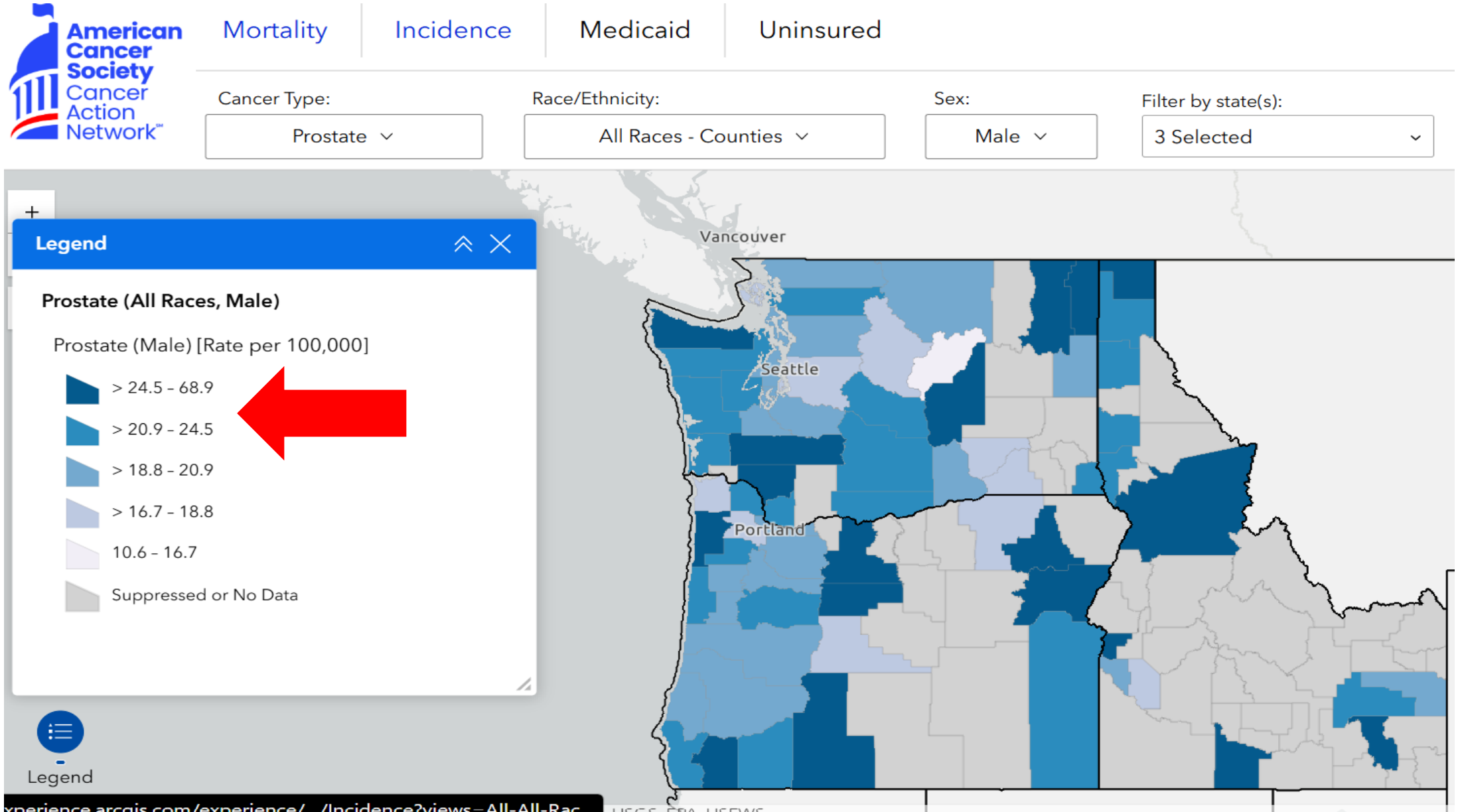

Additional Chartbook Sections

- Addendum Table of Contents: List of Figures by Disparity Type
- Source of Statistics
- Appendix: American Cancer Society Guidelines

Thank You!

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gladys.arias@cancer.org

State Specific Challenges

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Insurance Navigation & Patient Access

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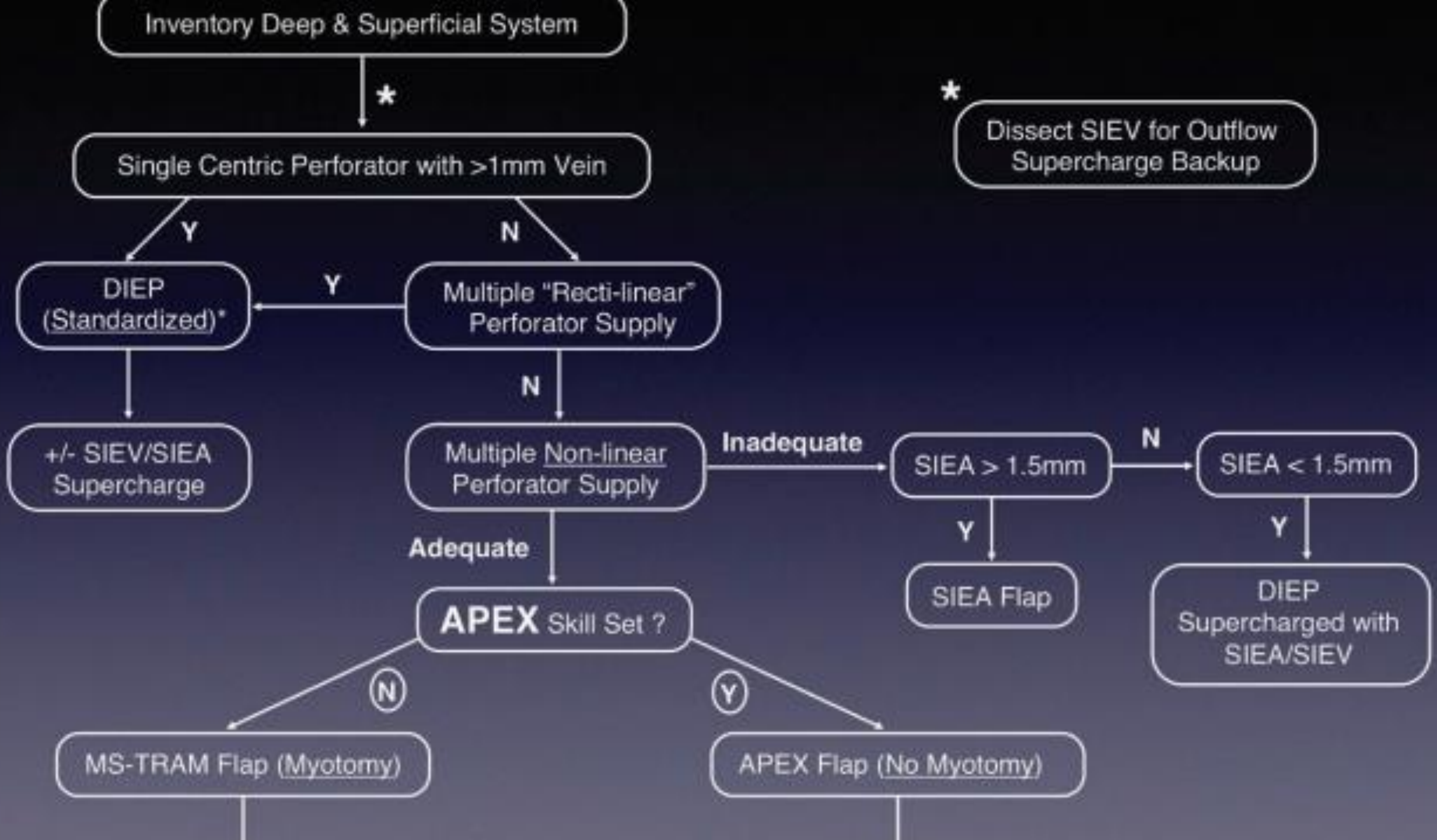
When Geography and Insurance Limit Cancer Care

Gail Menasco: BRA Society

Breast Reconstruction Advocate Society

October 2026

My Story


Inventory Deep & Superficial System
*
Single Centric Perforator with >1mm Vein
Y
N
DIEP (Standardized)*
Y
Multiple "Recti-linear" Perforator Supply
+/- SIEV/SIEA Supercharge
N
Multiple Non-linear Perforator Supply
Inadequate
SIEA > 1.5mm
N
SIEA < 1.5mm
Y
SIEA Flap
Y
DIEP Supercharged with SIEA/SIEV
Adequate
APEX Skill Set ?
N
Y
MS-TRAM Flap (Myotomy)
APEX Flap (No Myotomy)
*
Dissect SIEV for Outflow Supercharge Backup

My Muscle was Preserved




NOTICE
American Cancer Society®
← Patrick F. Taylor Hope Lodge



BRA SOCIETY | BREAST RECONSTRUCTION ADVOCATE SOCIETY

- My story showed me that one person, one story can make change.
- SB 1137 passed unanimously in 2025 that expands access to autologous breast reconstruction procedures that don’t compromise the muscle for commercial insurance in Oregon.
- Since then, I have continued in advocacy to be the change.

Barriers in Care

THE BARRIERS TO CANCER CARE

Five interconnected challenges affecting access to cancer services

01 Geographic and provider access

Distance to treatment • specialist shortages • limited clinical trials

02 Insurance and coverage

Narrow networks • limited plan choices • coverage and enrollment barriers

03 Financial and logistical burdens

Transportation • lodging • time away from work

04 Prevention and early detection

Primary care shortages • screening and follow-up barriers

05 Patient support and navigation

Limited navigation • education • supportive care services

Source: ACS CAN, Policy Recommendations for Improving Cancer Care in Rural America (May 13, 2026).

Oregon Example: Individual Marketplace

DIVE BRIEF

Providence shuts down most insurance businesses for 2027

The nonprofit giant has offered health insurance for decades. But recent challenges, including higher costs and regulatory changes, have created an untenable situation, according to Providence's CEO.

Published May 21, 2026

PacificSource latest insurer to exit the ACA

The not-for-profit insurer said it is exiting the individual market across all states and the state of Montana across all lines of business.

Moda Is Ending Individual Plans in 8 Oregon Counties

Access to NCI-Designated Cancer Centers

What they are, why they are important, and how far patients travel

WHAT IS AN NCI-DESIGNATED CANCER CENTER?

