# Influences on African American and Black Men's Decisions about Colorectal Cancer Screening



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# BACKGROUND

Colorectal cancer (CRC) is the second leading cause of cancer death in Lancaster County.<sup>1</sup> There are racial disparities in cancer screening, diagnosis, and outcomes across the United States, and these disparities also exist in Lancaster County.<sup>2</sup> The age-adjusted death rate for CRC is higher in Lancaster among Black individuals (15.5 per 100,000) than among white (12.5 per 100,000) and Hispanic (14.5 per 100,000) individuals.<sup>3</sup>

Research studies have concluded that large numbers of deaths from cancer could be prevented through increased use of evidence-based screenings, including 58% to 68% of CRC deaths.<sup>4</sup> At Penn Medicine Lancaster General Health, 75.1% of all eligible patients and 72.0% of Black patients were up to date with CRC screening in Fiscal Year (FY) 2022. LG Health has set a goal to increase colorectal cancer screening rates among all patients and to reduce the disparity in screening rates for Black patients. To achieve this goal, LG Health has already implemented several strategies, including a text-based campaign asking patients to make an active decision about scheduling a screening, as well as an initiative to mail at-home fecal immunochemical test (FIT) kits to patients who were not up to date with screening.

In Summer 2022, LG Health partnered with the NAACP Lancaster Branch and researchers at Allium Development Group LLC to study Black men's perceptions about colorectal screenings. Our research questions were:

- How do Black male patients perceive their risk of colorectal cancer?
- What do patients perceive are the benefits of screening for colorectal cancer?
- What are the barriers to completing screening?
- What are the factors that encourage screening?

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• What do patients recommend for the content and format of interventions to improve screening rates among Black males?

The overall goal of this project was to gather community feedback to improve LG Health's colorectal cancer screening services for Black male patients.

# **METHODS**

We conducted this study between June and September of 2022. We initially planned to conduct a mixed-methods study, including an online survey and focus group discussions with Black and African American men. However, due to recruitment challenges, we changed our approach to gather data through individual interviews.

To recruit participants, LG Health and the NAACP Lancaster Branch canvassed neighborhoods and Black-owned businesses, passed out flyers at church events, sent out mass emails, and posted information about the study in community centers and at community partner organizations. LG Health staff emailed a study invitation to a list of Black males, ages 50-85 years old, from patient contact information in LG Health's electronic medical record. However, we were unable to recruit any participants for the online survey and few for focus groups. Overall, 11 individuals contacted LG Health with interest in the study, and seven individual interviews were scheduled and completed. Most of the participants were directly asked by NAACP staff to participate in the study.

The final study included seven Black men from Lancaster County between the ages of 50 and 85 years. All seven participants had undergone colorectal cancer screenings. Participants were given \$50 in compensation for their time. The interviews were completed by one interviewer, a staff member at Allium.

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The interviews were conducted over the phone using a semi-structured guide developed by LG Health and Allium and lasted approximately 30-45 minutes. Once the interviews were completed, Allium transcribed the conversations to text. Next, the researchers used thematic coding to analyze the transcripts for answers to the research questions. Coding in qualitative research is the process of using short phrases or words to categorize information in the text. A codebook is used to track codes and their definitions to use them consistently across all interviews. These codes were used to identify common themes across all interview transcripts. The themes were summarized in a written report answering the research questions. The Institutional Review Board at LG Health reviewed and approved the study on July 13, 2022, and all participants provided informed consent. The study was supported by LG Health's internal community benefit budget and received no external funding.

# RESULTS

# Reasons Why Black Men Choose to Be Screened for CRC

Families play an important role in advocating for Black men to be screened for colorectal cancer. The findings from the interviews suggest that men are more likely to be screened if they have a family member who has died from cancer, specifically colorectal cancer. Several of the men interviewed had close family members who had died from cancer. They also had family members, such as spouses, parents, and uncles, who specifically and repeatedly talked to them about the value of being screened. This family influence was by far the largest outside influence on why individuals went on to participate in colon cancer screening.

Among the men interviewed, medical professionals – specifically primary care physicians – were important advocates for them to complete screening for colorectal cancer. Of the men who participated in the interviews, their physicians' influence was second in importance only to influence provided by their families. The men who mentioned their physicians were important in their screening decision had long-term and trusting relationships with physicians who advocated for screening. Several men mentioned that they respected their physicians' advice because they paired encouragement with up-to-date medical information and genuine care for their patients' well-being.

Looking back, several men felt that the sense of relief they got from a negative test result would encourage them to be screened in the future or to encourage others to be screened. Some of the men interviewed were screened because it would allow them to know their status and experience a feeling of relief if their result was negative. Many of these men had family histories of colorectal cancer and felt being screened was an important step toward peace of mind.

#### Reasons Why Black Men Aren't Screened for CRC

Based on our interviews, fear, mistrust, avoidance, and information sources all play a role in why Black men are not screened for colorectal cancer. All the men who were interviewed had been screened, but they gave this list of reasons for why they believe other Black men do not want to be screened.

