Opportunities for Cancer Control and Care Delivery: Extra Focus on Rural Counties

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VANDERBILT-INGRAM CANCER CENTER

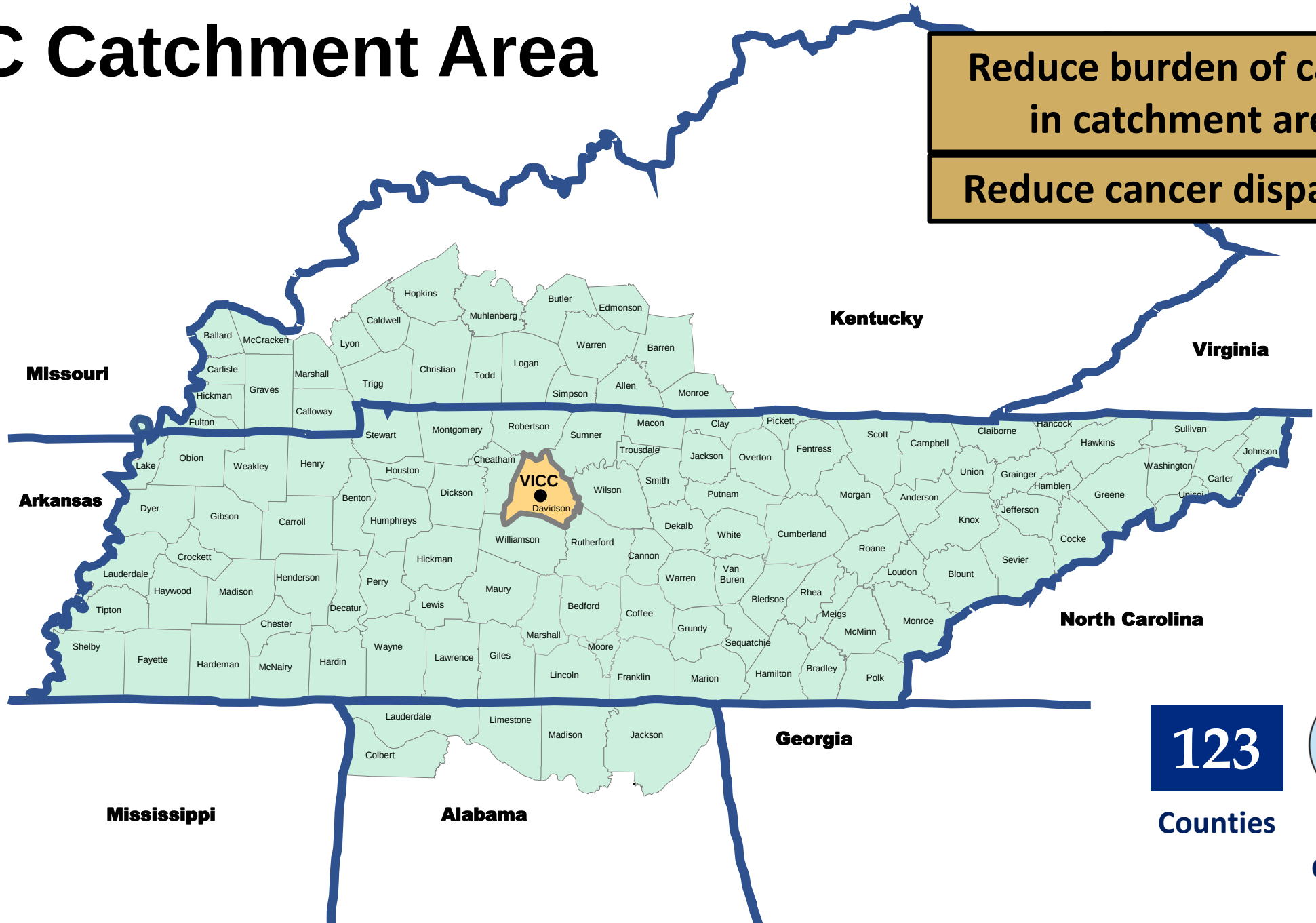
Meharry-Vanderbilt-TSU Cancer Partnership

RURAL CANCER CONTROL RESEARCH

VICC Catchment Area

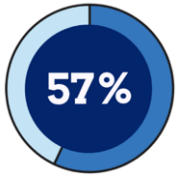
Reduce burden of cancer in catchment area

Reduce cancer disparities



123

Counties



Rural Counties

Aims

Aim 1 Conduct a multi-level needs assessment in rural counties in the VICC catchment area

Aim 2 Establish network of rural health care providers and pilot–test telehealth initiatives

Community Engagement

VICC Community Advisory Board

Community organizations and patient advocates across TN, KY, AL

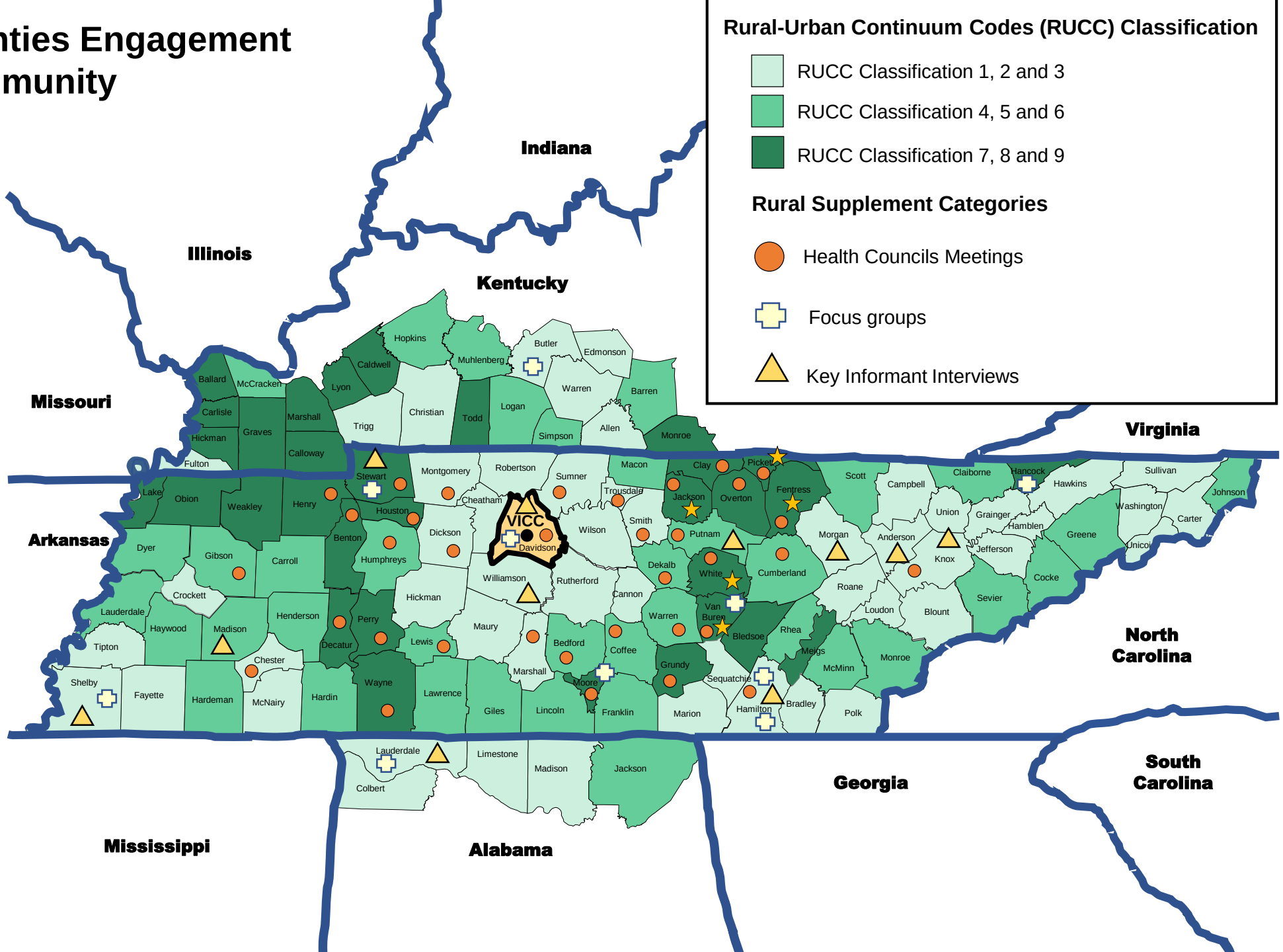
Facilitates building collaborations with partners in new areas

MVT Cancer Partnership CAB

Community members, survivors and organizations from Nashville area

Advice on culturally-appropriate research and community engagement strategies

Rural Counties Engagement In the Community



Advisory, Focus Groups & Key Informant Interviews

Top Needs:

1. Access to educational information
   - Nutrition & behavioral changes to decrease cancer risk (prevention) & enhance health after cancer care
2. Barriers to care
   - Fear of detecting cancer, lack of education
   - Distance to facilities, inadequate transportation
   - Insurance concerns
3. Better support for patients and caregivers
   - Support groups and patient navigators

Recommended strategies:

- Access Barriers: Telehealth services and local on-site patient navigators
- Improved coordination between oncology and primary care