A research institution recognized by the National Cancer Institute for meeting rigorous standards in cancer research focused on prevention, diagnosis, and treatment.

WHY THE DESIGNATION IS IMPORTANT

These centers lead cancer research and clinical trials that test new ways to prevent, detect, and treat cancer. Centers providing patient care may also offer specialized teams and access to trials not available locally.

74

Designated centers nationwide

58

Comprehensive centers

37 + DC

States and DC with a center

Distance remains a barrier

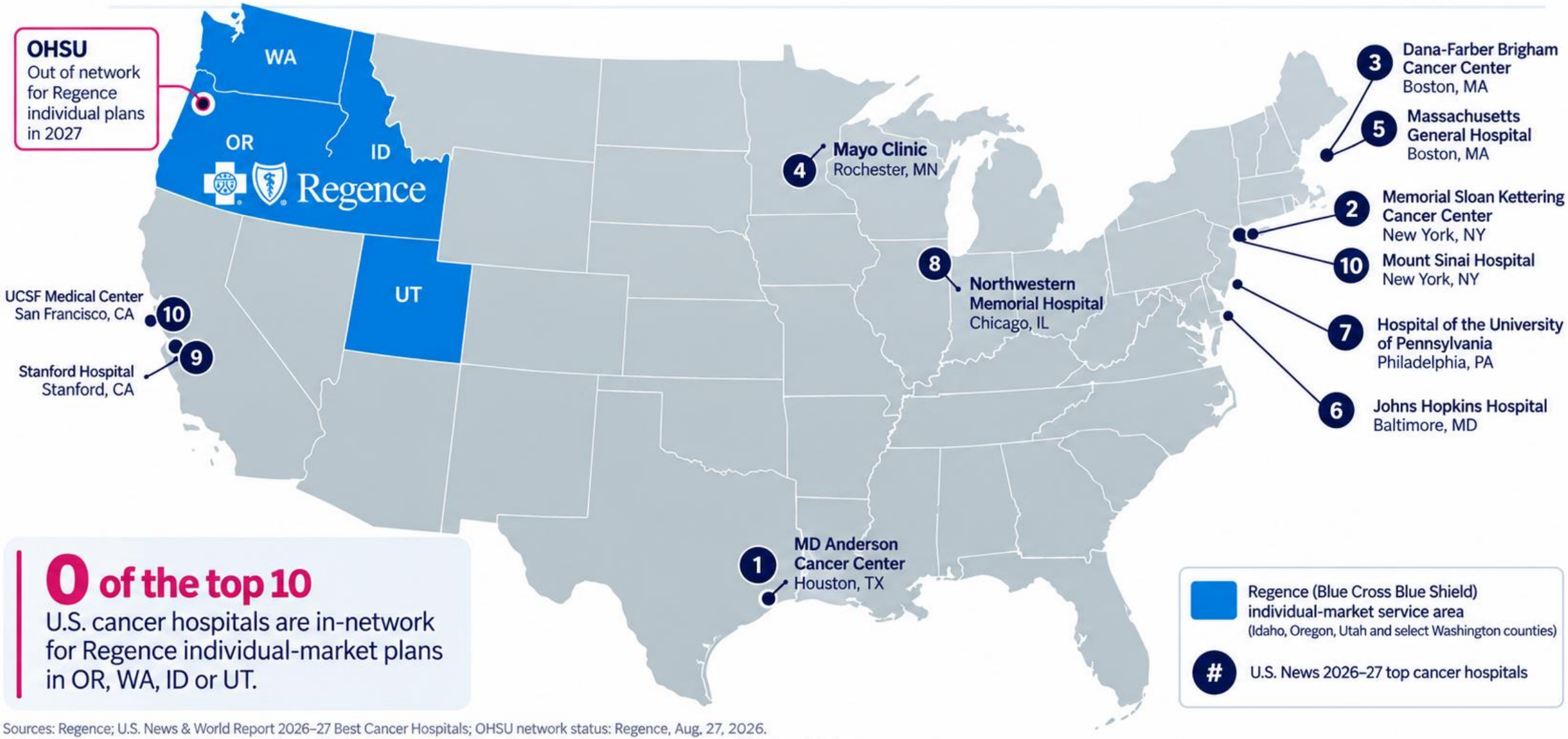
Estimated U.S. population driving time to a parent NCI cancer center facility (2014 data)



Sources: NCI Cancer Centers Program (2026); Onega et al., Cancer (2017), Table 1. Travel-time estimates use 2014 locations. Clinical trials are also offered outside NCI centers.

When the care you need is outside the network

Regence individual-market service area and the nation's top-ranked cancer hospitals



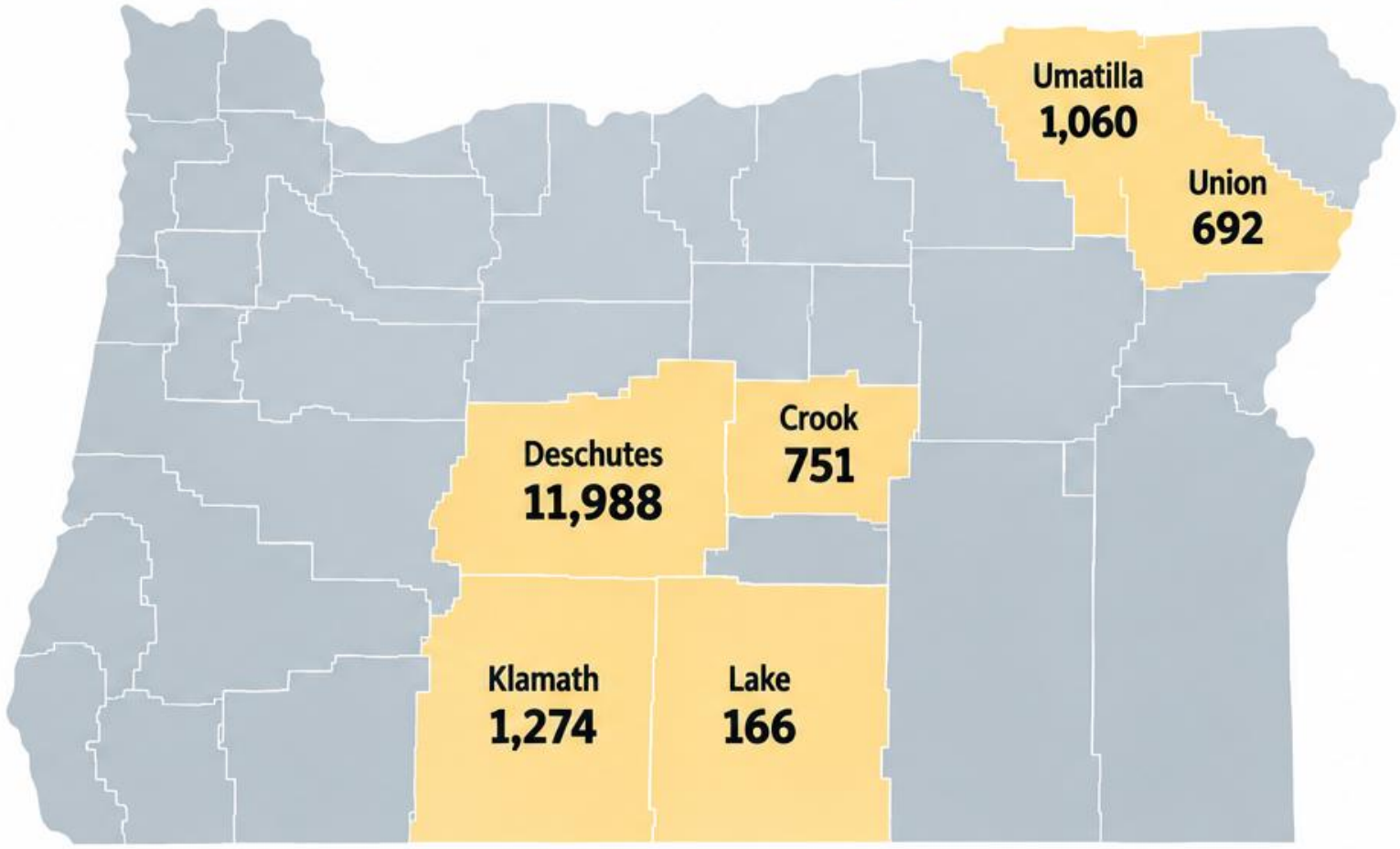
0 of the top 10

U.S. cancer hospitals are in-network for Regence individual-market plans in OR, WA, ID or UT.

Sources: Regence; U.S. News & World Report 2026–27 Best Cancer Hospitals; OHSU network status: Regence, Aug. 27, 2026.
Note: Map shows top 10 hospitals from U.S. News 2026–27 Cancer rankings. Network participation based on Regence individual-market plans.

Nearly 16,000

Oregonians enrolled in individual ACA plans face limited options in 2027.



OHSU

Oregon's only NCI-designated comprehensive cancer center

Only two individual ACA insurers in these six counties for 2027

BridgeSpan | Regence

26,285

Oregonians enrolled in Regence or BridgeSpan individual ACA plans statewide in 2026

✕ **Neither insurer includes OHSU in its individual ACA network in 2027**

2026 enrollment: Oregon DCBS, June 30, 2026

OHSU and Regence BlueCross BlueShield renew network agreement

By OHSU Communications August 27, 2026 Portland, Oregon



Oregon Health & Science University and Regence BlueCross BlueShield of Oregon today jointly announced a new agreement that will keep OHSU and its clinics, hospitals and healthcare professionals as in-network providers for Regence BlueCross BlueShield commercial members. This agreement includes OHSU Hospital and OHSU Doernbecher Children's Hospital. Hillsboro Medical Center also reached a new agreement with Regence. The agreement does not include Medicare Advantage or Individual (Marketplace) networks for 2027.

The agreement **does not** include Medicare Advantage or Individual (Marketplace) networks for 2027

Case Study: Kasey



- Young Breast Cancer Patient
- Single Mom
- Lives in a town with an oncology department but has to travel 175 miles for more specialized care at OHSU
- Is on Individual ACA (Affordable Care Act) Plan
- In 2027, she won’t have access to an insurance plan that works at OHSU and will be dependent on a single case agreement that’s hard to get.

