ACCC
Association of Community Cancer Centers

Appalachian Community Cancer Alliance

Who We Are and What We Can Accomplish

Friday March 24, 2023

VIRGINIA ASSOCIATION OF HEMATOLOGISTS AND ONCOLOGISTS

SOUTH CAROLINA ONCOLOGY SOCIETY

American Cancer Society®

West Virginia Oncology Society

KYSCO KENTUCKY SOCIETY OF CLINICAL ONCOLOGY

TOPS Tennessee Oncology Practice Society

NORTH CAROLINA Oncology Association

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Disclosure of Conflicts of Interest

Nicole L. Stout, DPT, CLT-LANA, FAPTA, has no relevant financial relationships to disclose.

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BACKGROUND

How We Started

- Established in 2021 by six oncology state societies (OSS)
- Initial groundwork of identifying shared challenges and discussing future of the group
- Partnership with ACCC and invitation to additional stakeholders to form a steering committee
- Develop year 1 deliverables and engagement strategy

BACKGROUND

How We Started

Mission and Goals

Support community oncology practitioners to improve access to the entire cancer care continuum and reduce cancer health disparities in the rural Appalachian population by:

- Identifying and addressing challenges in providing care
- Evaluating provider perceptions regarding equity in access to care
- Implementing patient-centric approaches to increase guideline-concordant cancer screening
- Developing interventions for promoting guideline-concordant treatment
- Implementing patient-centered communication strategies to overcome informational barriers
- Discussing relevant cancer clinical trial opportunities within the treatment plan
- Increasing the quality of life and survivorship of cancer patients

Priority focus areas: Improving screening for colorectal, cervical, and lung cancers

Appalachian Community Cancer Alliance

Who?

Network of individuals and organizations committed to the vision and mission of the Alliance. Multidisciplinary cancer program staff, cancer survivors, patient advocacy groups, primary care, other specialties, government stakeholders, research or professional organizations are welcome to participate

What?

Ongoing network/platform for learning, discussion, sharing of promising practices and tools/resources, performing targeted projects related to Alliance goals, partnership building

How?

Staying informed and engaged through the Alliance listserv, website, educational offerings, and regular meetings

Appalachian Community Cancer Alliance

Current Activities

- Rural Appalachian Lung Cancer Screening Initiative – *White House Announcement*
- Monthly steering committee meetings
- Landscape analysis
- Stakeholder engagement, increasing awareness of the Alliance
- Action planning for 2023

State of Cancer Care in Appalachia

- Literature review and focus groups to establish current state of cancer care delivery in Appalachia and identify effective practices
- Preliminary overview to serve as a starting point for activities moving forward