Community Hospital Surveys

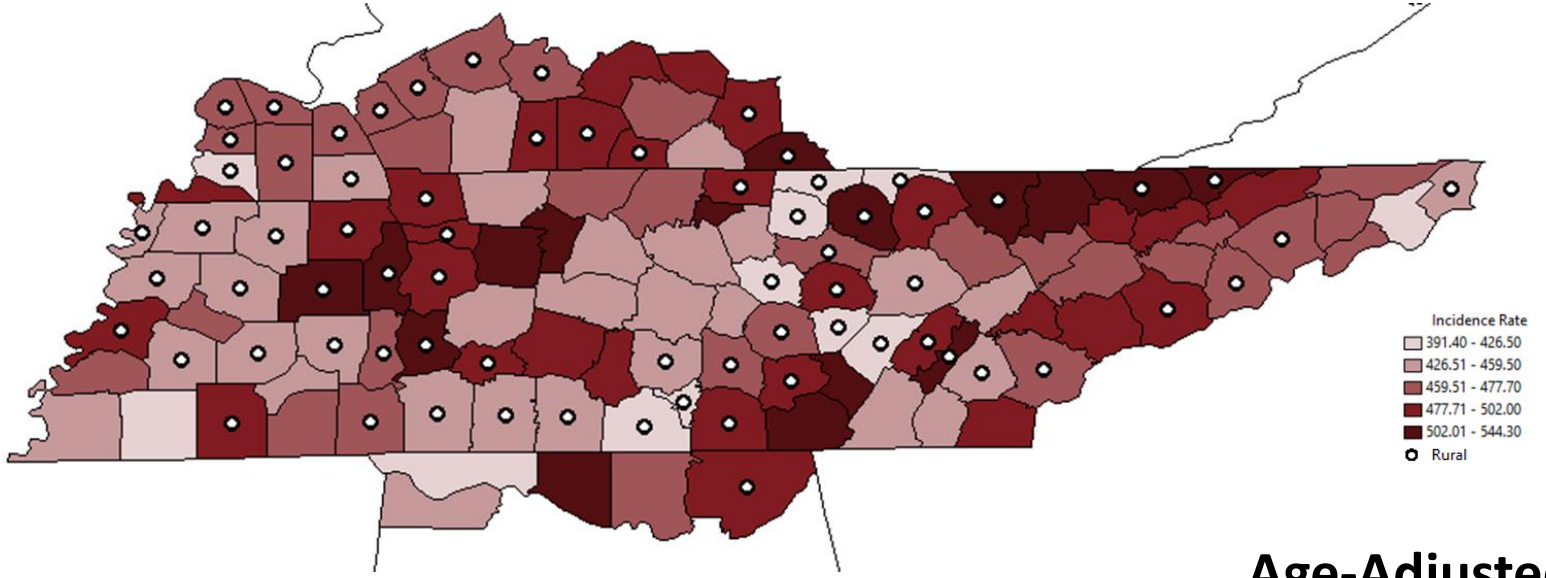
State and Federal Sources

Stakeholder Telehealth Surveys

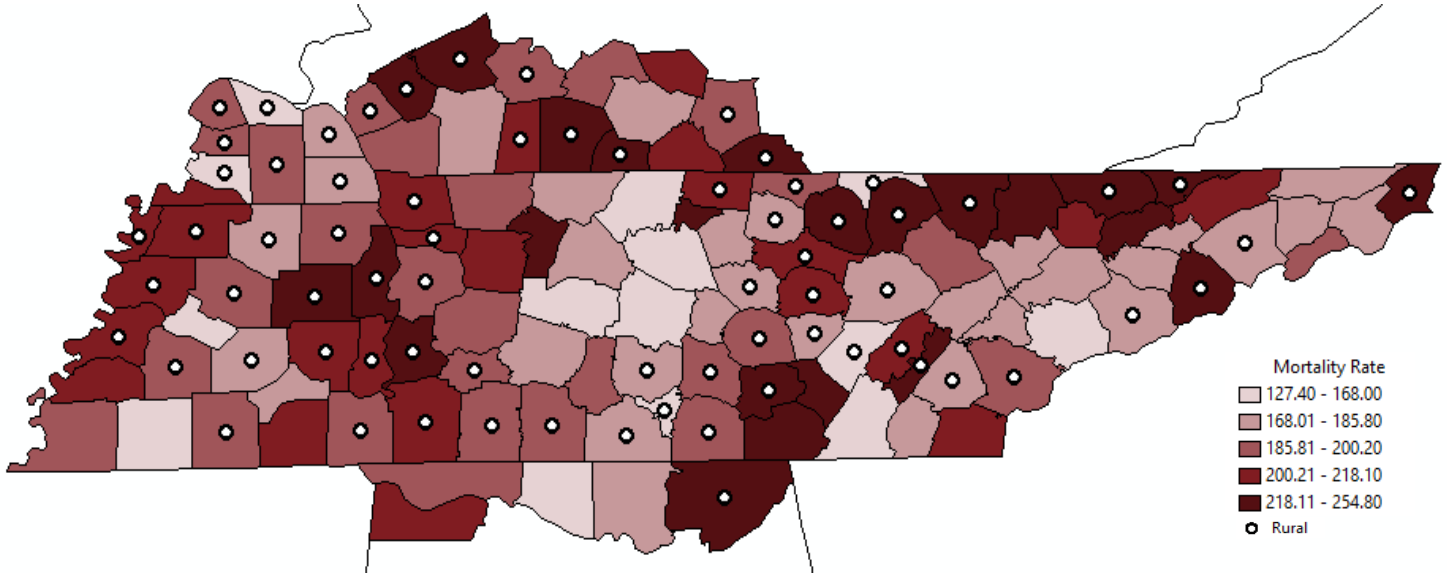
Primary and Secondary Data Collection

Age-Adjusted Incidence, 2011-2015

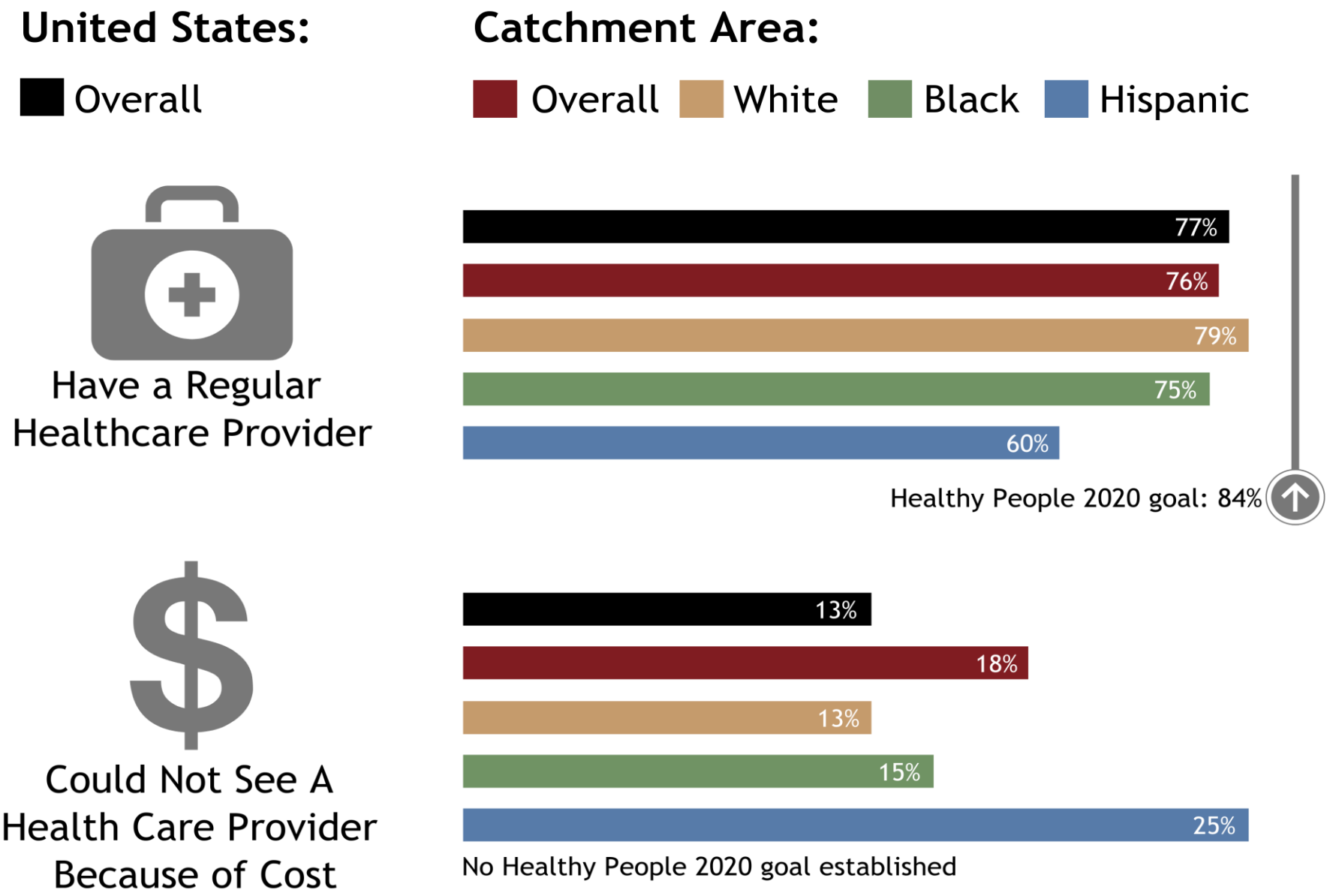
Overall Cancer



Age-Adjusted Mortality, 2011-2015



Health Care, Health Behavior and Prevention



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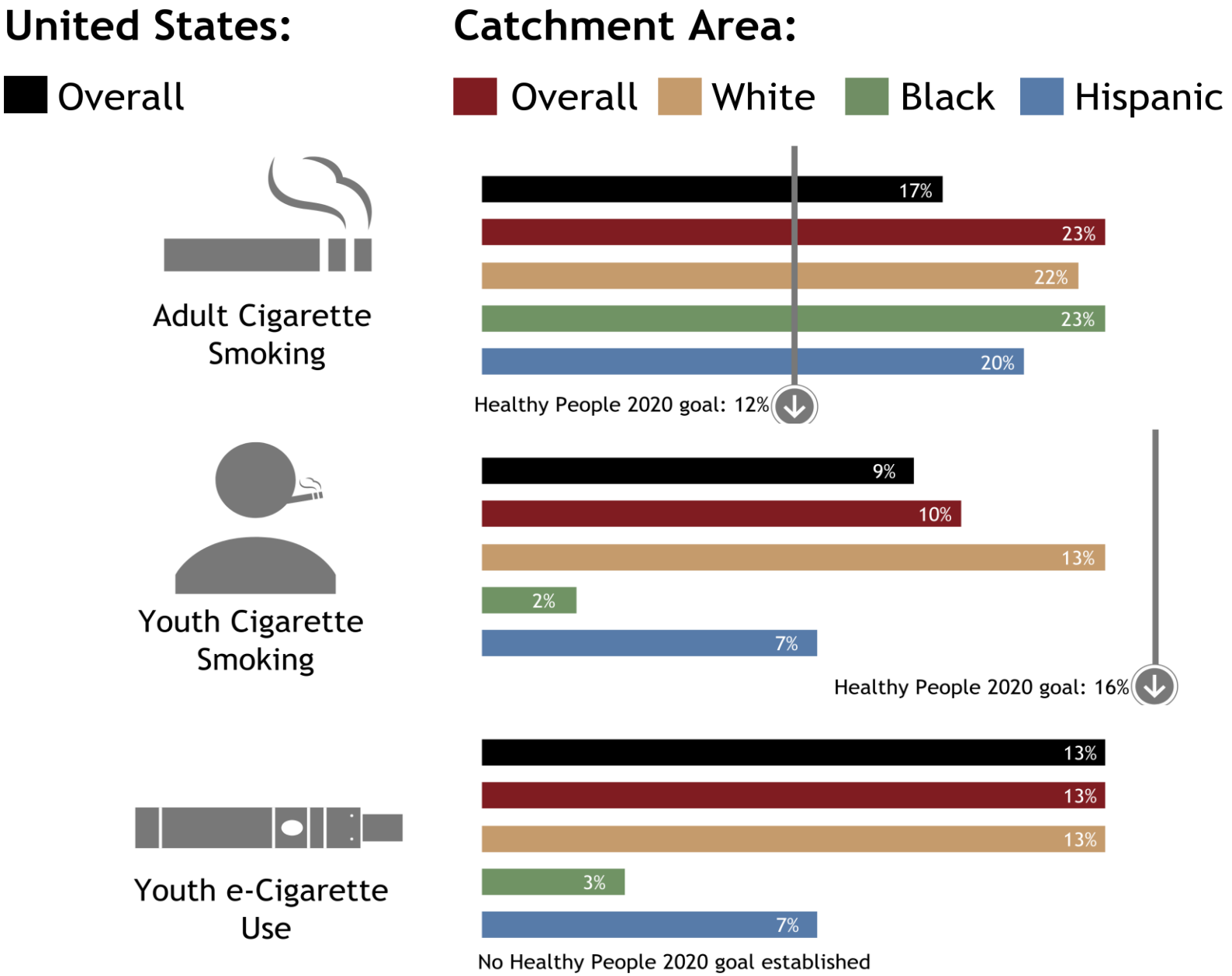