Case Study: Jenn

- Second Time Breast Cancer Patient
- Lives in a town with an oncology department
- Is on Medicaid/OHP
- Doesn’t have access to recommended care due to Medicaid insurance networks





Annual Insurance Rates Keep Going Up

- The ACA protects people with pre-existing conditions, including cancer survivors.
- As premiums rise, healthier individuals may leave the individual market, potentially increasing the average health risks and costs of those who remain

ACA-COMPLIANT PLANS
2027 HEALTH INSURANCE RATE REQUESTS

INDIVIDUAL MARKET						
Company	Average rate request increase	Average DFR adjusted rate increase	Final rate increase	Requested Portland silver 40-year-old rate	DFR adjusted for Portland silver 40-year-old rate	Final Portland silver 40-year-old rate
BridgeSpan Health Company	11.7%	10.0%	19.3%	$687	$677	$734
Kaiser Foundation Health Plan of the Northwest	12.2%	10.2%	15.8%	$581	$571	$599
Moda Health Plan, Inc.	25%	23.9%	27%	$695	$689	$706
Regence BlueCross BlueShield of Oregon	12.2%	10.5%	20.3%	$660	$650	$708
Average	17.5%	16%	21.6%			

Questions for Consideration

- **Geography:** What does access to cancer care look like when the treatment a patient needs isn't available close to home?
- **Insurance:** What happens when someone has health insurance, but the cancer center they need is outside their network?
- **Affordability**: How do rising premiums, travel expenses, and out-of-pocket costs affect a patient's ability to pursue care?
- **Patient choice:** How can patients make informed treatment decisions when their options are limited by geography or insurance?

BRA SOCIETY
BREAST RECONSTRUCTION ADVOCATE SOCIETY

Thank You

Lunch!

American Cancer Society Cancer Action Network℠

Panel: Building Relationships with Tribal Communities

American Cancer Society Cancer Action Network℠

Volunteering on the Frontier

American Cancer Society Cancer Action Network℠

Volunteering on the Frontier, what motivates us for long term engagement and growth?

Saturday October 17, 2026

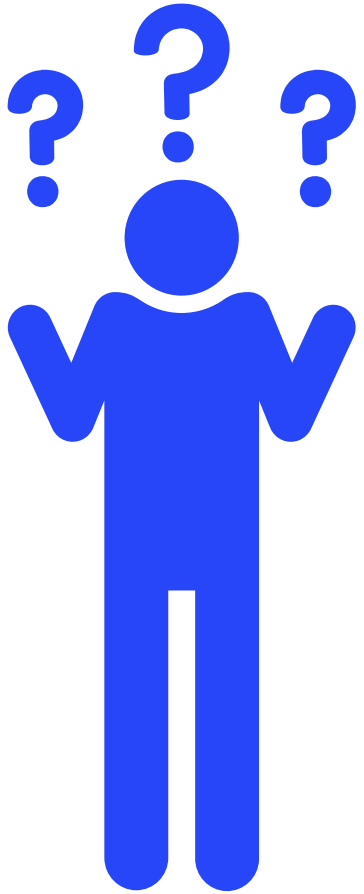


Agenda

- What is rural? Why is defining rural so hard?
- Thesis work
- Self Determination Theory (SDT)
- Intrinsic vs. Extrinsic motivation
- How to cultivate motivation in your state
- Questions
- Group exercise

Why is defining rural so hard?

- There is no single federal definition of rural
- Often a bundle of ideas: population density, distance from services, small community size, economy tied to land, and a cultural identity
- Common definitions
  - *US Census Bureau* - population density
  - *Office of Management and Budget* - Metro/nonmetro status of a county
  - *Federal Office of Rural Health Policy* - Rural Urban Commuting Codes



Thesis work

- Mental health in rural communities, specifically farmers and ranchers in the Rockies
- Mental Wellness Conversation Curriculum (MWCC)
    - Conversation based mental health and wellness tool designed to be administered to rural populations by volunteers in the community
- Trained rural volunteers to administer MWCC



Photo 1

MONTANA STATE UNIVERSITY EXTENSION

Photo 2

WRASAP
Western Regional Agricultural Stress Assistance Program

Photo 3

Thesis work, continued

- Identified that barriers to care often keep people from utilizing services
- Common barriers: lack of public transportation, insurance coverage, lack of quality providers, social stigma
- Trusted messengers and community members (volunteers) could fill existing gaps in behavioral healthcare
- Bring the resource to the community, let the community (volunteers) guide the implementation



Photo 4

Deficit based > Strengths based

- Disparities are often framed with a deficit-based lens
- Rural communities present a plethora of strengths that should be leveraged
- Strong social bonds, community ties and strength, cohesion
- Deficit based frameworks keep populations stuck and can influence community and individual morale



Acknowledge disparities AND acknowledge strengths

Start with strong, not what is missing

Deficit-based thinking

- “What’s missing in this town?”
- Outside experts always bring the right answers
- Volunteers fill our gaps



Strengths-based thinking

- “What is already working here?”
- Locals are the community experts
- Volunteers lead with what they are good at and what they know





Photo 5

“Rural communities are close-knit. People know each other. They come to each other's aid. They are resilient. There are a lot of positive factors about being a rural community that can be leveraged”

- Robert Meit, Co-director of NORC Walsh Center for Rural Health

Self Determination Theory (SDT) in volunteering

- Psychological framework to better understand personality, well-being, and human motivation
- Richard Ryan and Edward Deci (1970s/80s)
- Extrinsic and intrinsic motivations both drive behavior change
- When individuals are intrinsically motivated, they participate in activities they enjoy
- When individuals receive extrinsic gain, motivation can also increase

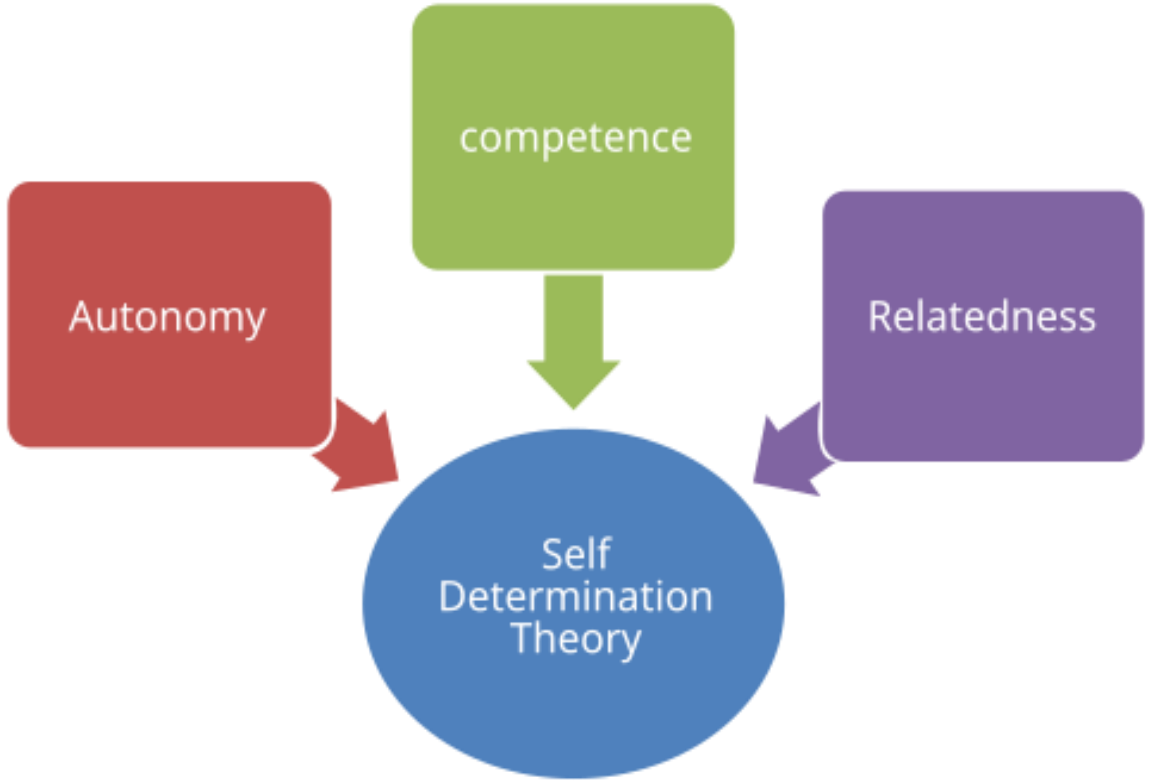


Photo 6

Autonomy

Local volunteers choose the approach that fits their town.

Competence

Start from skills people already have, then build on them.

Relatedness

Work through networks that already exist churches, schools, Ag groups, etc.