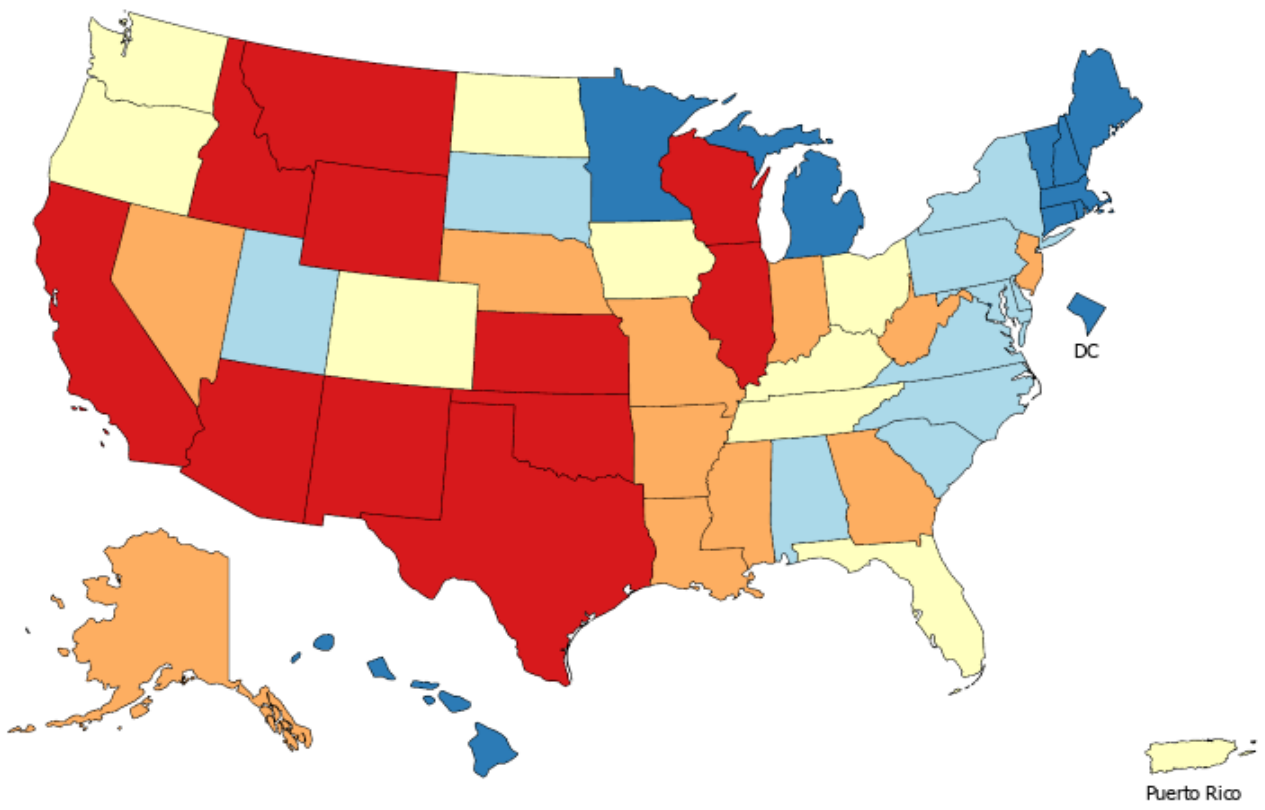
LANDSCAPE ANALYSIS HIGHLIGHTS

Epidemiology – Colorectal Cancer

- Incidence (2014-2018)
  - Especially high in counties in KY & MS
- Last-stage incidence (2014-2018)
  - Especially high in southwest VA, KY, MS
- Mortality (2015-2019)
  - Especially high in VA, WV, KY, MS
- Early onset CRC (diagnosis before age 50)
  - Hotspots for women: parts of PA, NY, OH, NC, SC
  - Hotspots for men: WV, VA, KY, TN, AL, NC, SC

Screening Rates – Colorectal Cancer

State	Percent
Pennsylvania	74.83
Maryland	74.51
New York	74.5
Alabama	74.24
South Carolina	74.17
Virginia	73.89
North Carolina	73.8
Tennessee	72.1
Ohio	71.92
Kentucky	71.26
Georgia	70.08
West Virginia	69.12
Mississippi	68.97



Notes:
Note: Alaska, DC, Hawaii and Puerto Rico are not drawn to scale.
BRFSS Survey Data is the source for this data collected by the Behavioral Risk Factor Surveillance System (BRFSS) sponsored by the Centers for Disease Control and Prevention. Data for the US is a median and not a percent. BRFSS Prevalence estimates presented here may vary from other published estimates due to differences in the methodology used to generate estimates.
Healthy People 2020 Goal C-16 : Increase the proportion of adults who receive a colorectal cancer screening to 70.5.
Healthy People 2020 Objectives provided by the Centers for Disease Control and Prevention.
Data for the United States does not include data from Puerto Rico