Health Care, Health Behavior and Prevention

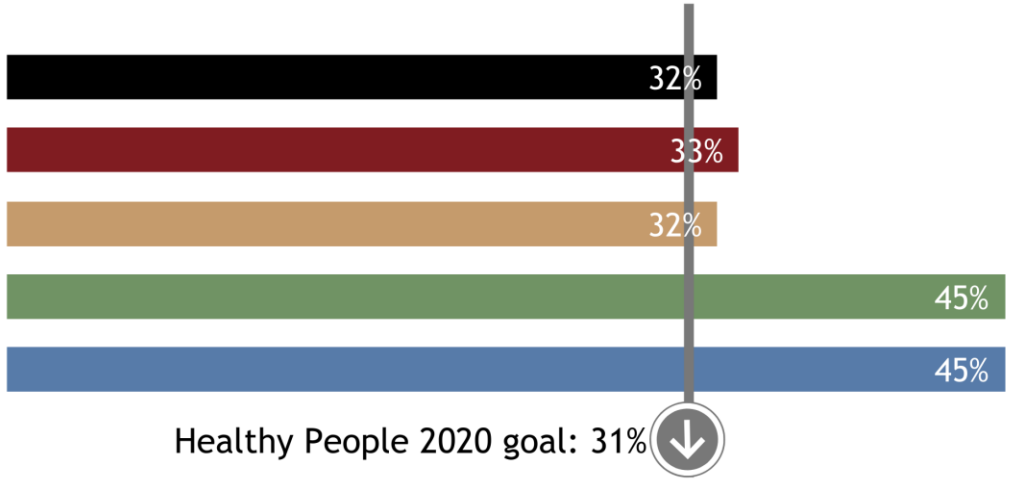
United States:

Overall

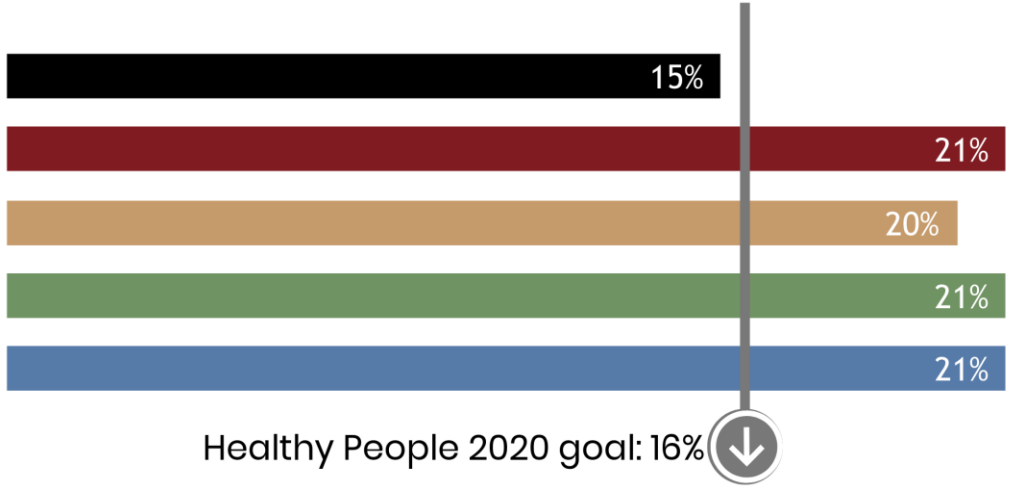
Catchment Area:

Overall White Black Hispanic

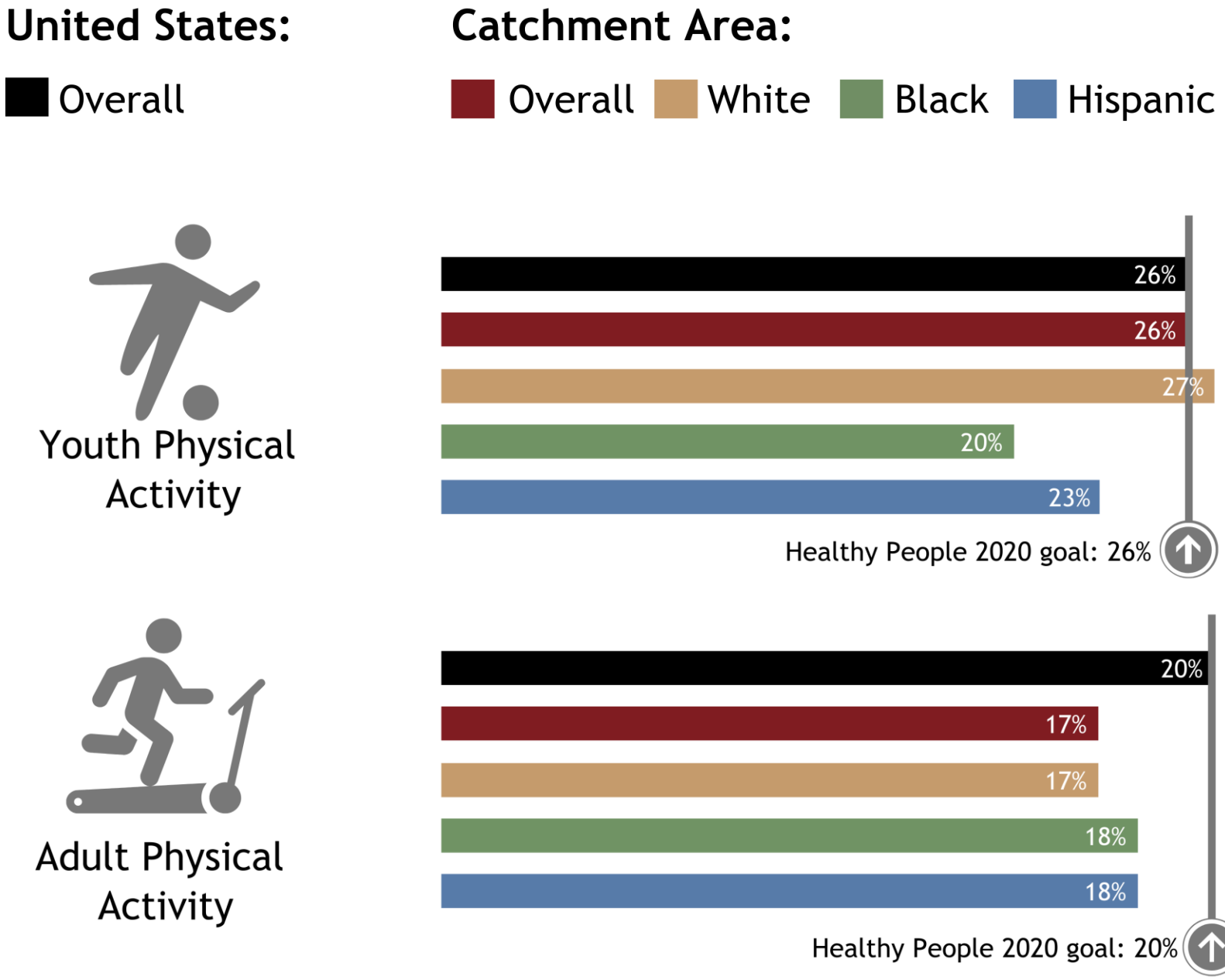
Adult Obesity



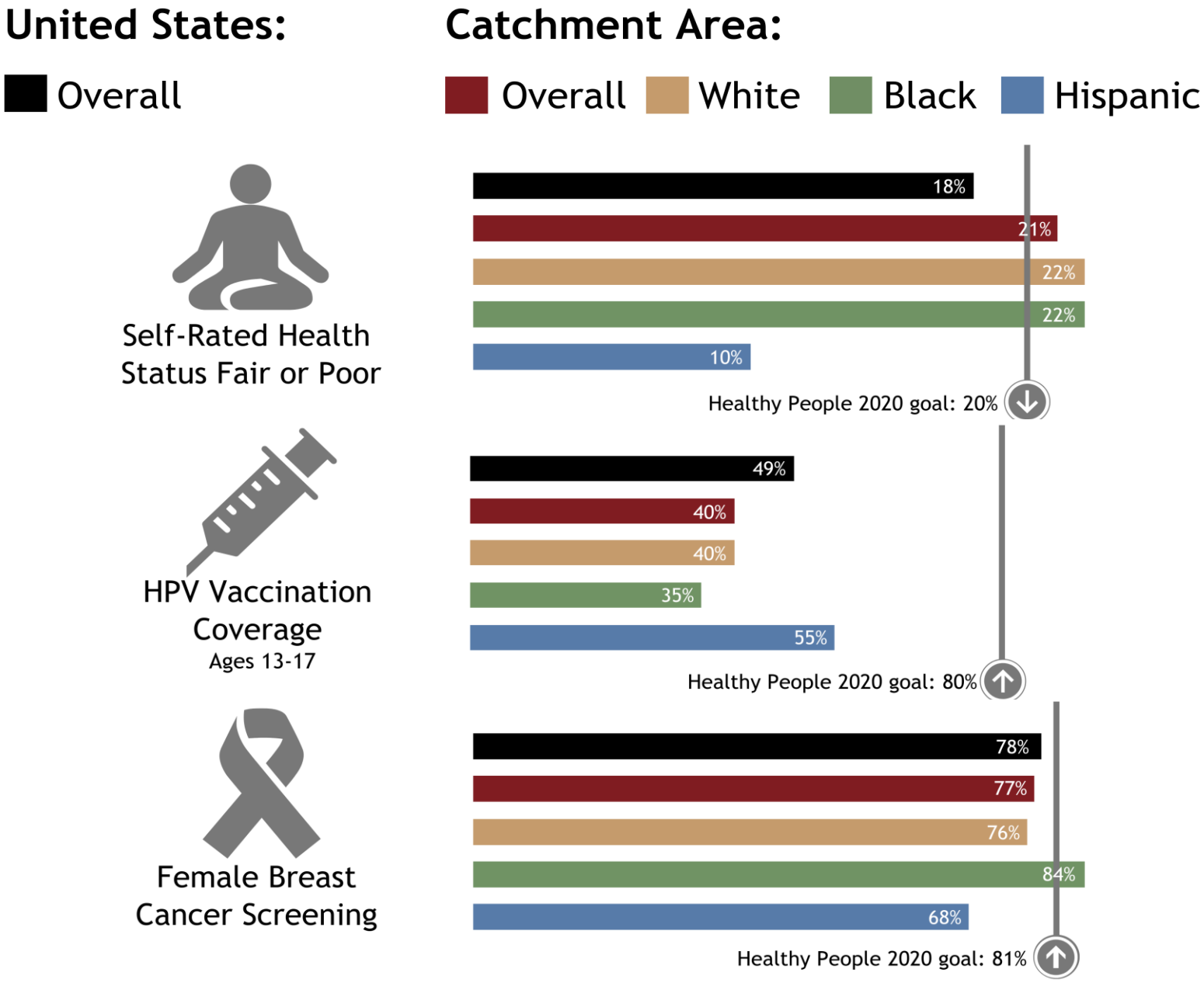
Youth Obesity



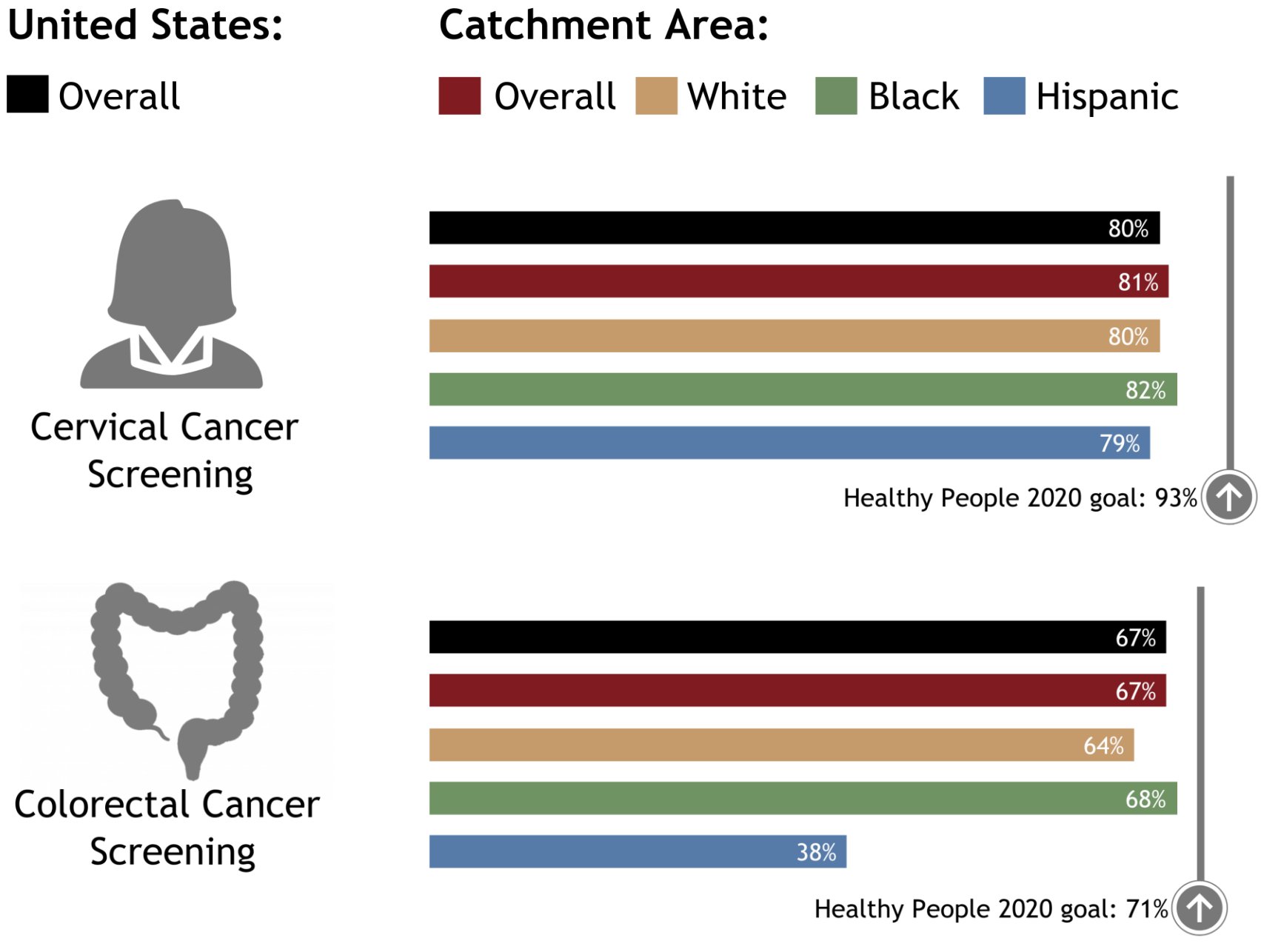
Health Care, Health Behavior and Prevention



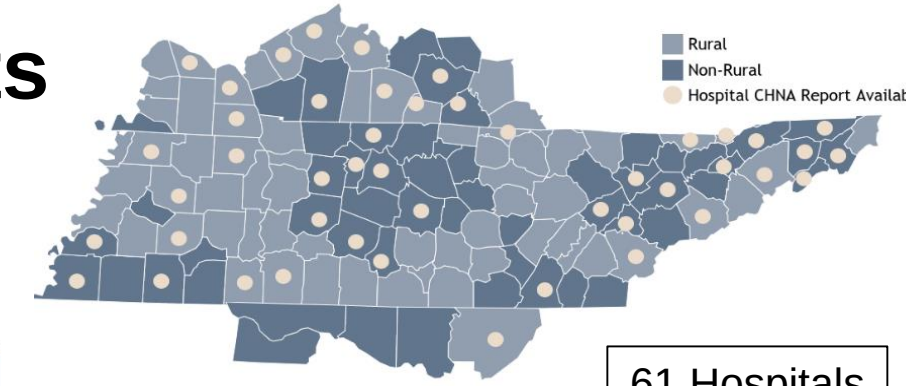
Health Care, Health Behavior and Prevention



Health Care, Health Behavior and Prevention

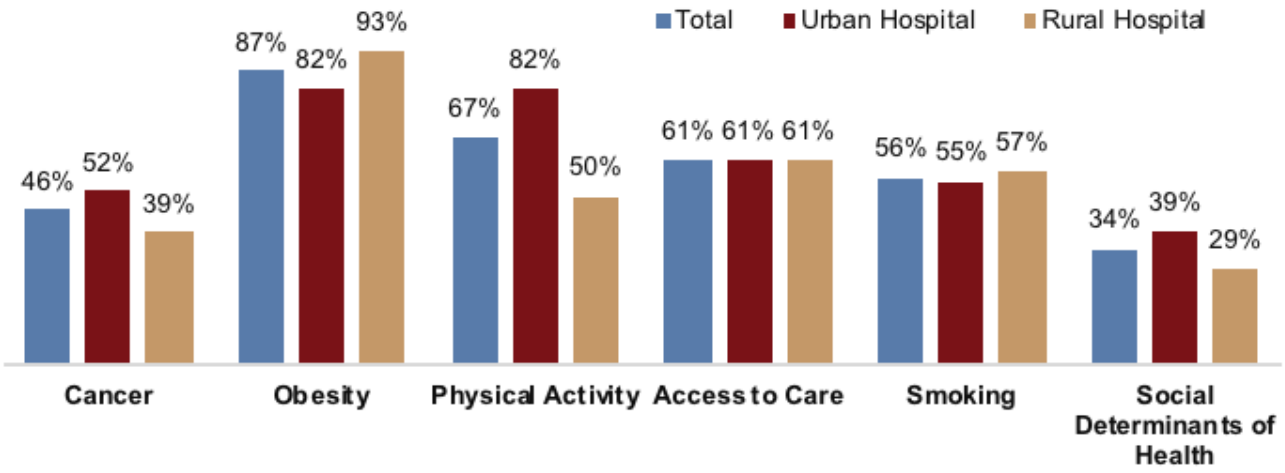


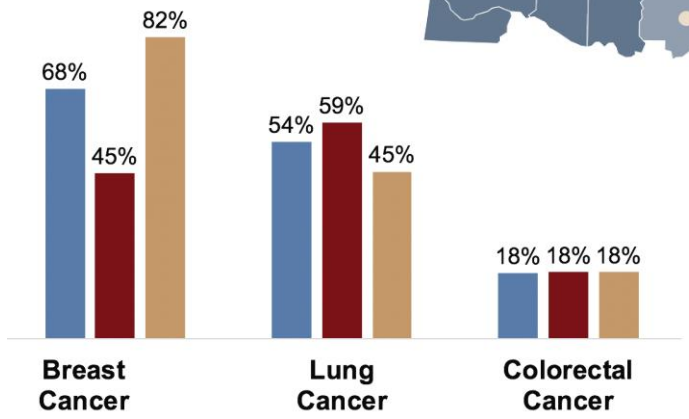
Community Health Needs Assessments



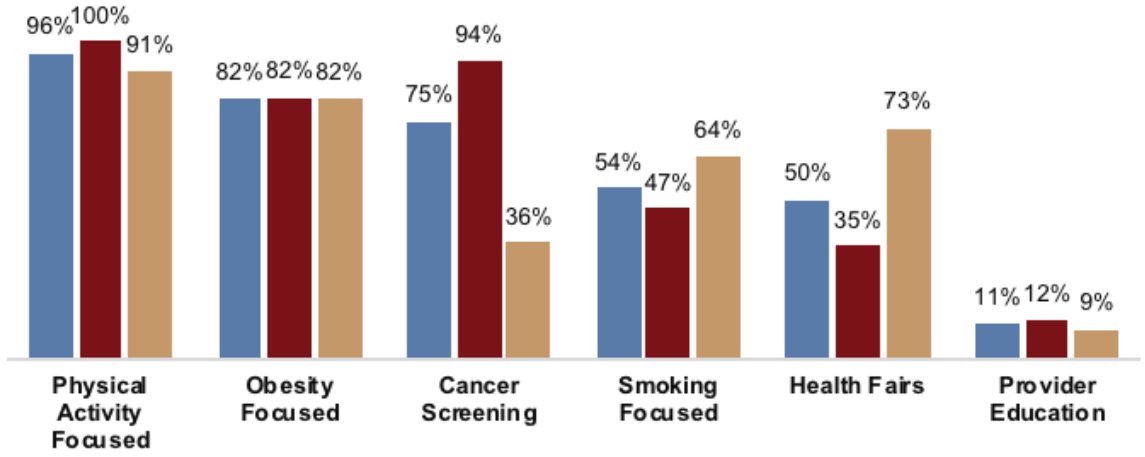
61 Hospitals

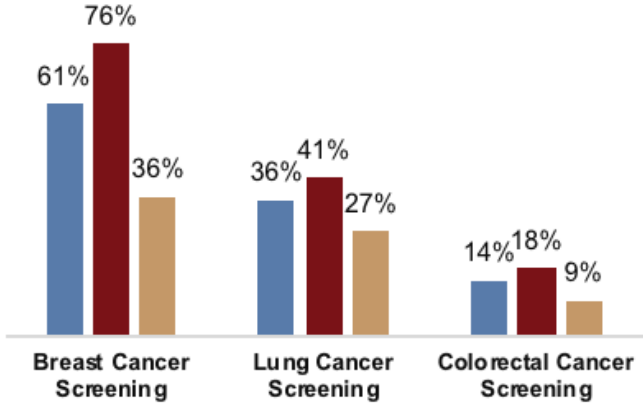
Priorities Selected:



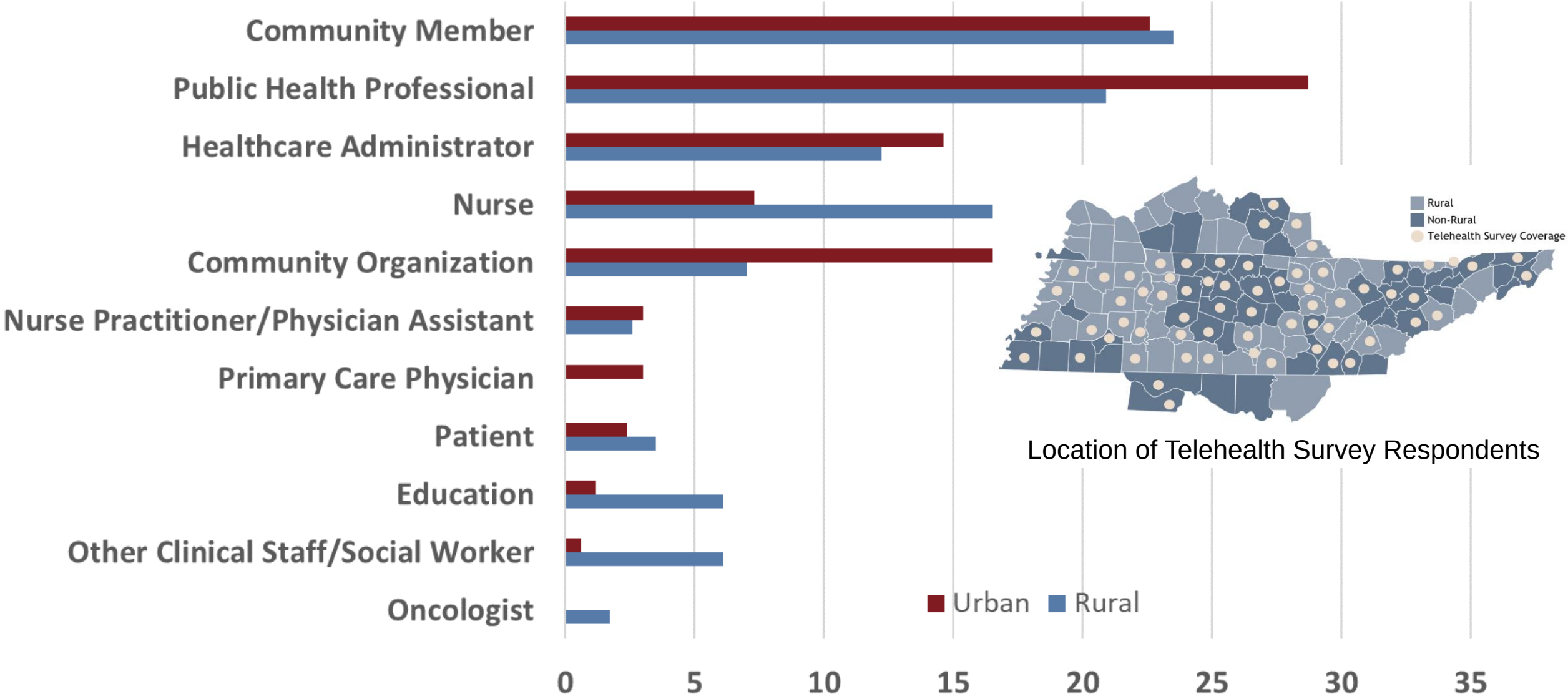


Implementation Strategies:



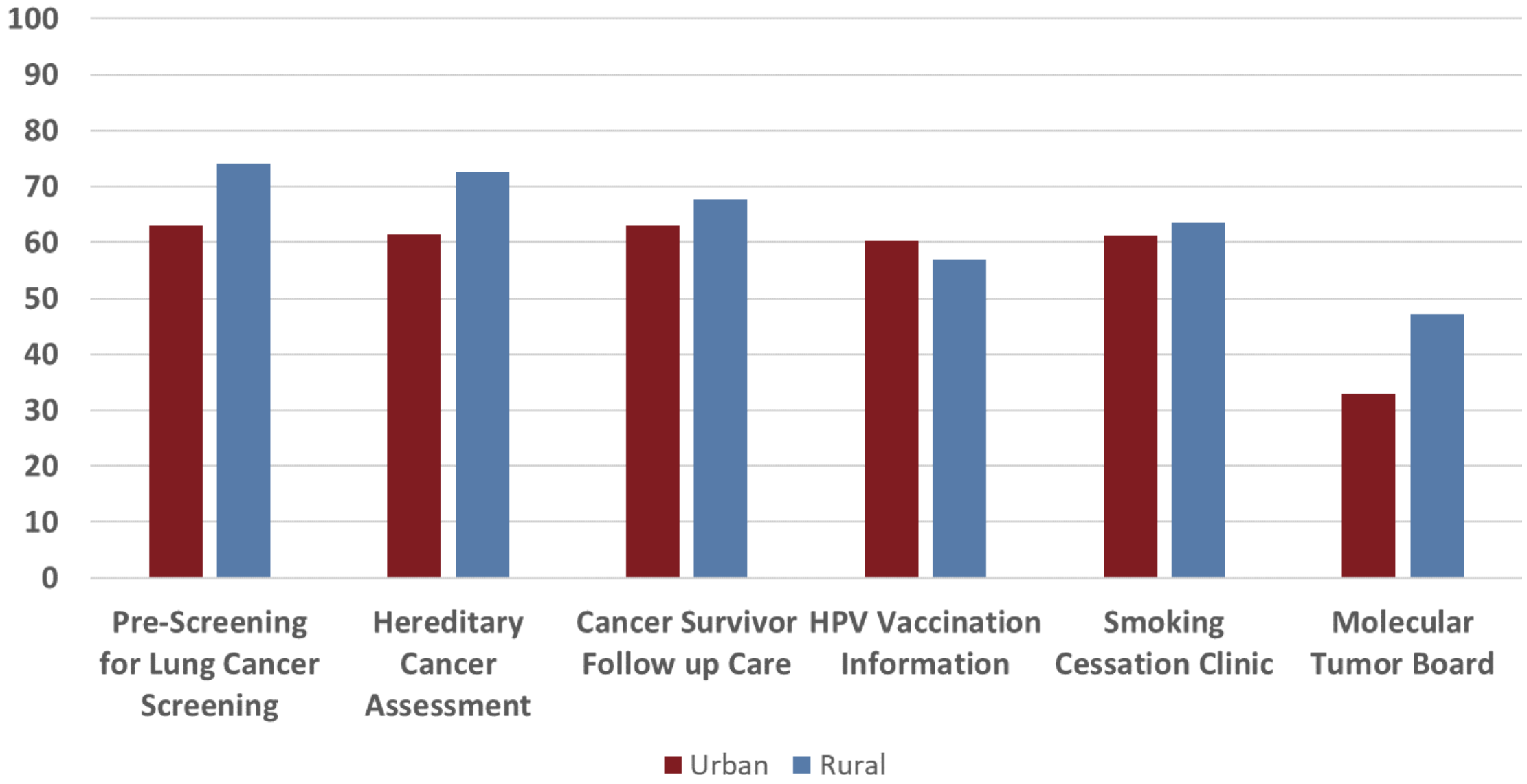


Telehealth Services Interest Survey Participant Occupation by Rural Classification

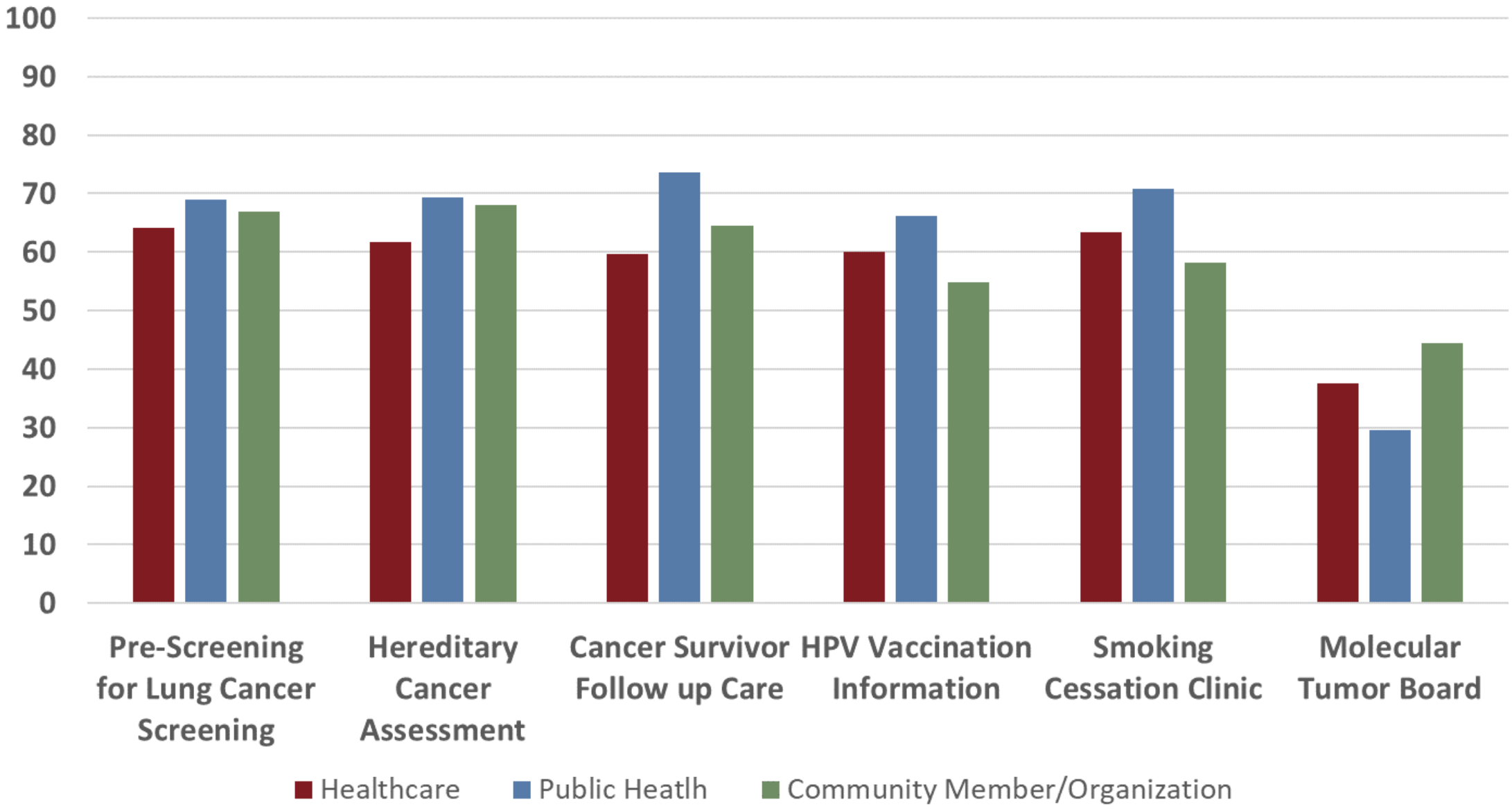


Location of Telehealth Survey Respondents

Telehealth Interest Survey: High/Very High Interest in Services by Rural Classification