Intrinsic vs. Extrinsic

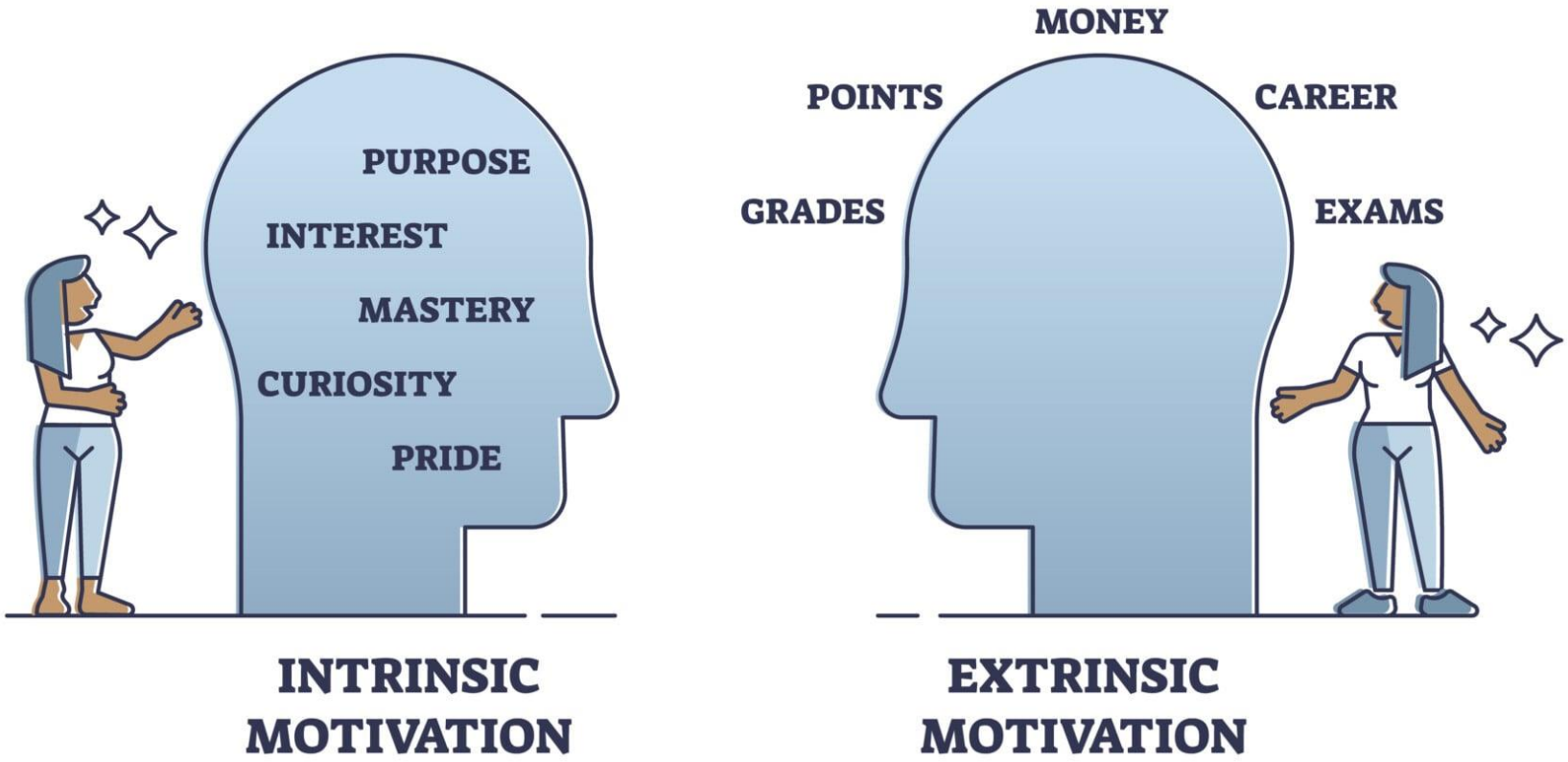


Photo 7

Extrinsic Motivation

- Gets people in the door
- Doing something for an outcome separate from the activity itself: a reward, recognition, or an obligation to someone
- Might sound like...
  - “My neighbor asked me to come”
  - “It’ll look good on my resume”
  - “They said there would be lunch”



Photo 8

Intrinsic Motivation

- What keeps people coming back
- Driven from the inside matches your values, interests, or sense of purpose
- Doing something because it is meaningful or satisfying in itself
- Might sound like…
  - “Cancer touched my family and I want to help”
  - “I care about this community”
  - “I like being the one who gets thing done and contributes”



Photo 9

Your Power

- Rural constituents/volunteers carry a lot of political weight
- Rural voices are far reaching
- Lawmakers are neighbors, not strangers
- Rural lawmakers can be the deciding votes
- Rural communities carry a significant cancer burden



In a small town, you are the ask

Ask

Invite someone you know, personally.

Welcome

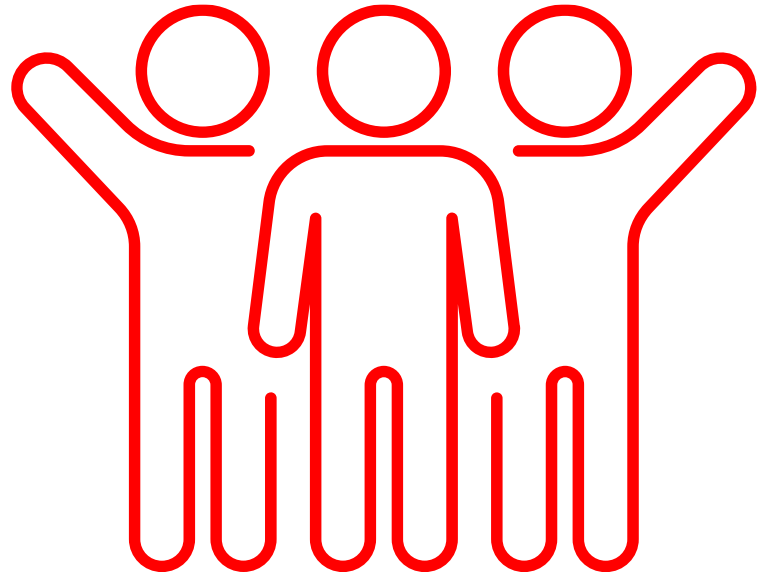
Make the first task easy and social.

Grow

Build skills and show them the impact.

Lead

Hand them ownership, they ask the next person.



Putting it to work

- Look at volunteers as the experts in their community, apply that to communication
- Leverage their expertise and networks to connect to other volunteers in their community
- Cultivate autonomy, competency, relatedness
- Don’t try and change the why



Photo 10

- Get frank about what motivates them, don't try and change it.
- At the end of the day, they are volunteering their time.
  - This is important for your college resume? *We have a place for that; we love young voices/advocates!*
  - I want to help my community? *Wonderful, let's leverage that investment.*
  - Cancer has impacted you and your family? *Thank you for sharing and being vulnerable, your story is valuable.*
- Look at every volunteer as unique individuals with interests, motivations, commitments, and ideas to bring to the team.

Capacity grows when extrinsic motivation brings people in, intrinsic motivation helps them grow into leaders.

Activity/Q&A

Sources

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Break

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Regional Media Advocacy Communications

Staff training:

Shooting B-roll and Soundbites

American Cancer Society Cancer Action Network℠

Regional Media Advocacy Communications

What is it?

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-B-Roll is video shown while a reporter or anchor is talking.

-Soundbites are clips of an individual talking in interview style.

Setting the Stage:

Tell us:
When does the media team need help with b-roll and soundbites?

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May 2025

B-roll Example



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GA CAD 2025

How it Looked on TV



American Cancer Society Cancer Action Network℠

GA CAD 2025

What did you notice in the previous b-roll video?

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Shooting B-roll

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- Hold phone horizontally
- Candid shots, no looking at camera or staging
- Want steady shots
  - Can hold your breath if possible
- Each shot should be about 5 seconds long
- Still shots; no pans or zooms



Shooting B-roll

- **Wide, Medium, Tight Shots**



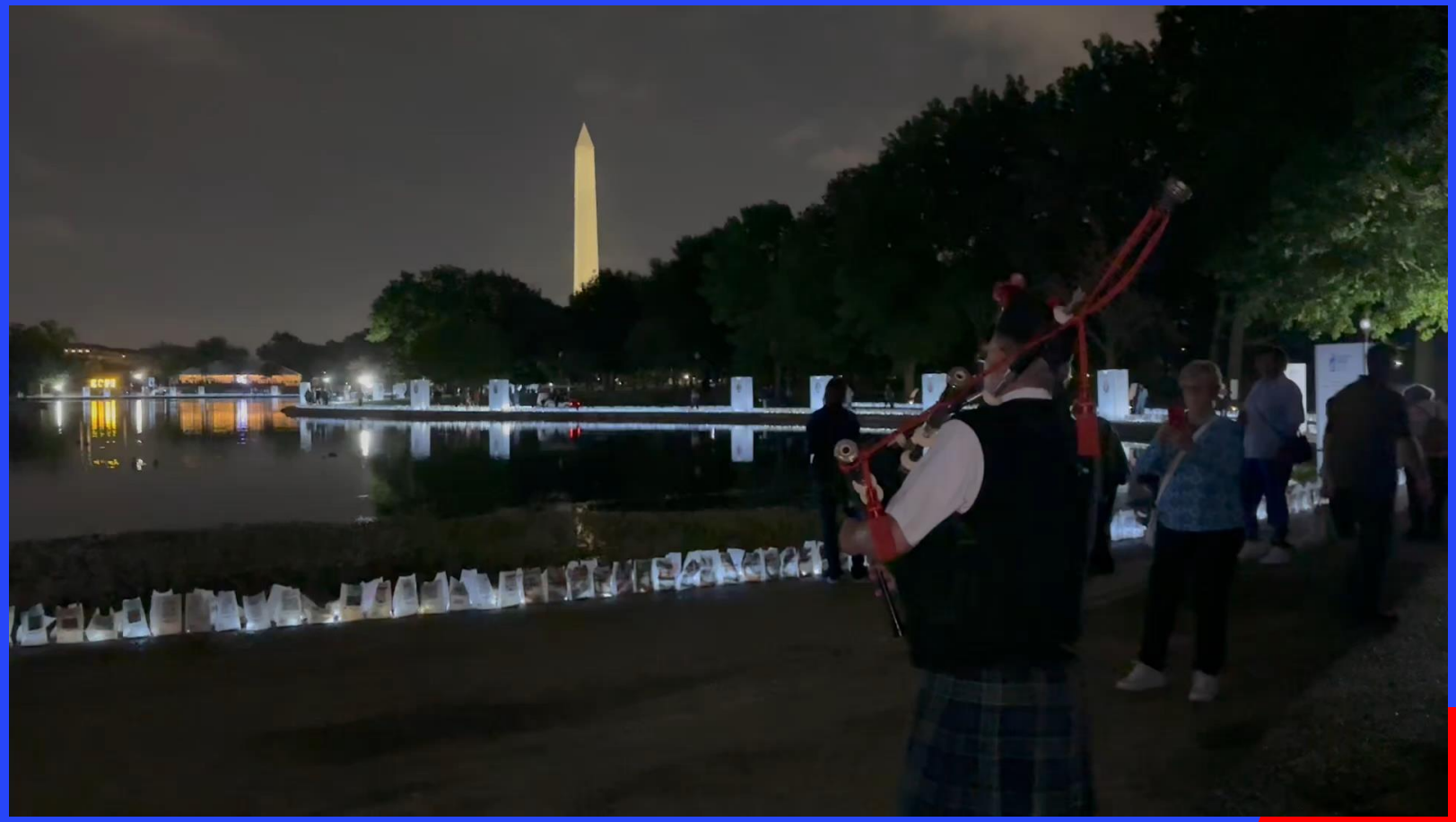
- **Show our logo**
  - **Establishment shot**



Click play above
Starts with establishment logo shot
Medium to tight shot around :23