#### ABSTRACT

**Background:** Colorectal cancer (CRC) is the second leading cause of cancer death in Lancaster County, and Black individuals are at higher risk of colorectal cancer death than are individuals of other race groups. In the summer of 2022, Penn Medicine Lancaster General Health partnered with the NAACP Lancaster Branch and researchers at Allium Development Group LLC to gather community feedback to improve LG Health's colorectal cancer screening services for Black male patients.

**Methods:** We conducted interviews with seven Black men from Lancaster County between the ages of 50 and 85 years. The interviews were completed by one interviewer over the phone using a semi-structured interview guide and lasted approximately 30-45 minutes. Once the interviews were completed, we transcribed the conversations to text, used coding to identify themes across all interviews, and summarized the findings.

**Results:** The Black men who participated in this small qualitative study indicated that family members and trusted physicians influenced their decisions about participating in CRC screening. Further, relief from receiving a negative result also encourages repeat screenings. The barriers to screening include fear and mistrust of health care systems, fear of getting a cancer diagnosis, concerns about cost, and the invasiveness of a colonoscopy. Results of this small survey suggest word of mouth is an important communication tool for the Black community, and communication strategies should include traditional media as well as distribution of clear and updated information through churches, community organizations, and neighborhood leaders.

**Conclusion:** Based on the participant feedback and existing research, increased CRC screening will require several approaches, including tailored communications for the Black community, patient navigation services, long-term trusting relationships between Black men and primary care providers, and continued efforts to increase diversity and reduce bias and racism in health care.

Number one on this list is fear. Some men fear finding out that they already have colorectal cancer. Said one study participant: "A lot of older Black guys don't like going to the doctors, and then they tell you a story, 'Every time I go to the doctor, I come back with something worse."

According to the participants, Black men avoid going to the doctor from fear of more medical bad news or because they fear they are being treated like "guinea pigs." The example that was cited by multiple men was the Tuskegee Syphilis Study, which enrolled hundreds of Black men without consent and for whom appropriate treatment was withheld.<sup>5</sup> The participants in this LG Health study perceived that the history of the mistreatment of the Black community by the medical community has led many men to avoid seeking medical care.

Several men also noted that when people attempt to do online research, even in medical journals, they find information that scares them about colorectal cancer and other diseases. They also reported hearing misinformation within the Black community that screening is not important, which they suggest discourages men from getting what is seen as an invasive procedure. The participants perceived that fear and desire to avoid colonoscopies was high on many men's lists for why they do not want to be screened. Many would prefer to not spend their free time undergoing the procedure. Another fear that the men observed was the unknown cost and unknown insurance coverage for screening.

# Participant Recommendations to Improve Screening for the Black Community

The men interviewed believe that raising general awareness across the Black community can have a positive impact on the number of people screened. The men interviewed said that when friends and family members are aware, have up-to-date information, and are regularly discussing the need for screening, men are more likely to be screened. Women can play a key role in advocating for screenings by reminding partners and family members about the need to be screened. The interview participants also felt that older males should talk to younger males about their experiences to set an example and to decrease any associated stigma around the procedure.

The men interviewed indicated that word of mouth is very important within the Black community and can be supported by pamphlets and flyers that are available in churches, barber shops, community clinics, and other community centers. Finally, doctors have an important communication role due to the value of the trust they have built with patients, and they should be prepared to talk in detail about the screening process. The interviewees shared that having a long-term, ongoing, trusting relationship with their doctor played an important role in their willingness to get screened through education and advocacy.

The interviews indicated that the Black community needs clearer information about the benefits of colorectal cancer screening. Topics that the men suggested would be interesting to the community include age recommendations for screening, how much screening costs, and statistics and stories of those who have survived. "It's your life, and you have to be proactive with your life," noted a study participant.

The Black men interviewed reported that their community members want to be informed consumers about medical care and are more likely to be screened if they understand the causes of colorectal cancer, the benefits of screening, and the options for screening tests. They would like physicians to share up-to-date recommendations, offer options for different types of screenings, and start the conversation before men reach the medical age for screening. The men interviewed said that physicians, family members, and friends who urged them to be screened out of a desire for their well-being had a significant positive impact on their decision to be screened. Overall, the participants identified a need to shift the narrative from cancer and screening as a negative experience to preventive cancer care as a normal part of a man's healthy and long life.

# DISCUSSION

This study gathered community input from local Black men who had completed a CRC screening. We explored the reasons they chose to be screened, barriers to screening, and their recommendations for increasing screening in the Black community. The themes raised in their interviews aligned with evidence in the literature about effective ways to increase screening.

