

ASSOCIATION OF COMMUNITY
CANCER CENTERS

EXAMINING COLORECTAL AND CERVICAL CANCER CARE IN APPALACHIA

A REVIEW OF BARRIERS AND
INTERVENTIONS TO CANCER
SCREENING, GENETIC SERVICES,
AND CONTINUITY OF CARE



Examining Colorectal and Cervical Cancer Care in Appalachia

A review of barriers and interventions to cancer screening, genetic services, and continuity of care

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Appalachia encompasses 13 states, spanning 206,000 square miles.¹ It is home to nearly 26 million people. A fourth of Appalachia's 423 counties are rural, characterized by generational poverty and a lack of key resources, such as adequate healthcare. This is evidenced in an overall Appalachian cancer mortality rate that runs 10 percent higher than the national average.² Appalachia's most rural populations experience cancer death rates more than 15 percent higher than the rest of the nation. In central Appalachia, the mortality rate is 32 percent higher than the rest of the U.S. In fact, Appalachian Kentucky has the highest rates of cancer burden, exceeding the national average by 35 percent.

Lung, cervical, and colorectal cancer incidence and mortality are higher in the Appalachian areas of Ohio, Kentucky, Pennsylvania, Virginia, and West Virginia than any other parts of the U.S.³ In addition, there is a general lack of genetics professionals in Appalachia, and services tend to be clustered around major cities resulting in barriers of distance, transportation, and time.⁴⁻⁶ Other barriers to genetic screening and counseling include lack of awareness about genetic testing and potential benefits, low demand, perception of high cost, low prioritization, lack of physician recommendation, and lack of insurance coverage.^{4,5}

With multiple providers delivering care to patients with cancer, there are increased opportunities for gaps in communication and role confusion among primary care providers (PCPs) and cancer specialists. The transition from active treatment to survivorship care is a critical piece to patients' long-term health outcomes. Barriers faced by patients during this transition of care may include fragmented care, poor communication

(especially among providers and patients), and a lack of understanding of future risks or a follow-up plan.⁷

The Association of Community Cancer Centers (ACCC) has joined with state oncology societies from throughout the region to create the Appalachian Community Cancer Alliance (the "Alliance"). The Alliance seeks to provide residents of Appalachia and beyond with interdisciplinary, patient-centered approaches to cancer care from prevention through survivorship, with an emphasis on enhanced quality-of-life. A landscape analysis was conducted to inform the Alliance's strategic planning by providing an overview of current locoregional activities, barriers, and interventions around colorectal and cervical cancer screenings, genetics services, and continuity of care along the cancer continuum.


Barriers

Barriers to care, and especially cancer screenings, are well documented in all patient populations. There are often multiple, confounding factors, for example, patient fear, community distrust, cost, and lack of transportation. Some barriers are out of patient control, such as distance to a healthcare facility, inconvenient clinic hours, or limited capacity. Reducing such structural barriers leads to increased access to cancer screenings.

ACCC's literature review identified the following barriers to screenings and related services.

Cervical Cancer

Incidence and mortality rates of cervical cancer are higher in Appalachian areas of Ohio, Kentucky, West



Virginia, and Virginia when compared to other parts of the U.S.⁸ Similarly, this area has lower screening and vaccination (for Human Papilloma Virus) rates, and high smoking rates. These rates are attributed to a region that is rural, often described as geographically isolated, with above-average poverty rates, low household income, and below-average educational attainment.⁹

Identified barriers to cervical cancer screening include:

- Preference for a female provider^{10,11}
- Competing priorities, such as caregiving and lack of childcare^{11,12}
- Lack of patient-centered communication: demeaning or discriminatory attitudes towards women (language, culture, low socio-economic status)¹¹
- Lack of accommodation for women's logistical needs around clinic hours and location¹¹
- Human papillomavirus infection (HPV) self-sampling-specific: forgetting, fear, lack of time, worry about using test incorrectly.¹³

Colorectal Cancer

Colorectal cancer is preventable with routine screenings. However, it remains the second leading cause of cancer mortality in the United States. In Appalachia, colorectal cancer incidence and mortality rates are higher when compared to the U.S.¹⁴ There are many factors attributable to the high mortality and incidence rates including unfamiliarity and lack of adherence to screening guidelines, feelings of worry about colorectal cancer, and poor overall health.

Identified barriers to colorectal cancer screening include:

- Lack of knowledge about stool-based testing options (e.g., FIT, FOBT) and appropriate frequency of each, doubt about the quality of tests, incorrect completion, inconvenience (e.g., some need multiple samples)¹⁵
- Colonoscopy-specific: perceived discomfort of prep and/or procedure, sense of violation (especially among men), embarrassment, and privacy and/or confidentiality concerns, especially in rural areas where people may personally know healthcare staff^{15,16}

- 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.¹⁵

Genetic Services

Generally, genetic services are more available around major cities, which creates a problem for those living in rural Appalachia. Tele-genetics, or the provision of remote genetics services, is a promising strategy for extending reach into rural areas and addressing distance-related access barriers. Further unintended access challenges may occur, however, for some rural, older, etc. patients in Appalachia due to lack of equipment or connectivity issues.¹⁷

Identified genetic services barriers include:

- Distance, transportation, and/or time barriers¹⁸⁻²⁰
- Technological access, literacy, and infrastructure limitations, such as lack of internet and mail service coverage^{5,18,21}
- High cost perceptions¹⁸
- Low prioritization^{19,21}
- Lack of physician recommendation (in part because of lack of physician skills and knowledge around genetic risk assessment, referral, and guidelines)^{18,21,23}
- Lack of insurance coverage and/or costs.^{18,21}

Interventions

Cervical Cancer

Numerous factors appear to facilitate cervical cancer screening. These factors include prior screening participation, referral by a healthcare professional, experience of positive symptoms, perceived need, prior HPV diagnosis, perception of convenience, interest in health status, and having family or friends who had cancer experiences.^{20,23,24}

Specific facilitating interventions and strategies include:

- HPV self-sampling

- Patient navigation and/or community health workers
- Community outreach
- Patient education
- Material supports
- Clinic-level interventions
- Community and/or systems-level interventions
- Policy interventions.