- **Lighting: bright on the object, not in the background**

Another Example



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Lights of Hope 2024

Another Example



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CA Tobacco News Conference



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Soundbites



Shooting Soundbites

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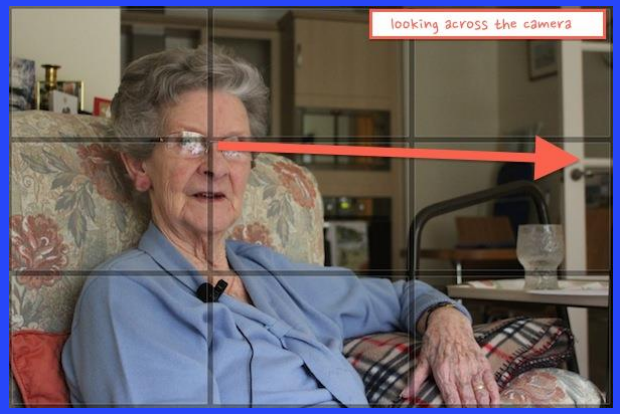
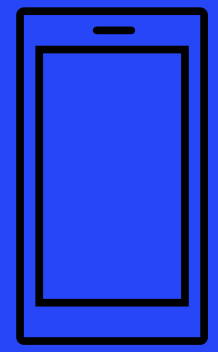
- Subject looking next to the camera, not at camera
- Hold horizontal
- Framing follows “rule of thirds”
  - Subject looking in direction of space next to head →
- Pre-write or practice





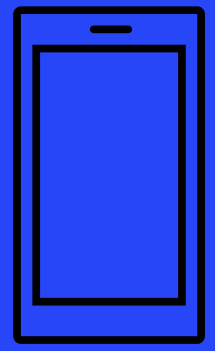
Tools

- Phone
- Helpful to have a microphone, but not necessary if recording in a quiet place
- How are you going to get the files?
  - Wetransfer, Dropbox, Google, Teams, Whatsapp, etc.
  - Work with your staff to streamline your preferred sharing method and make sure it works beforehand



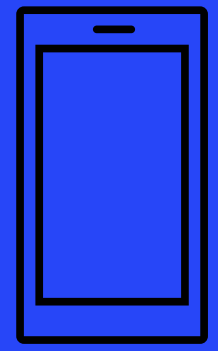
Final Key Points

- **Soundbites are the gravy on top! Prioritize B-roll, it's okay if you can't get soundbites**
- **Please send us B-roll and soundbites ASAP -- prior to the event ending. Sending right away increases our chances of earning coverage.**
- **Practice! If you have free time, send us your clips so we can give you feedback and you feel prepared! We're here to help!**



Final Key Points

- **Plan!**
  - **Think about b-roll shooting in your discussions about any activity that could get media attention.**
  - **Identify the staff member who will shoot b-roll ahead of time.**



Questions

Thank You

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From Discovery to Delivery

American Cancer Society Cancer Action Network℠

From Discovery to Delivery

Closing the Gap in Cancer Care

Scientific progress matters when patients and families can benefit from it.



Ruben Rathnasingham
Executive Director, Jen-Hsun Huang and Lori Mills Huang Collaborative Innovation Complex
Oregon State University

Oregon State University

The Patient Experiences One Journey, Not Separate Systems

Gaps can appear at every step of cancer care

Understand risk	When and why should someone seek screening?
Access care	Can they reach screening and specialists?
Make a decision	Does the evidence fit this patient?
Navigate treatment	What happens next for patient and caregiver?
Live well	Is support there during treatment and survivorship?

One gap can delay care. Several gaps can shape an outcome.

Closing the Gap Requires Two Kinds of Progress

Better science and better delivery must advance together

DISCOVERY

Generate evidence

Test new approaches

Measure effectiveness

DELIVERY

Reach people

Fit real care settings

Earn trust in use

Discovery matters when care teams and communities can use it.

Volunteers Help People Cross the Gaps

Volunteers turn awareness, advocacy and relationships into action



Trusted guides

Explain screening, services and next steps.



Community connectors

Bring lived experience and local barriers into decisions.



Agents of change

Advocate for access, participation and better systems.

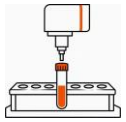
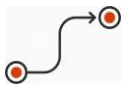


Volunteers can see barriers that institutions miss.

Oregon State University

Oregon State University Connects Research Across the Cancer Journey

From prevention and detection to treatment and survivorship

 **Prevent**	Exposures, nutrition, vaccination, screening and policy
 **Detect**	Imaging, biomarkers, diagnostics and data science
 **Treat**	Tumor biology and experimental nanomedicine
 **Navigate and live well**	Care navigation, survivorship and health equity

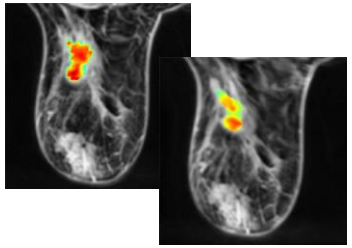
Connect research with questions from patients and communities.

Oregon State University

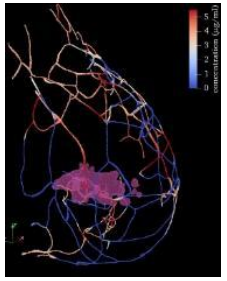
Cancer Is Not One Disease, and Patients Are Not Averages

Exploring patient-specific predictions to inform decisions

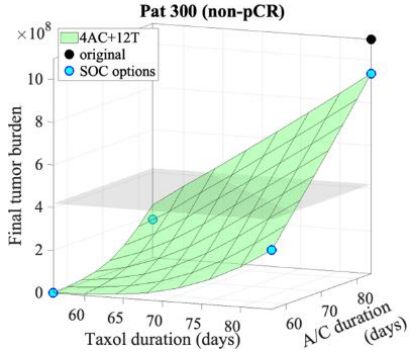
01 PATIENT MRI



02 TUMOR MODEL



03 PREDICTION



04 SHARED DECISION



Oregon State University

Better Prediction Can Build Trust

Evidence should be relevant, understandable and accountable



Relevant to the patient

Who was represented in testing?



Transparent about uncertainty

What does the prediction leave uncertain?



Tested in real settings

Where was the tool tested in care?



Used with human judgment

How do patients and clinicians use the result?

These questions help people judge whether evidence is useful.

Oregon State University

Models Can Fail When Training and Care Data Differ

Training-like images

Similar, curated close-ups



Care-setting variation

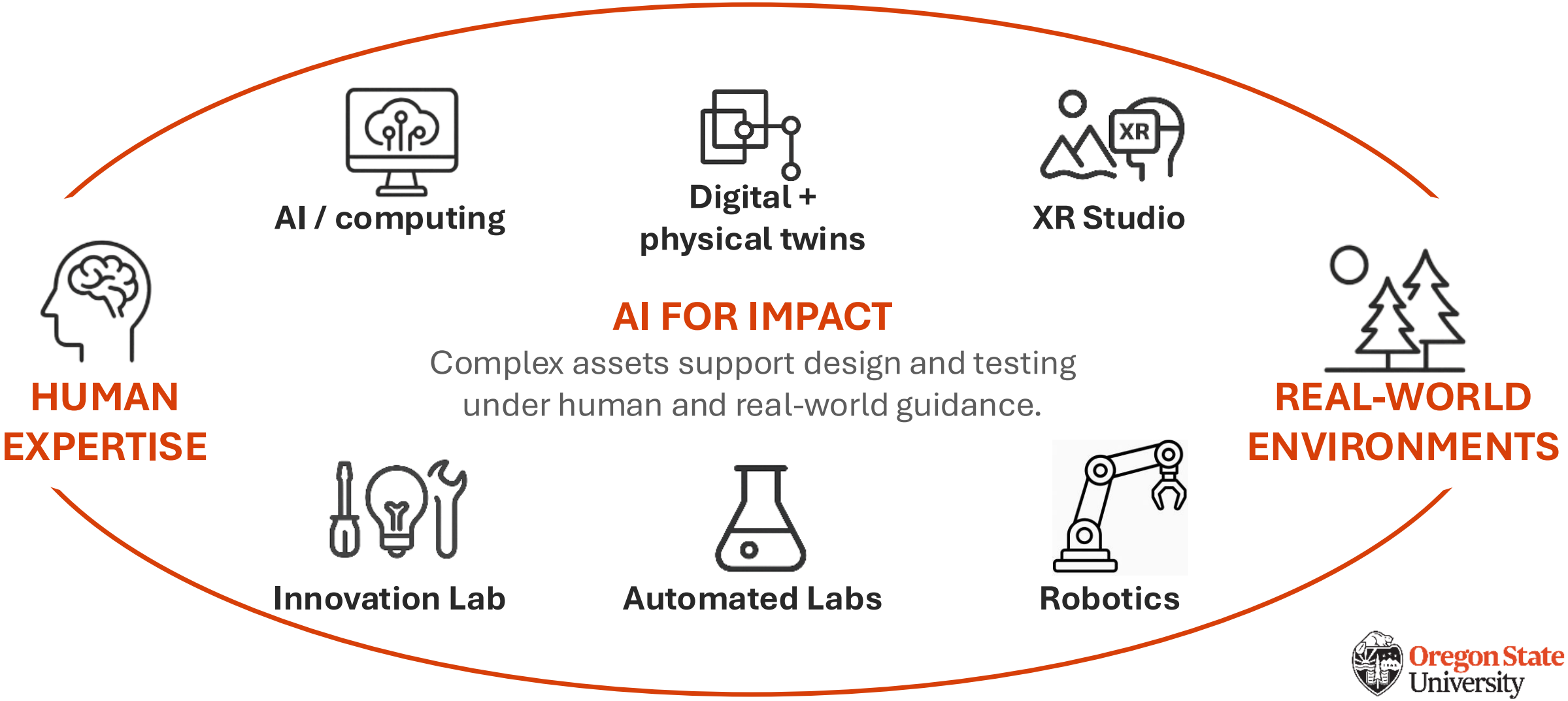
Different body sites and views



Oregon State University

The Huang Complex Could Test Ideas in Real Care

Human expertise and real conditions guide the work



Oregon State University

A Proposed Pilot Could Bridge Cancer-Care Gaps

Illustrative idea: improve follow-up after an abnormal screen



Recognition
Advocates identify missed follow-up.

Access
Care teams map referral barriers.

Translation
Researchers test clearer next steps.

Trust
Patients check clarity and usefulness.

Proposed measures: time to next step and patient understanding.

Create the Next Ripple With Us

Bring a barrier, a relationship and a question

Bring a barrier

Where are people being missed or left uncertain?

Bring a relationship

Who must be involved from the beginning?

Bring a focused question

What could we learn or test together?

From Discovery to Delivery

Closing the Gap in Cancer Care

Scientific progress matters when patients and families can benefit from it.