Telehealth Interest Survey: High/Very High Interest in Services by Healthcare vs Non-Healthcare Occupation



Inherited Cancer Registry (ICARE)

- Launched in 2010 to create a registry of individuals with inherited cancer predisposition
- Most individuals with inherited cancer tested and treated in community hospitals/practices
- Created mechanism to Promote Community-Academic Partnerships

ICARE
INHERITED
CANCER REGISTRY

Mission Statement:
*"To end the cycle of inherited cancer through **research, education, and engagement**."*

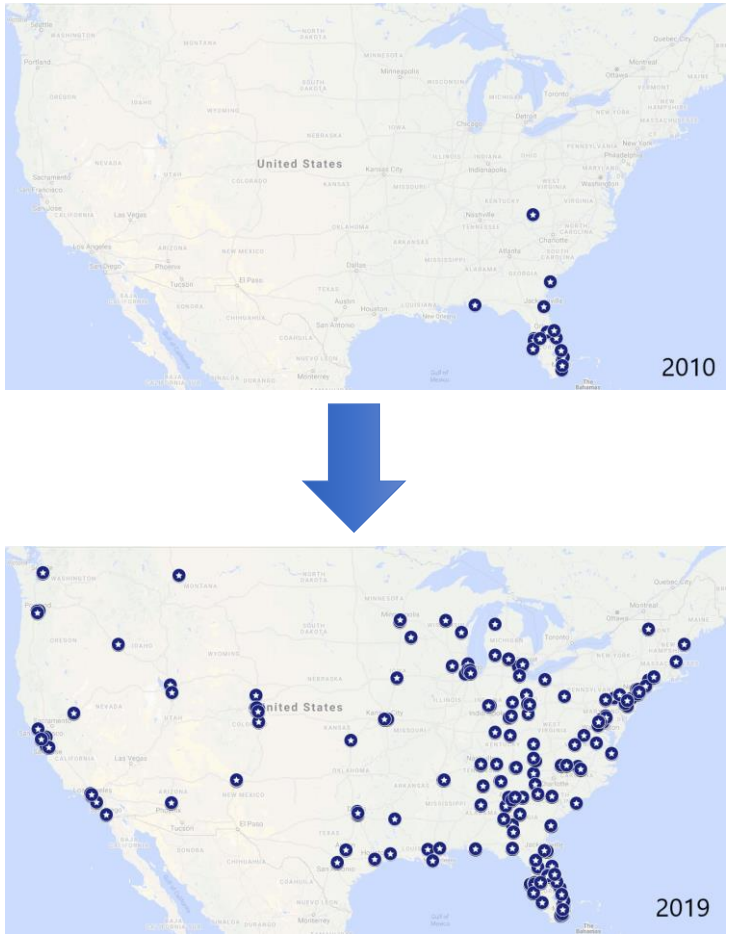
Common Goal:
"To improve the lives of patients and families at risk for inherited cancer."

Access at:

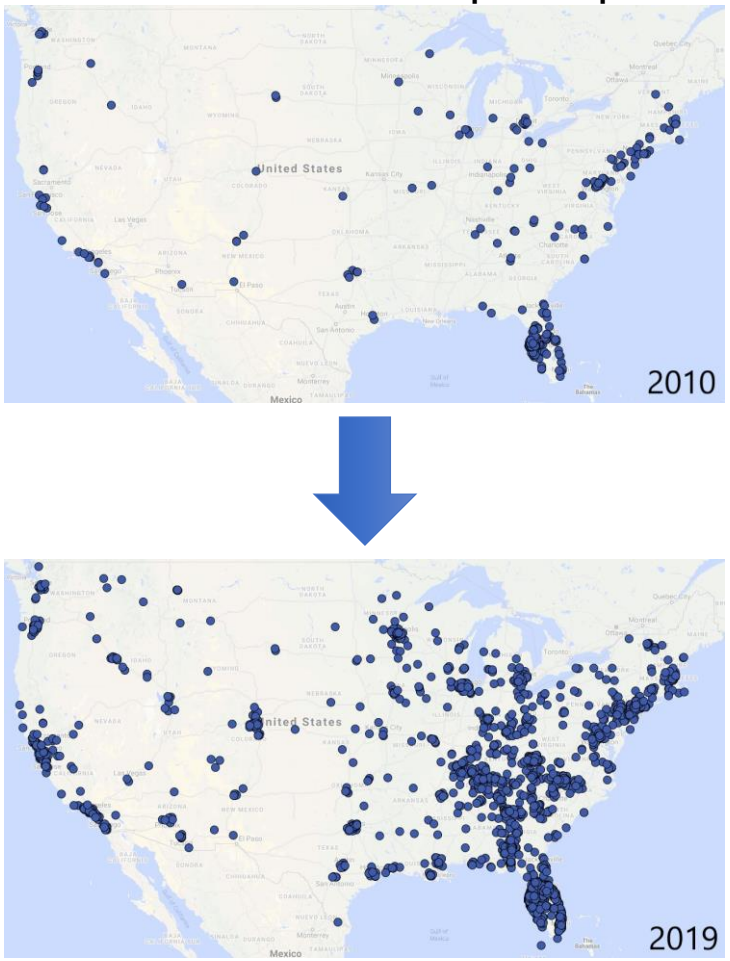
Inheritedcancer.net

Inherited Cancer Registry (ICARE)

ICARE Provider Partners: >200 providers who recruit to our registry and/or attend our case conferences

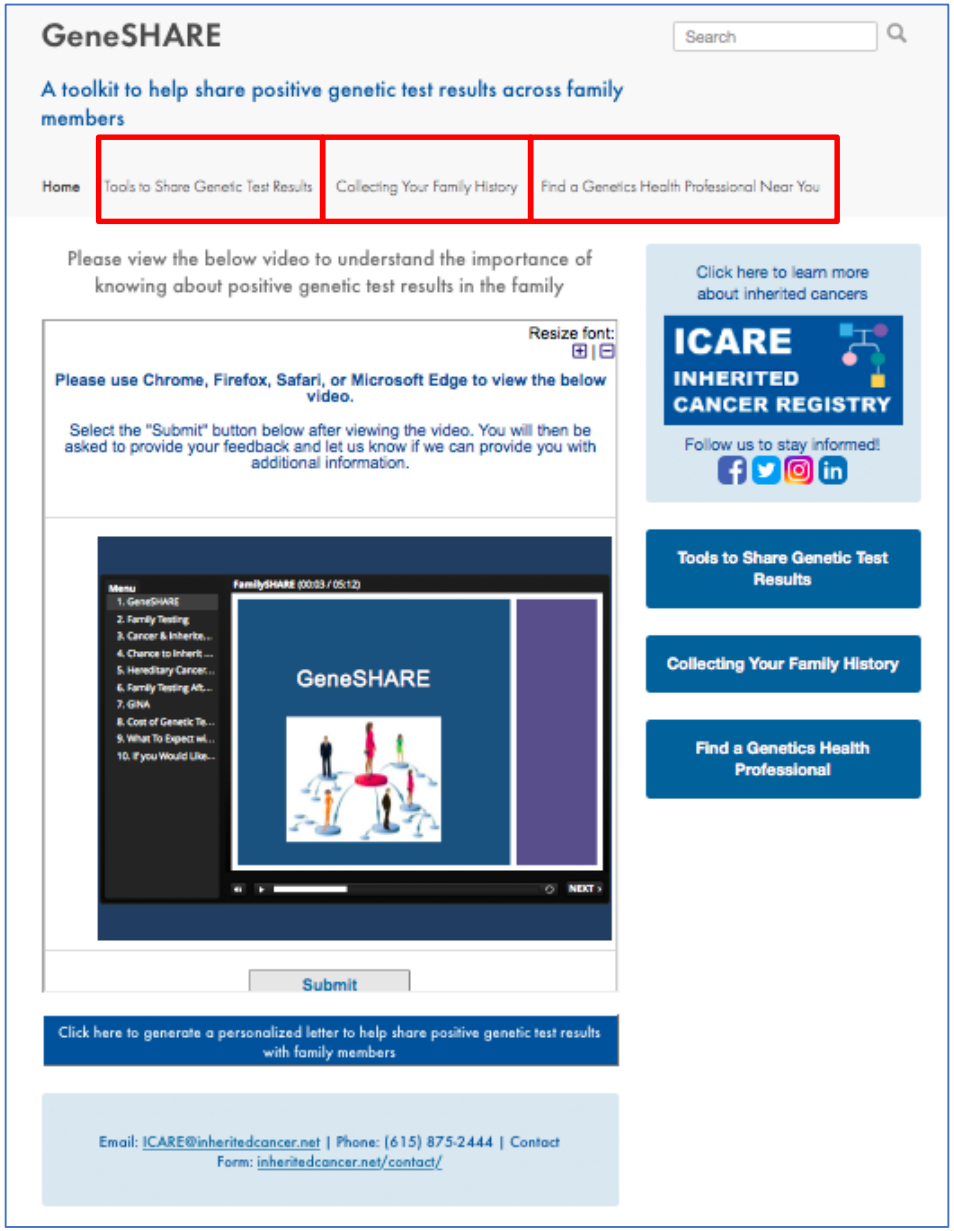


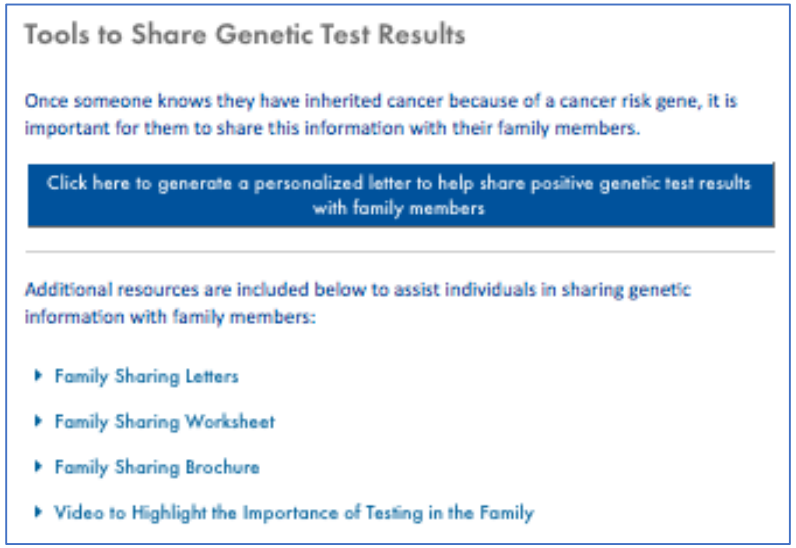
ICARE Participants: Amongst the largest inherited cancer registries in the US with over 3400 participants

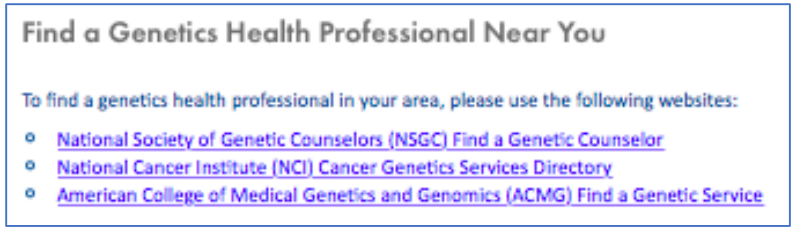


Developed based on study feedback to enhance family sharing of genetic test results:

GeneSHARE Toolkit:
www.geneshare.net







ICARE

Inherited Cancer Registry

GeneSHARE

A free online toolkit for participants to help share positive test results with family members

Family Sharing Letter

Please fill in the below fields in order to populate a family sharing letter to assist you in sharing your positive genetic test results with your family. Please use first names only.