Colorectal Cancer

Colorectal cancer screening rates are affected by provider recommendation, family support and encouragement, perceived risk, family history of colorectal cancer, and knowing people with this type of cancer.^{11,13,20}

A systematic review found these interventions were associated with increased colorectal cancer screening completion: outreach, patient navigation, patient education, patient reminders, clinician interventions of academic detailing, clinician reminders, repeated mailed FOBT (fecal occult blood tests) with navigation.¹⁶

In fact, interventions designed to remove barriers for patients have increased colorectal cancer screenings by 37 percent.²⁵ Interventions specifically focused on patient navigation services provided through healthcare systems. Patient navigation services target populations experiencing greater disparities in cancer screening, including historically disadvantaged racial and ethnic populations, as well as those with lower incomes.

Specific facilitating interventions and strategies include:

- Test choice
- Community outreach
- Patient education
- Material supports
- Clinic-level interventions
- Community and/or systems-level interventions
- Policy interventions.

Continuity of Care

As diagnosis and treatment options evolve in cancer care, so too do the number of providers patients see for their care. The cancer care continuum spans primary care through specialty and sub-specialty care providers. Collaboration between PCPs and specialty care providers can be challenging, and there are many opportunities to develop issues around care transitions. Continuity of care, therefore, becomes imperative to ensure quality outcomes for patients. The focus for continuity of care is around care transitions early in the cancer continuum, interactions between primary care and oncology, and follow-up after an abnormal cervical or colorectal screening.

Primary Care and Cancer Specialist Team Interactions

Primary care providers interact with specialty providers regularly. Those conversations and interactions are important regarding patient care. The landscape analysis found the following concerns among providers:

- Primary care providers prefer more communication from cancer specialists and report a significant gap between diagnosis through end of treatment. Oncologists also report infrequent communication and see room for improvement.²⁷
- Primary care providers prefer a shared-care model, oncologists prefer specialist-based care.²⁸

Cervical Cancer

There were logistical and psychological barriers identified for follow-up care after an abnormal (positive) Pap test result.²⁹

Colorectal Cancer

The main barrier under continuity of care for colorectal cancer was follow-up care after an abnormal (positive) FIT test result.³⁰ Secondary barriers included cost concerns, lack of insurance, lack of transportation, and psychological state after a positive screen.

Interventions

Strategies identified to mitigate care continuity issues and improve provider communication include:

- Using a memorandum of understanding (MOU) between primary care and local cancer programs

to formalize workflows and shared care processes

- Examining feasibility of shared electronic health records (EHR) or communication systems
- Agreeing to a referral system among providers
- Piloting embedding an oncologist in the primary care setting, or vice versa
- Examining opportunities for informal rapport-building between multidisciplinary care teams
- Identifying and sharing primary contact information for ease of ongoing contact
- Ensuring clear documentation including follow-up recommendations³¹
- Sharing data on cancer volume and stage to encourage collaboration among oncology programs
- Engaging with cancer care networks to collaborate on funding.

Interventions identified in the landscape analysis for cervical and colorectal cancer focus on provider-to-provider communications (examining how specialists such as cardiologists or endocrinologists interact with primary care providers), medical centers providing rural sites with technical assistance and services, and patient navigation.³²

Next Steps

The Alliance has chosen to focus its efforts on optimizing colorectal cancer screenings in Appalachia for 2023. The Alliance will prioritize relationship building among multidisciplinary providers through an e-newsletter, local, regional, and/or national meetings, and educational webinars. In addition, the Alliance will use an implementation framework to map evidence-based solutions to identified barriers and leverage existing resources and Alliance expertise to develop new solutions. Information and materials created will be disseminated amongst ACCC member programs and partners. Organizations or individuals interested in staying informed or participating in the Alliance can [sign up on the website accc-cancer.org/acca](https://acc-cancer.org/acca).

Key Highlights from the Landscape Analysis

- Incidence rates for colorectal cancer in Appalachia range from 19.9 per 100,000 in Virginia to 29.5 in Mississippi (2015 to 2019) compared to the U.S. national rate of 21.8. Four Appalachian states (Mississippi, Kentucky, West Virginia, and Pennsylvania) fall within the highest late-stage incidence, and five (Mississippi, West Virginia, Kentucky, Tennessee, Alabama) fall within the highest mortality quintile of states in the U.S.³¹
- Parts of Appalachia have been identified as early onset colorectal cancer hotspots.³² Colorectal cancer screening prevalence among people aged 50 and above ranged from 68.97 percent in Mississippi to 74.83 percent in Pennsylvania, compared to 71.9 percent in the U.S, with nine states above the national average.³¹
- Incidence rates for cervical cancer in Appalachia range from 2.6 in Virginia to 5.1 in Kentucky compared to the U.S. national rate of 3.6. Mortality rates range from 1.9 in Virginia, New York, and North Carolina, to 3.4 in Mississippi compared to the U.S. national rate of 2.2.³¹

For more information on the **Appalachian Community Cancer Alliance**, visit [ACCC's website accc-cancer.org/acca](https://acc-cancer.org/acca).



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