Ruben Rathnasingham
Executive Director, Jen-Hsun Huang and Lori Mills Huang Collaborative Innovation Complex
Oregon State University

Oregon State University

See you at dinner!

American Cancer Society Cancer Action Network℠

Good Morning Reflections

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Power of Storytelling

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American Cancer Society Cancer Action Network℠

Own Your Power:

Turn Your Story Into Impact

Why We Collect Stories

- Stories put a face behind an issue
- Identify a community's needs
- Empower people, families, and communities to use their voices and advocate.
- Challenge assumptions and misconceptions.
- Personalize an issue and dispel myths.
- Influence decision makers, media, and community leaders.

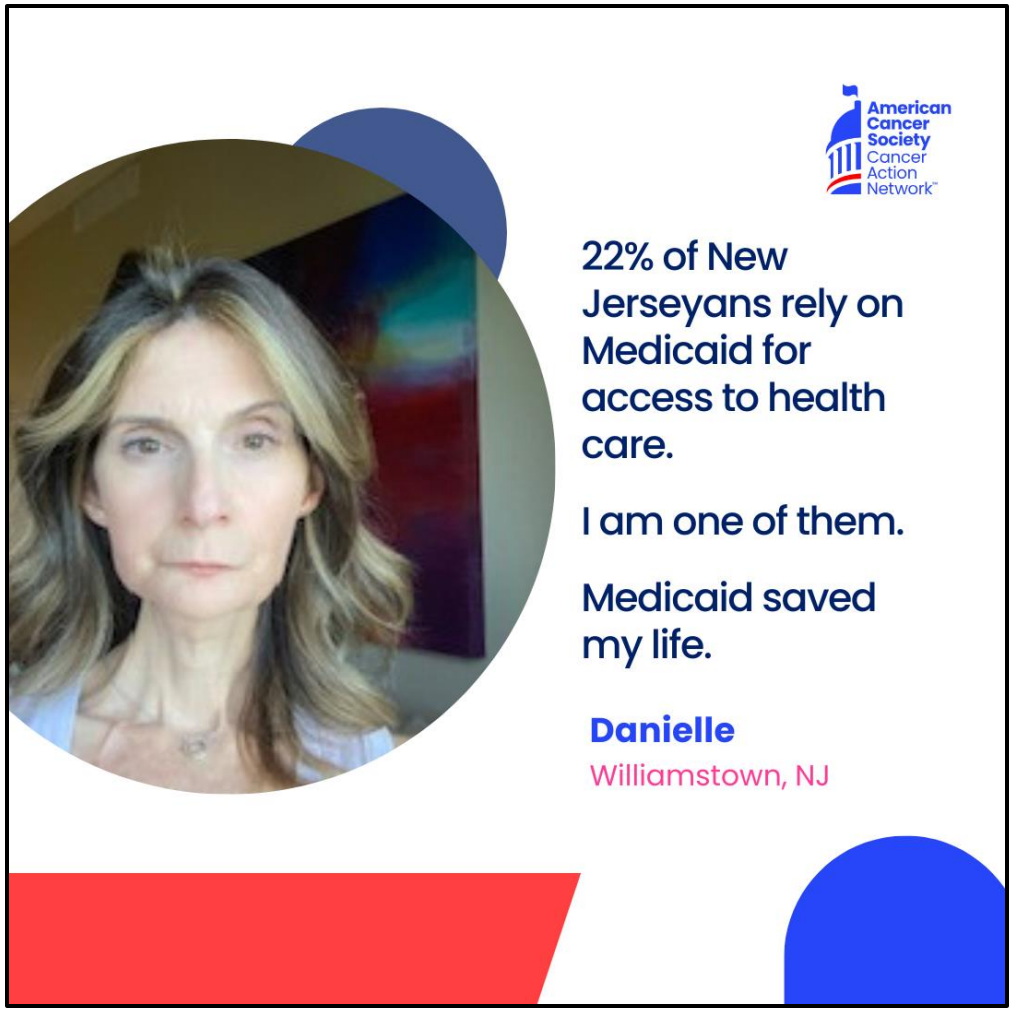








Stories Educate





Stories Educate

The Costs of Prostate Cancer

Cancer takes a huge physical toll on people facing the disease and comes with many costs. This fact sheet explores the costs of prostate cancer, which is the most common cancer among men in the U.S. (after skin cancer).

The financial costs of cancer do not impact all people with cancer equally. Evidence consistently shows that certain factors impact cancer diagnosis, treatment, survival and financial hardship experienced by people with a cancer history and their families:

- Age
- Race/ethnicity
- Sexual orientation
- Health insurance status
- Family income
- Where you live
- Cancer type

Men with a history of prostate cancer incur more health care expenses and pay more out-of-pocket annually than men who have never had cancer.

Men with a prostate cancer history between the ages of 18-64 years incur almost triple the amount of overall health care expenditures as those men who have never had cancer. Older men with a history of prostate cancer also incur more expenses.[1] Additionally, men who are diagnosed with later-stage prostate cancer have higher average expenditures than those diagnosed at earlier stages.[2]

Annual Average Health Care Expenditures, 2018-2020

The Costs of Cancer in My Own Words

John Bushnell

Texas



A prostate cancer diagnosis didn't surprise John Bushnell, of Seguin, Texas. "I assumed I'd have cancer by age 60." That's when his father received a diagnosis of advanced prostate cancer. John's maternal grandfather and paternal uncle also had prostate cancer. John's father endured intense radiation treatment that damaged his bladder and intestines. He spent the last eight months of his life in a hospital. So, John started screening at age 40. A routine check after his 50th birthday revealed elevated PSA levels. Additional tests and a biopsy confirmed aggressive, yet localized, prostate cancer.

John was a full-time, unpaid caregiver for his mother at the time. With no health insurance, he was also responsible for the full cost of his care. He was able to negotiate with the



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Stories Move Decision Makers

American Cancer Society Cancer Action Network℠

American Cancer Society Cancer Action Network

Research is a Lifeline for Cancer Patients in Maine: A Storybook








Introduction

This year, around 11,080 Mainers are expected to be diagnosed with cancer. For years there has been a bipartisan commitment to reliable funding for our leading researchers and their institutions. But the current actions that have frozen funding, slashed staffing, and the talk of future funding cuts for lifesaving cancer research is unacceptable. These cuts will have life-threatening consequences. Fewer people will have access to clinical trials; researchers on the cusp of new discoveries will be forced to shut off the lights; hope will be lost.

Cuts have consequences. And those consequences are life threatening for cancer patients who could be waiting for the next clinical trial or research breakthrough, including many who share their stories in this book. **As our voice in Congress, we ask that you stand up for continued progress in the fight against cancer, not take us backward.**

Closing the Health Insurance Gap in North Carolina

American Cancer Society Cancer Action Network



Dr. Arif Kamal

Chief Patient Officer, American Cancer Society
Oncologist, Duke Cancer Center
Chapel Hill, NC

"Cancer is curable if it's caught early, and it's only caught early if it's screened for, and screening requires appropriate health insurance. That's why Medicaid expansion is so crucial for North Carolina."

Stephanie

Kinston, NC

"At our clinic we think a lot about the word 'quality.' Quality of health. Quality of life. Medicaid was created to provide that quality to those without the resources to access it otherwise."



For more information contact John Broome, Government Relations Director, ACS CAN at John.Broome@cancer.org.

Ohio Cancer Action Day 2022

POLICY OVERVIEW AND LEGISLATIVE ASK

20 YEARS Cancer Action Network

Biomarker Testing

Understanding biomarker testing

A "biomarker" is a sign of a normal biological process, disease or abnormal function that can be measured in blood, tissue or other biospecimen. Biomarker testing is an important step for accessing precision medicine including targeted therapies that can lead to improved survivorship and better quality of life for cancer patients. Timely access to appropriate biomarker testing can help achieve better health outcomes, improve quality of life and reduce costs by connecting patients to the most effective treatment for their cancer.

Ensure biomarker testing is available to all Ohioans who need it

Biomarker testing is a key to unlocking precision or personalized medicine. Therapies can be targeted using information about a person's own genes or proteins to treat diseases like cancer. Biomarker testing is part of standard of care treatment for many cancer patients, but insurance coverage for biomarker testing is failing to keep pace with innovations and advancements in treatment.

2022 Ask: Will you support HB XXX to expand appropriate coverage of biomarker testing for public and private insurance plans?

Quick Facts:

- Nearly 60% of all cancer drugs approved in the last 5 years require or recommend biomarker testing before use.
- The number and percentage of cancer clinical trials that involve biomarkers has grown significantly, from 15% in 2000 to 55% in 2018.
- In a 2021 survey, 68% of oncology providers reported that insurance coverage for biomarker testing is a significant or moderate barrier for their patients to access biomarker testing.

Patient Perspective:

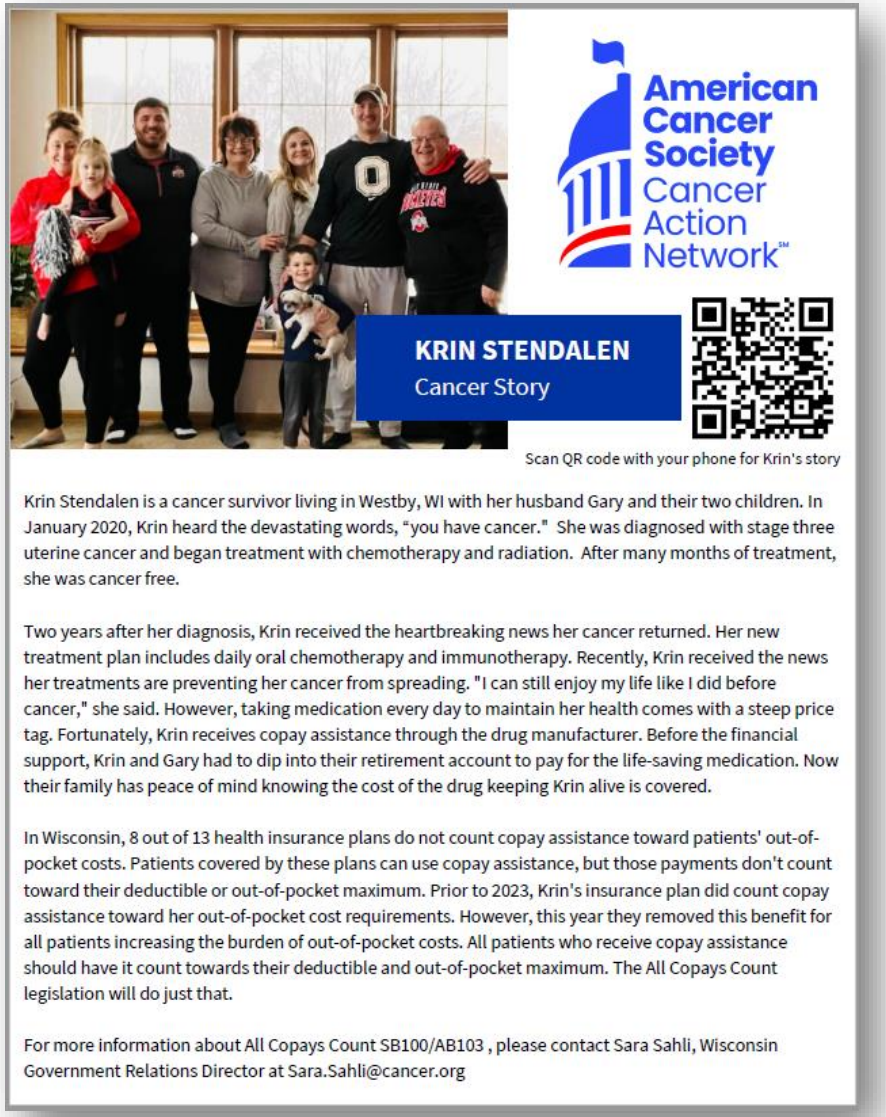


"In 2017, at the age of 47, I was diagnosed with prostate cancer. After my biopsy, the urologist sent samples of my tumor to the lab, not just for the "normal" testing to confirm the cancer diagnosis, but also for biomarker testing to determine the aggressiveness of the cancer. With those results, I was armed with even more information to help me make decisions about my treatment options. **Biomarker testing is such a valuable resource for cancer patients and should be an accessible option for all Ohioans who need it.**"

-Tom Fuoss, Springfield

Stories Move Decision Makers





Krin Stendalen is a cancer survivor living in Westby, WI with her husband Gary and their two children. In January 2020, Krin heard the devastating words, “you have cancer.” She was diagnosed with stage three uterine cancer and began treatment with chemotherapy and radiation. After many months of treatment, she was cancer free.

Two years after her diagnosis, Krin received the heartbreaking news her cancer returned. Her new treatment plan includes daily oral chemotherapy and immunotherapy. Recently, Krin received the news her treatments are preventing her cancer from spreading. "I can still enjoy my life like I did before cancer," she said. However, taking medication every day to maintain her health comes with a steep price tag. Fortunately, Krin receives copay assistance through the drug manufacturer. Before the financial support, Krin and Gary had to dip into their retirement account to pay for the life-saving medication. Now their family has peace of mind knowing the cost of the drug keeping Krin alive is covered.

In Wisconsin, 8 out of 13 health insurance plans do not count copay assistance toward patients' out-of-pocket costs. Patients covered by these plans can use copay assistance, but those payments don't count toward their deductible or out-of-pocket maximum. Prior to 2023, Krin's insurance plan did count copay assistance toward her out-of-pocket cost requirements. However, this year they removed this benefit for all patients increasing the burden of out-of-pocket costs. All patients who receive copay assistance should have it count towards their deductible and out-of-pocket maximum. The All Copays Count legislation will do just that.

For more information about All Copays Count SB100/AB103 , please contact Sara Sahli, Wisconsin Government Relations Director at Sara.Sahli@cancer.org

Stories Build Public Awareness

The New York Times

Democrats' Bill Would Go Far Toward 'Patching the Holes' in Health Coverage

Taken together, the provisions in the social policy bill represent the biggest step toward universal coverage since the passage of the Affordable Care Act.



Tim Floyd lives in one of 12 states where Republicans have refused to expand Medicaid, making health insurance even less accessible for an estimated 2.2 million low-income adults. Andrea Morales for The New York Times

Erasing the 'Coverage Gap' for Poor Adults

Tim Floyd of Guntown, Miss., was working construction jobs in



Stories Build Public Awareness



Stories Inspire Communities

American Cancer Society Cancer Action Network℠





Stories Help Us Listen

Stories don’t just help us communicate.

They help us discover.

Stories reveal:

- Barriers to care
- Confusion
- Misinformation
- Unintended Consequences
- Emerging Issues







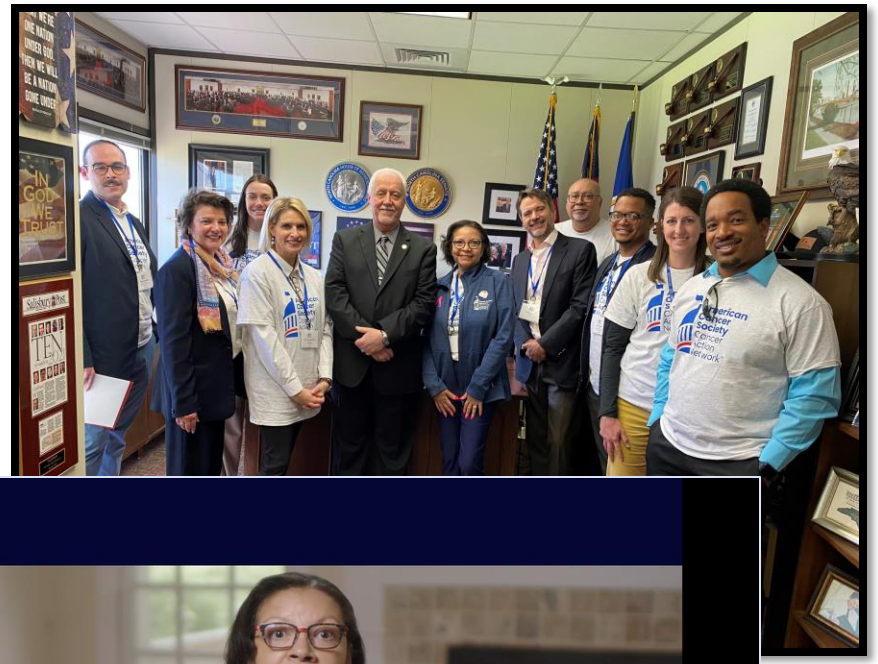


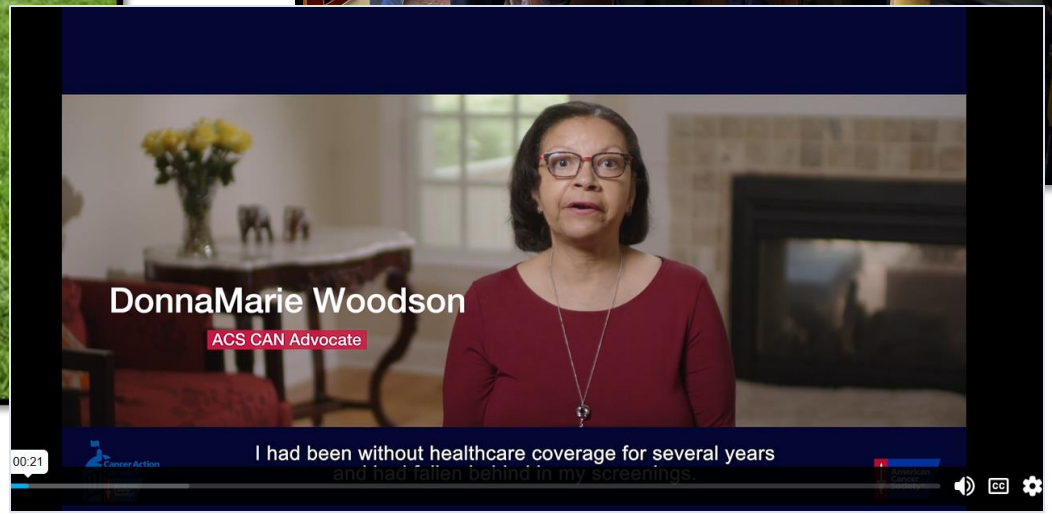
One Story. Many Possibilities

DonnaMarie, a long time ACS CAN volunteer, shared her breast and colon cancer story.



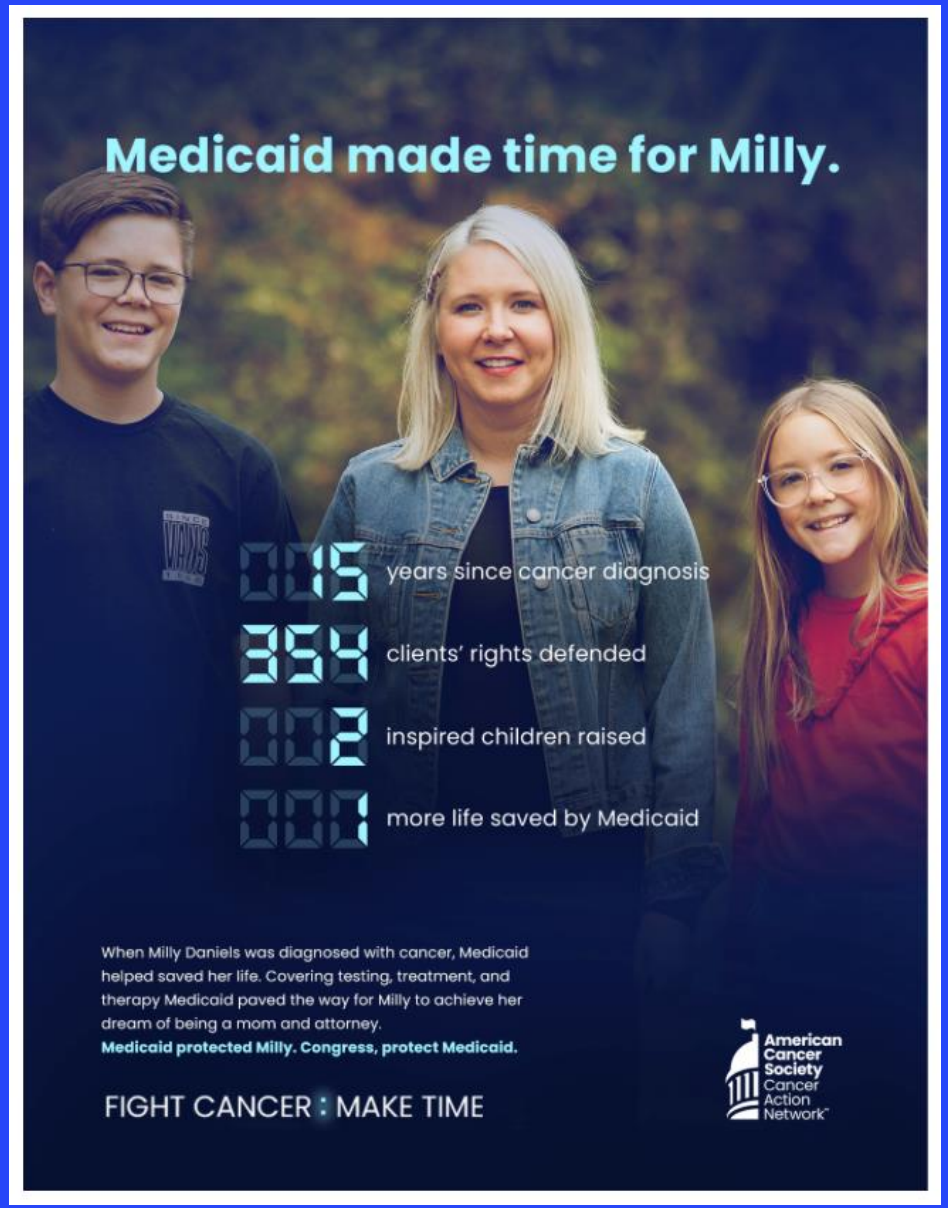






How we collect stories

- Build rapport
- Listen more than talk
- Ask follow-up questions
- Capture feelings – not just facts
- Don’t worry about getting the perfect wording.
- Maintain the connection.
- Always obtain consent when sharing their story.