Today's Date: Please enter today's date

Your First Name: Please enter your first name

Family Member's First Name: Please enter the first name of the family member you wish to share your results

Gene: Please list the gene(s) you tested positive for

By completing this form, you consent to having this website store your submitted information in order to generate a family sharing letter for you.

Submit!

Presented by: ICARE
Inherited Cancer Registry

Dear _____ ,

I hope you are doing well. I recently had genetic testing for inherited cancers and learned some information that may help you. I have a gene mutation (pathogenic variant) in the _____ gene.

Because we are blood relatives, you may also have this gene mutation. People with a gene mutation in this gene have higher risks for cancer. Knowing this information can often help them lower their risks or find cancer early (when it is easier to treat).

Experts recommend that you share this information with your healthcare provider and schedule an appointment with a genetics expert. They can explain what my test result might mean for you and your family. They can also help you decide if genetic testing is right for you. Genetic counseling and testing may help you and your healthcare providers manage your cancer risk.

If you would like to find a certified genetics healthcare provider near you, please visit the National Society of Genetic Counselors (www.nsgc.org) or the American College of Medical Genetics (www.acmg.net) website. To view a 5-minute video that explains how genetic testing can help family members, please visit www.geneshare.net. More information about inherited cancers can be found at www.inheritedcancer.net.

With best wishes for good health,

ICARE: Genetics Case Conferences

Now offering CME/CEU credits!

As part of our educational engagement efforts, ICARE hosts an hour-long monthly web-based Genetics Case Conference. Healthcare provid… regula… expert…

Thursday, March 5th 11:30am – 12:30pm	Colorectal Cancer & Polyposis Syndromes *In recognition of Colorectal Cancer Awareness Month*
Thursday, April 9th 11:30am – 12:30pm	Presenter Choice
Thursday, May 14th 11:30am – 12:30pm	Variant Classification Guest Expert: Rebecca Smith, PhD

Contact ICARE for more information: ICARE@inheritedcancer.net

- To…
  - Inherited blood cancers
- Total conferences held: **83**
  - #unique sites: **132**
  - #unique individuals: **400**
- Cumulative totals for all conferences:
  - #sites: **1372**
  - #individuals: **2800**

…hedule

…Case Conference

Thursday, June 11th 11:30am – 12:30pm	Presenter Choice
Thursday, July 9th 11:30am – 12:30pm	*BAP1* Guest Expert: Mohamed Abdel-Rahman, MD, PhD
Thursday, August 13th 11:30am – 12:30pm	Presenter Choice
Thursday, September 10th 11:30am – 12:30pm	Inherited Blood Cancers Guest Expert: Sarah Bannon, MS, CGC
Thursday, October 8th 11:30am – 12:30pm	Breast Cancer *In recognition of Breast Cancer Awareness Month*
Thursday, November 12th 11:30am – 12:30pm	*TBD*
Thursday, December 10th 11:30am – 12:30pm	Presenter Choice

**Focus may change due to unforeseen circumstances. If there is a change in the focus, ICARE partners will be notified.*

Access at:
inheritedcancer.net/newsletters

ICARE Newsletters

The ICARE bi-annual newsletters are a means to disseminate updated information to healthcare professionals and ICARE participants. Each newsletter briefly outlines recent clinical and research updates pertaining to risk assessment, testing options, and management of those with inherited cancer predisposition, among other topics.

Please use the following drop-down menus to access each newsletter edition:

English Newsletters

Spanish Newsletters

Click here to search ICARE newsletter articles & posts

CAPS Updates

@inheritedcancer

ICARE NEWSLETTER
WINTER 2020

Updated Pancreatic Cancer Screening Guidelines through CAPS Consortium

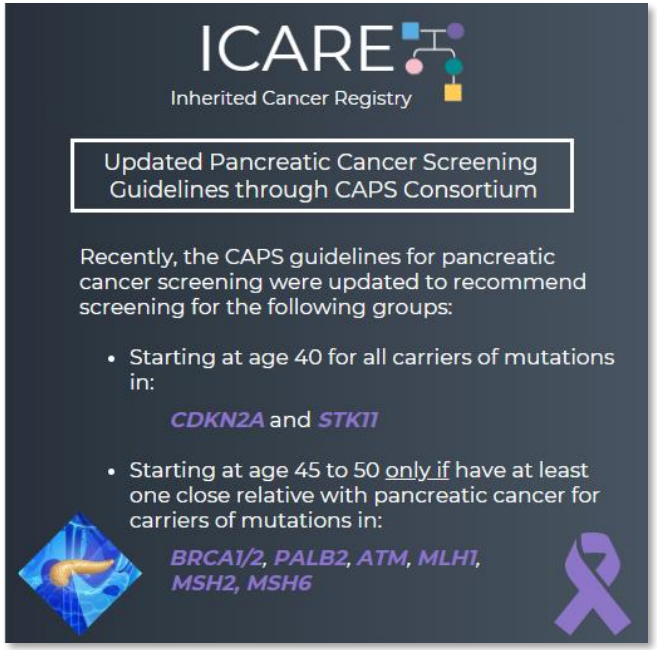
The International Cancer of the Pancreas Screening (CAPS) Consortium recently published updated recommendations about pancreatic cancer screening through MRI/magnetic retrograde cholangiopancreatography (MRCP) and/or an endoscopic ultrasound (EUS).[1] Specifically, these guidelines now recommend that individuals with a *CDKN2A* or *STK11* mutation begin screening at age 40. Screening for individuals with a *BRCA1/2*, *ATM*, *PALB2*, *MLH1*, or *MSH2* mutation is only recommended if they have at least one first-degree relative with pancreatic cancer, beginning at age 45-50 or 10 years younger than the youngest relative diagnosed with pancreatic cancer. These guidelines were developed through expert consensus based on existing research; however, there remains a need for more information to understand the benefits and risks of pancreatic cancer screening. Both patients and their treating providers should be aware that these guidelines have some differences from the recently published NCCN genetic/familial breast, ovarian, and pancreatic guidelines, as outlined in the table below.[2]

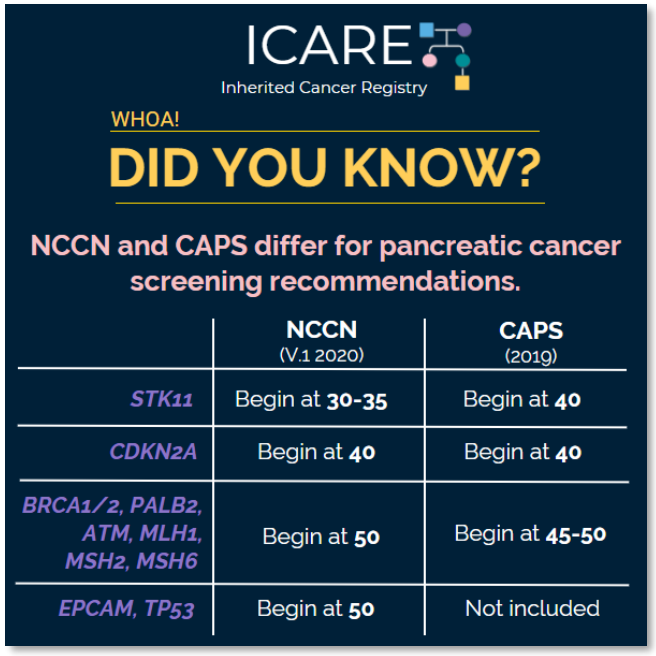
Age to Begin Pancreatic Cancer Screening per NCCN & CAPS

Gene	**NCCN** (V.1.2020)	**CAPS** (2019)
STK11	Begin at 30-35	Begin at 40
CDKN2A	Begin at 40	Begin at 40
BRCA1/2, PALB2, ATM, MLH1, MSH2, MSH6	Begin at 50	Begin at 45-50
EPCAM, TP53	Begin at 50	*Not included*

[1]Goggins, et al. Gut. 2020 Jan. PMID: 31672839; [2]NCCN Practice Guidelines. V.1.2020. 2019 Dec. Available at: NCCN.org

Social media post: *https://tinyurl.com/ICARE202026*





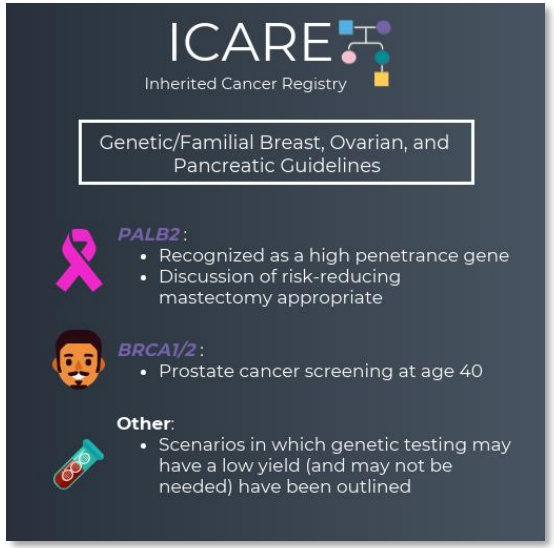
More Featured Items in Winter 2020 Newsletter