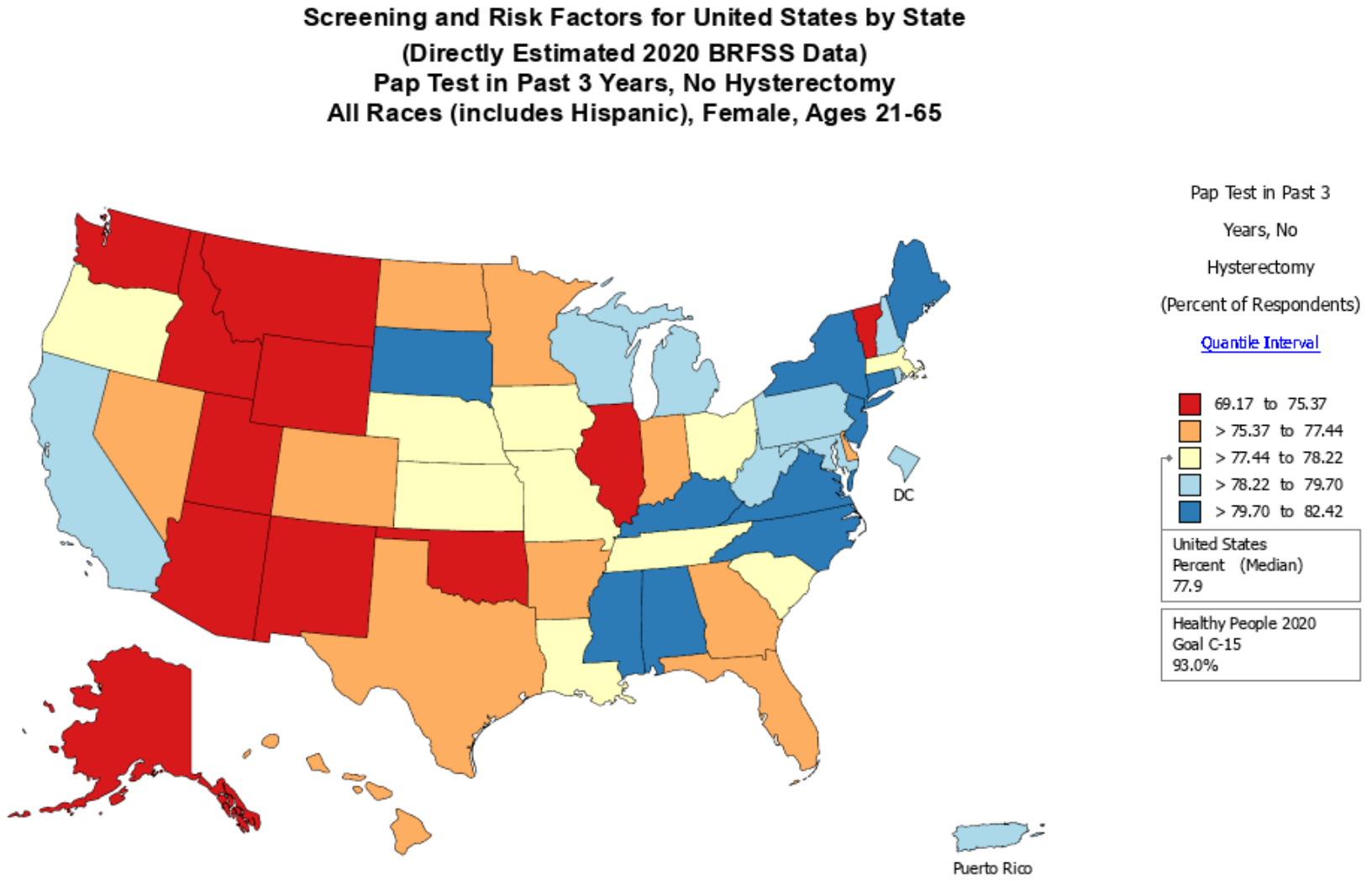
Source: CDC/ NCI State Cancer Profiles

Epidemiology – Cervical Cancer

- Incidence (2014-2018)
  - Especially high in KY, WV, MS, AL
- Last-stage incidence (2014-2018): regional or distant cases
  - Especially high in KY, MS, WV
- Mortality (2015-2019)
  - Especially high in MS, AL, WV, TN

Screening Rates – Cervical Cancer

State	Percent
Mississippi	82.39
North Carolina	81.76
Kentucky	80.75
New York	79.94
Virginia	79.91
Alabama	79.86
Maryland	79.5
West Virginia	79.14
Pennsylvania	78.47
South Carolina	78.12
Tennessee	77.89
Ohio	77.49
Georgia	77.11



Source: CDC/ NCI State Cancer Profiles

Barriers

Common	Colorectal	Cervical
• **Psychological barriers** (lack of preventive care orientation, fatalism, fear of procedure or cancer, lack of perceived risk especially in the absence of symptoms, lack of knowledge about screening guidelines and options, mistrust of medical system) • **Language[6] and literacy** barriers • **Costs, both direct and indirect, lack of insurance** • **Logistical barriers** (transportation/ distance, time, childcare) • **Lack of provider recommendation; recommendation, lack of provider time, competing patient priorities** • **Lack of patient-centered communication** • **Lack of clinic EHR capacity** for tracking and reminders, lack of standard workflows for screening • **Lack of geographic access** to healthcare providers (e.g., gastroenterologists, OBGYN specialists) • **COVID-19 disruptions** to healthcare (e.g., staffing, social distancing implications for space needs, pause in elective procedures)	**Lack of knowledge about stool-based testing options** (e.g., FIT, FOBT) and appropriate frequency of each, doubt quality of tests, incorrect completion, inconvenience (e.g., some need multiple samples) **Colonoscopy-specific:** perceived discomfort of prep/procedure, sense of violation (especially among men), embarrassment, privacy/confidentiality concerns especially in rural areas where people may personally know healthcare staff Some in primary care (especially pre-pandemic) recommended colonoscopy over home-based stool-testing, or only offered stool-based testing if colonoscopy was refused, instead of engaging in shared decision-making	**Preference for female provider** **Competing priorities**, caregiving, lack of childcare **Lack of patient-centered communication**: demeaning or discriminatory attitudes towards women (language, culture, low SES) **Lack of accommodation for women's logistical needs**, around clinic hours and location **HPV self-sampling-specific**: forgetting, fear, lack of time, worry about using test incorrectly