Crafting your story

Sharing My Story

American Cancer Society Cancer Action Network

Introduction
Share your name, age, city, state.

What Happened?
In 3 to 10 sentences, start at the beginning of your cancer journey and move through your treatment and survivorship. What was the experience like for you? For your family, friends, and community?

The Impact
In 1 to 5 sentences, share a little about what your life was like before cancer. What plans did you change due to your cancer treatment? How has your life and your family's lives changed due to cancer?

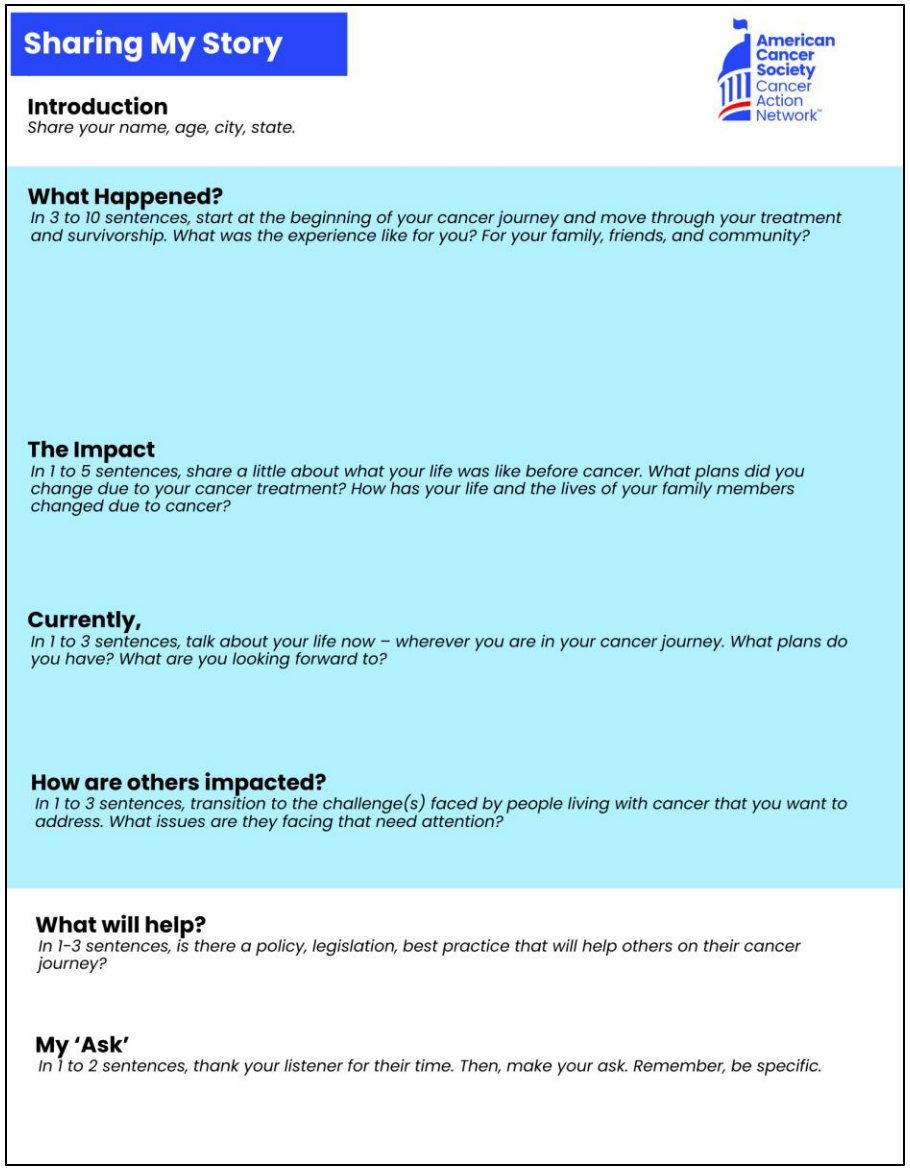
Currently,
In 1 to 3 sentences, talk about your life now – wherever you are in your cancer journey. What plans do you have? What are you looking forward to?

How are others impacted?
In 1 to 3 sentences, transition to the challenge(s) faced by people living with cancer that you want to address. What issues are they facing that need attention?

What will help?
In 1-3 sentences, is there a policy, legislation, best practice that will help others on their cancer journey?

My 'Ask'
In 1 to 2 sentences, thank your listener for their time. Then, make your ask. Remember, be specific.

Hook, Line, Sinker Method



Sharing My Story

American Cancer Society Cancer Action Network

Introduction
Share your name, age, city, state.

What Happened?
In 3 to 10 sentences, start at the beginning of your cancer journey and move through your treatment and survivorship. What was the experience like for you? For your family, friends, and community?

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My 'Ask'
In 1 to 2 sentences, thank your listener for their time. Then, make your ask. Remember, be specific.

Hook

Line

Sinker

Turning a Long Story into Advocacy



60 Seconds for Impact

Hi, I'm _____, I'm from _____.
I'm sharing my story as a _____.
(patient, survivor, parent, caregiver, provider, supporter)
Cancer became part of my life when

_____.
(diagnosis, supporting a loved one, providing care, etc.)
At the time, I was

_____, and everything changed.
(what was happening in your life)
One of the hardest parts of this experience was

_____.
(physical, emotional, financial, caregiving, or professional challenge)
Because of this experience, I've learned how important it is to

_____.
(support others, advocate, listen, speak up, provide care)
That's why I care about

_____.
(issue or change you want to see)
I'm speaking up today to help make sure

_____.
(your "why" / what needs to change)
Thank you for listening. I'd appreciate it if you could

_____.
(specific action to take)

Every Story Matters

- Every advocate has a story.
- Every caregiver has a story.
- Every provider has a story.
- Every volunteer has a story.
- Every patient has a story.









Questions?

Thank you!

ACS CAN Federal Priorities: Your Voice in Action

Maggie Osborne
Director, Grassroots Organizing

American Cancer Society Cancer Action Network℠

PNW Summit

ACS CAN Policy Areas

American Cancer Society Cancer Action Network℠



Access to Care



Access to Cures



Tobacco Control

Eliminating health disparities + building health equity

Our Impact

American Cancer Society Cancer Action Network℠



62.7%
of the U.S. population protected from secondhand smoke exposure by local or statewide smoke-free laws.



34%
decline in cancer death rates from 1991-2023



33.5 million
people benefited from expanded access to health insurance

Key Priorities

Clinical Trials Moderanization Act



Action through advocacy

Cancer Research and Prevention



Funding for Cancer Research and Prevention

For the past 50 years…

every major scientific advancement in the fight against cancer has been in some way funded by the federal government.

American Cancer Society Cancer Action Network℠

American Cancer Society Cancer Action Network℠

Federal funding for cancer research is at risk.



American Cancer Society Cancer Action Network℠

Federal funding for cancer research is at risk.



Funding for Cancer Research and Prevention

American Cancer Society Cancer Action Network℠

NIH NATIONAL CANCER INSTITUTE

- Funds and leads biomedical research & clinical trials across nation
- Key to reducing the nation's cancer mortality rate by 34% since 1991
- Creates jobs and spurs economic growth

ARPA-H

- "High potential, high impact" research not traditionally supported by NIH or NCI
- Potential for transformative breakthroughs in cancer and other diseases

CDC

- Programs include cancer registries, breast and cervical screening programs, and tobacco control and cessation services
- Reduces substantial cost of advanced disease

Sign the petition.

American Cancer Society Cancer Action Network℠

Progress in the fight against cancer is possible, but not guaranteed. Cancer research is delivering lifesaving breakthroughs, treatments and cures, but that progress depends on consistent increased federal funding. Cancer patients and their families cannot wait. Reject any cuts to funding and increase cancer research funding in the next budget bill.

Congress: Progress is Possible, Fund Cures

Clinical Trial Modernization Act

Patient Barriers to Clinical Trial Participation

- **89%** would be more likely to enroll with financial support
- **93%** say trial location affects participation
- Rural patients are **2x more likely** to lack local trial access
- Rural patients travel **2.5x farther** for trials



CTMA addresses barriers

1. Awareness
2. Everyday & Medical Costs
3. Time and Travel
4. Financial Security

What the Bill Does

- Supports enrollment among historically underrepresented populations
- Allows coverage of **essential participation costs** (food, transportation, lodging)
- Permits payment of **copays and co-insurance** tied to trial participation
- Enables **remote monitoring**, reducing unnecessary travel
- Makes up to **$2,000 in trial payments tax-exempt** while preserving Medicaid eligibility







American Cancer Society Cancer Action Network℠

Nishith Pandya
Director, Federal Advocacy

American Cancer Society Cancer Action Network℠

Urge your lawmakers to help more cancer patients participate in clinical trials





Thank you!

State Actions

Your staff partner is a resource for:

- Federal legislative priorities
- State legislative priorities
- Advocacy Actions

American Cancer Society Cancer Action Network℠

State Specific Planning

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Safe travels!

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