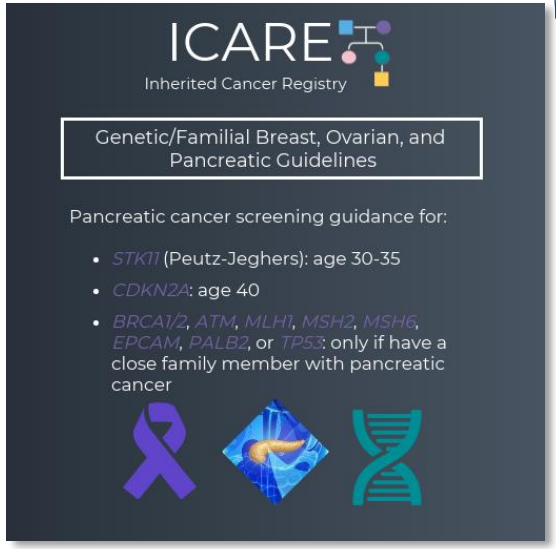
Updates to National Comprehensive Cancer Network (NCCN) Genetic/Familial High-Risk Assessment: Breast, Ovarian, and Pancreatic (*Version 1.2020, posted December 4, 2019*)

There were significant updates and restructuring of the guidelines, with some highlights included below:

- Substantial reorganization of the guidelines as follows:
  - Now organized by organ site, rather than primarily by certain high penetrance genes
  - Focused efforts to simplify genetic testing criteria
  - Only one flow diagram included, to outline the 'genetic testing process'
- Following scenarios now outlined:
  - Situations in which genetic testing may have low yield
  - Situations where referral to a genetics expert is recommended
- *PALB2*: Recognized as a high penetrance gene, for which discussion of risk-reducing mastectomy is appropriate
- *BRCA1/2*: Prostate cancer screening to be initiated at age 40
- Pancreatic screening guidance included:
  - *STK11* starting at age 30-35
  - *CDKN2A* starting at age 40
  - *BRCA2*, *MLH1*, *MSH2*, *EPCAM*, *PALB2*, or *TP53*: Only if there is a close family member with pancreatic cancer

For the complete updated versions of the NCCN guidelines, please visit NCCN.org
Follow this link to view our social media post: https://tinyurl.com/ICARE2019124
Full press release available at: https://www.nccn.org/about/news/newsinfo.aspx?NewsID=1790





Ask the Expert

Through each newsletter, we give our participants an opportunity to have their questions answered by experts. If you have a question you would like addressed, please email the study team at ICARE@InheritedCancer.net for consideration in future newsletters. The following question was addressed by Ben Ho Park, MD, PhD, who is the Donna S. Hall Chair in Breast Cancer, Co-Leader of the Breast Cancer Research Program, Associate Director for Translational Research, and Director of Precision Oncology at Vanderbilt-Ingram Cancer Center. Dr. Park is also a Professor of Medicine and Associate Director for Basic and Translational Research in the Department of Medicine's Division of Hematology and Oncology.

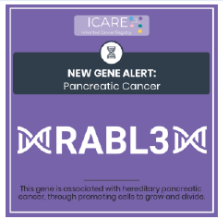
Q. How is DNA testing done on someone's tumor different from testing done on someone's normal DNA from their blood or saliva sample?

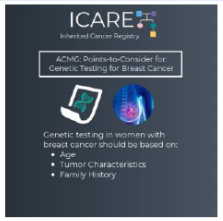
Community Spotlight

I was diagnosed with breast cancer in December 2018 and was found to be *PALB2+*. The *PALB2* gene had not been tested for when my older sister was diagnosed with breast cancer and had genetic testing done four years earlier. This was new! My cancer was very similar to my sister's, but being *PALB2+* changed my treatment plan and informed me of my possible higher cancer risks for recurrence and other cancers. Like my sister, I had one small tumor in one breast. I could have just had a lumpectomy with radiation and chemo (depending on ONCA result) followed by oral medication, and then just live with a risk of recurrence. The other treatment option was a skin saving, nipple sparing bilateral mastectomy with FLAP reconstruction followed by 5-10 years of oral medication. This would have reduced my risk of recurrence to below 10%. It was a no brainer for me -- I chose the latter. After my breast surgery, I was then told *PALB2* was linked to ovarian cancer, so I started seeing a high-risk gynecologist. After months of discussions with my gynecologist and oncologist, I decided to have an oophorectomy. This was prompted by my *PALB2* risk and my adverse reaction to Tamoxifen. The only way to get off the Tamoxifen was to put me into menopause by removing my ovaries, which at the same time, would lower my ovarian cancer risks. Again, this was a no brainer. It's two years after my diagnosis, and I'm in a really good place. My cancer is nearly behind me, as I don't think about it on a daily basis. I'm feeling great and look even better ;) My energy levels are back to normal, I'm playing competitive tennis, and I'm spending time with my family traveling and

@INHERITEDCANCER

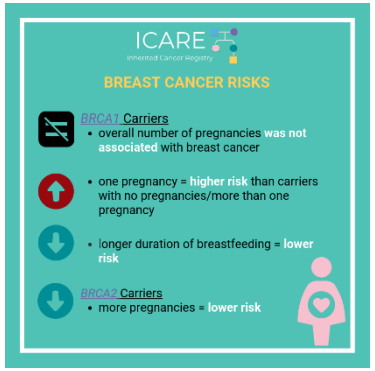
DID YOU KNOW? | TREATMENT ADVANCES | CANCER RISKS | NEW GENES | GUIDELINE UPDATES





All social media posts and newsletter articles can be searched on our ICARE website:
https://inheritedcancer.net/category/newsletter-articles/

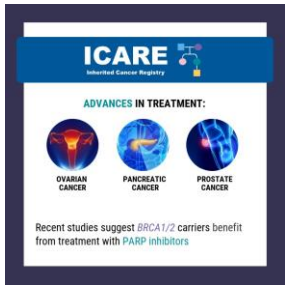
ICARE On the Web

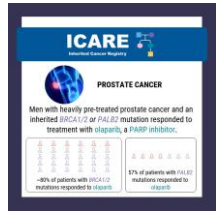


InheritedCancer.net

@inheritedcancer

linkedin.com/company/inherited-cancer-registry/

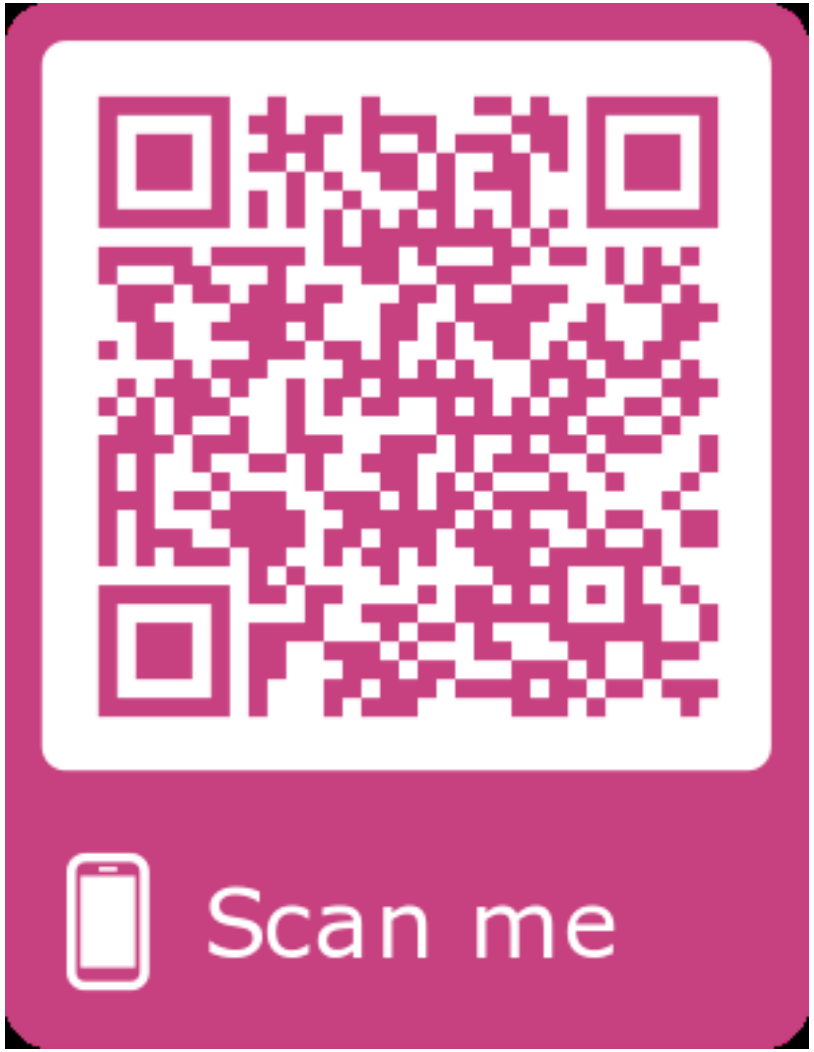




Global Molecular Tumor Board: Our Cancer Genomes

- Led by Dr. Ben Ho Park (VICC)
- Monthly 1 hour virtual case conference
- Discussion of complex cases including interpretation of tumor sequencing results
- Access to multi-disciplinary expertise for complex cases

Metrics/Details on how to access if interested



- Participating sites (Domestic): VICC, Johns Hopkins, UNC, Mayo, UWash/Fred Hutch, Allegheny Health, UPMC, UTHSC, OHSU, St. Lukes (Idaho), UWisconsin/Madison, UT Austin, VCU
- Participating sites (International): Singapore, Romania, Germany, Portugal, Ireland
- Meets virtually 4th Monday of every month at 9AM Central using HIPAA compliant Zoom web based meeting
- Upload redacted cases to secure REDCap database: (Our Cancer Genomes) (must be CLIA grade report or for International labs comply with ISO 15189 Medical laboratories standards)
- Contact Ben Park if you'd like to join at ben.h.park@vumc.org

Future Directions

Expanding Rural Health Cancer Control Capacity: Focus on Survivorship

Aims

To improve long-term health outcomes for underserved rural cancer survivors by building capacity to deliver risk-adapted guideline-based care focused on the unique needs of cancer survivors

Aim 1 Pilot test the implementation of guideline-based survivorship care planning in a rural setting using patient navigation plus telehealth

Aim 2 Identify the facilitators & barriers to future larger scale implementation of guideline-based survivorship care planning in rural settings

P30CA068485-24S3

Enhancing Cancer Care of Rural Dwellers Through Telehealth and Engagement

Aims

Aim 1 Test a multi-level telehealth-based intervention for rural hospitals

Provider level:

Molecular tumor board

Patient level:

Supportive care intervention

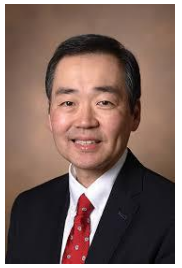
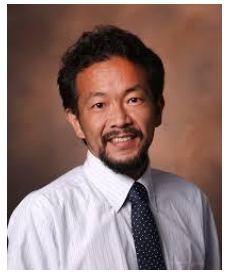
Cancer: Thriving and Surviving

Aim 2 Study facilitators & barriers to large-scale dissemination & implementation

R01CA240093

Acknowledgements







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NATIONAL® CANCER INSTITUTE

Telehealth Services Interest Survey

Give feedback on cancer related services needed in your area

Complete 5 minute survey:

1. Online: http://j.mp/2Rvxudf or scan QR code
2. Or fill out paper survey

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VANDERBILT-INGRAM CANCER CENTER

Thank You!