Barriers – Genetic screening and counseling

- **General lack of genetics professionals** in Appalachia, and services tend to be clustered around major cities resulting in distance/ transportation/time barrier
  - Remote strategies like tele-genetics and mailing of buccal swabs have been used to overcome distance barriers, but technological access and literacy and infrastructure limitations such as lack of internet and mail service coverage pose challenges
- **Other barriers to genetic screening and counseling included:**
  - Lack of awareness about genetic testing and potential benefits/ low demand
  - Perception of high cost
  - Low prioritization
  - Lack of physician recommendation (in part because of lack of physician skills and knowledge around genetic risk assessment, referral, and guidelines)
  - Lack of insurance coverage/ cost

Interventions – Colorectal screening, cervical screening, genetics services utilization

- Patient Navigation and/or use of community health workers
- Public outreach and education
- Material supports (e.g., use of financial incentives like a gift card, transportation assistance, charity care)
- Broader collaboration and partnerships
- Policy and advocacy around coverage, Medicaid expansion, program funding or paid time off for cancer screening

Interventions – Clinic-based

- Strategic planning - Determining baseline data, establishing protocols, and training staff
- Utilizing a clinical champion – reviewing progress, celebrating wins, solicit feedback, holding staff accountable
- Use of dedicated staff (e.g., coordinators, navigators) to identify patients due for screening, track progress and provide reminders
- Automated reminders reduced staff burden and consolidated reminders for breast, colorectal, and cervical reduced burden while streamlining communication
- EHR capabilities that document and track screening-related information, identifying overdue patients, provider reminders
- Interventions that maximized screening convenience and accessibility for patients

Continuity of Care - PCP/Cancer Specialist Relationship

Pain points

- Gaps in communication
- Discordance in role expectations

Interventions

- Foster formal and informal relationships
- Technical assistance
- Clear documentation and communication

Focus Group Highlights

For providers practicing in the region, common challenges were:

- Lack of providers and staff
- Infrastructure
- Overall capacity to address screening and/or continuity of care

Additional challenges included:

- Patients' access to services whether due to a lack of providers or insurance coverage
- Correct and up to date data on screening history
- Patients' and providers' ability to follow-up on an abnormal screen
- Lack of available appointment times due to the backlog of the COVID-19 pandemic

Focus Group Highlights
Use of Evidence-Based Interventions

Participants indicated there was a great deal of variation in how and when these interventions had been used

Participants noted the following as successful interventions they have seen and/or are utilizing:

- Patient navigators
- Interoperable/shared EMR
- Medical champion
- Policy approaches at the state and federal level

Focus Group Highlights
Potentially Impactful Evidence-Based Interventions

Participants frequently noted the use of patient navigation as most impactful but not always utilized

Additional interventions/approaches cited were:

- Shared EMR
- Improved communication between providers
- Multispecialty clinics and/or embedded providers
- Automated provider reminders/prompts
- Provider education

Key Takeaways

- Providers want an improved system
- Desire for dissemination of evidence-based practices and practical tips on "how to" implement/weigh evidence
- Increase connections between providers across disciplines and fields (e.g., public health, non-profit social services groups, industry, etc.) to improve care on the ground

The Path Forward

The Alliance proposes to focus on the colorectal cancer screening continuum for 2023. Proposed activities include:

- Review focus group data and categorize barriers by theme
- Use the Consolidated Framework for Implementation Research to map evidence-based solutions to identified barriers. In addition, leverage landscape analysis, other existing tools and resources (e.g., ACS, National Colorectal Cancer Roundtable, Local/Regional Colorectal Cancer Roundtables, Comprehensive Cancer Control Coalitions), and Alliance Steering Committee expertise to provide solutions to barriers
- Disseminate solutions via toolkit(s), e-newsletter, webpage, local/regional/national meetings, webinars, etc.
- Connect multidisciplinary providers and others working to address public health, SDOH, via e-newsletter, local/regional/national meetings, webinars, etc.

Get involved!

- Review our website and sign up to stay involved
  - Participate in upcoming events
  - Share or receive relevant resources or opportunities
  - Raise state-specific concerns
  - Network with your peers
- Review publication of landscape analysis in ACCC's *Oncology Issues* upcoming issue
- Share with your networks
- Contact ACCC Program Manager, Ashley Lile, at alile@accc-cancer.org for more information or questions

QUESTIONS

Thank you!

Please share these resources with a colleague!

accc-cancer.org/acca