Multicomponent interventions are one way to intervene. Multicomponent interventions are strategies that combine multiple modalities. There is strong evidence that multicomponent interventions are effective in increasing screening with colonoscopy or fecal occult blood test (median increase of 15.4 percentage points). Based on evidence from a systematic review of 88 studies, the best results come from combining three types of interventions, those that:

1. Increase interest in screening (such as patient re-

minders, and print and multimedia communication campaigns).

- 2. Increase access to screening (such as reducing outof-pocket costs, adding more convenient sites or hours, and assisting with transportation).
- 3. Increase screening recommendations from providers (such as clinical decision support or provider reminders).<sup>6</sup>

As a result, the Community Preventive Services Task Force recommends multicomponent interventions to increase screening for colorectal cancer.

Recent research studies specifically with African American and Hispanic patients found that combining mailed fecal occult blood test (FOBT) kits, tailored educational materials, follow-up communications, and patient navigation services was effective in increasing CRC screening.<sup>7-11</sup>

Our interview participants shared that the recommendation from a trusted doctor was important in their decision to be screened. Other studies have found that the lack of a recommendation from a doctor and lack of awareness about screening do contribute to racial and socioeconomic disparities in cancer screening.<sup>12</sup>

These findings have several practical implications for interventions, including increasing access to primary care for Black men and encouraging relationship-building between primary care providers and patients. Providing tailored educa-

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tion tools and clinical reminders can also help support providers' conversations about screening.

The participants in this small study focused on the need for increasing tailored communication to the Black community. Their suggestions about communication strategies and content reflect best practices in social marketing for health promotion, such as using trusted messengers within the Black community and focusing on communication channels that patients prefer to use. Because word of mouth is an important communication method, information around colorectal cancer and screenings should target two specific audiences: male patients who are nearing or at the age for screening and the Black community as a whole.

In addition to the neighborhood-level communication strategies the men recommended, more traditional marketing strategies would include public health an-

nouncements on TV, on social media, and at sporting events. The public health announcements should include local Black doctors, celebrities, and community members telling their personal stories. All these methods will help raise awareness and increase the volume of trusted voices on this topic. The men also recommended providing clear and updated information, clearly describing options for testing, and framing the messages in a positive way. Many in the community already know people who have died, so changing the narrative to those who caught polyps early and have been screened regularly could change the community perception from a death sentence to an opportunity for life. Using principles of health literacy, health care organizations should tailor communication materials to ensure that Black community members can find, understand, and use information to make an informed decision about CRC screening for themselves and others.<sup>13</sup>

Finally, our interviews raised the issue of racism and mistrust in the health care system, which is also reflected in the literature. Many quantitative studies link higher mistrust scores with lower rates of CRC screening among Black Americans. Fear of experimentation and

> intrusiveness of screening methods have appeared in other qualitative studies as unique barriers to CRC screening among Black men.<sup>14</sup> Mistrust may be rooted in the unjust differences that Black patients experience in the health care system, as sug-

gested in a recent systematic review showing that in 38 of 66 studies, Black patients reported experiencing worse patient-physician communication quality and satisfaction, less information-giving, less participatory decision-making with providers, shorter visits, and more experiences with physicians who were verbally dominant in conversations, compared with white patients.<sup>15</sup>

A diverse health care workforce with Black staff members, health care providers, and leaders at all levels is important to reduce disparities in care.<sup>16</sup> In addition, all providers and staff should be required to continue participating in Diversity, Equity, and Inclusion initiatives to improve knowledge about unconscious bias, cultural humility, root causes of health disparities, and strategies for reducing inequity in health care. In LG Health's 2022 Community Health Needs Assessment, Black and Hispanic/Latino patients indicated that one

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of the top three ways to improve access to health care in Lancaster County is to increase the diversity and cultural competence of health care providers.<sup>17</sup>

# LIMITATIONS

The limitations of this study include the small sample size and the lack of participation from individuals who have not been screened. Despite several months of recruitment using a variety of methods with a community partner organization, we found that men were reluctant to participate in a research study on this topic. Our community partner organization received feedback from eligible men that they were uneasy with the idea of being "research subjects." In addition, we originally planned for focus group discussions led by Black men in the community, hoping to encourage more open discussion by matching the discussion leader with the participants in race, gender, and age group. However, when we switched to interviews, the interviewer was a younger, white female. The difference in age, race, and gender may have had an impact on the information shared during the interviews. Finally, we did not have an opportunity to validate the conclusions by sharing the report with the participants and inviting their feedback.

# CONCLUSION

The Black men who participated in this small qualitative study indicated that family members and trusted physicians influenced their decisions about participating in CRC screening, and the sense of relief from knowing the result also encourages screening. The barriers to screening include fear and mistrust of health care systems, fear of getting a cancer diagnosis, concerns about cost, and the invasiveness of a colonoscopy. Based on the participant feedback and existing research, increasing CRC screening likely requires a multicomponent approach, including communications tailored for the Black community, patient navigation services, longterm trusting relationships between Black men and primary care providers, and continuing efforts to increase diversity and reduce bias and racism in health care.

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