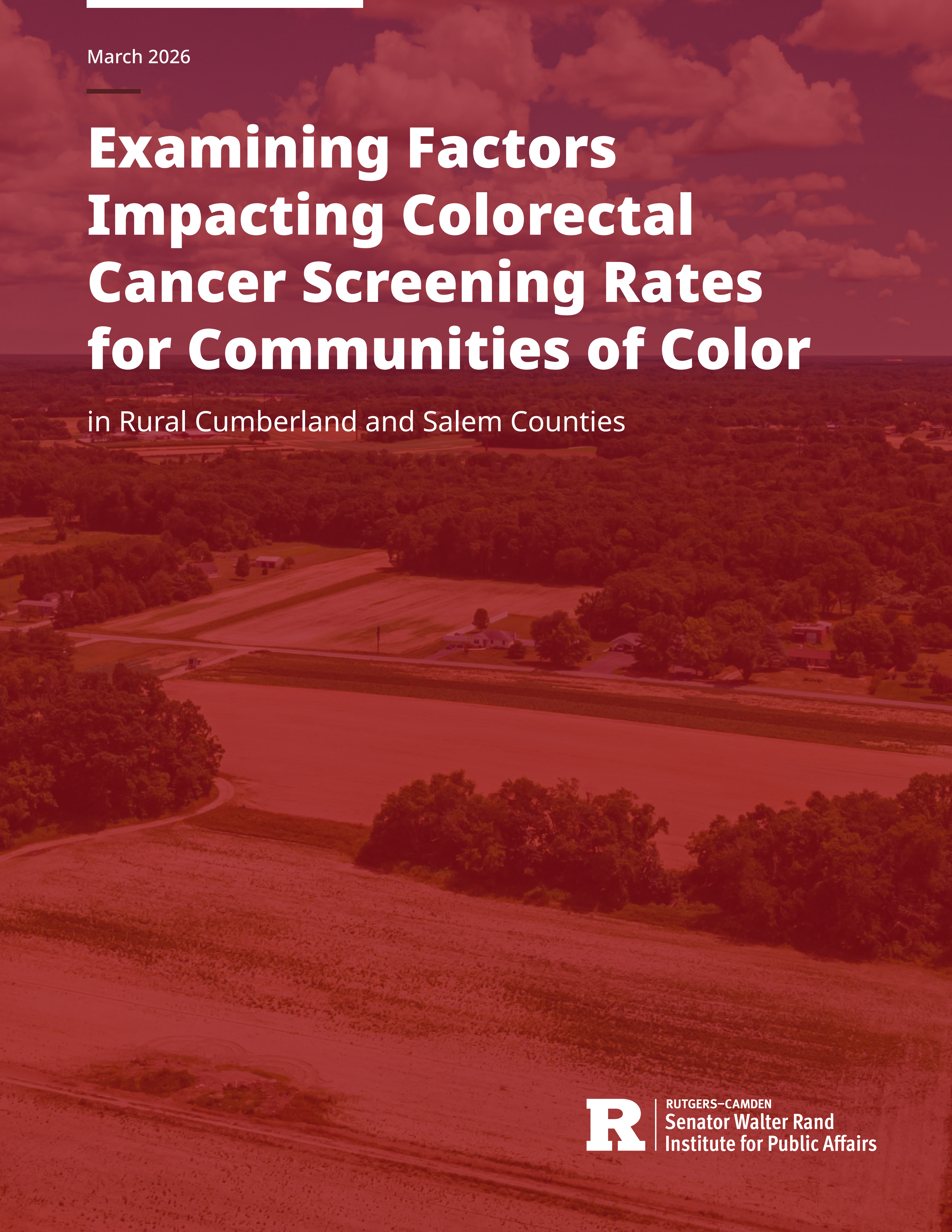

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Examining Factors Impacting Colorectal Cancer Screening Rates for Communities of Color

in Rural Cumberland and Salem Counties

RUTGERS–CAMDEN
Senator Walter Rand
Institute for Public Affairs

About the Walter Rand Institute

The Senator Walter Rand Institute for Public Affairs (WRI) at Rutgers–Camden has been a long-standing and trusted regional community partner for over 25 years. WRI honors former Senator Rand's dedication to Southern New Jersey and exists to produce and highlight community-focused research and evaluation leading to sound public policy and practice in the region. With that as a foundation, WRI convenes and engages stakeholders in making the connections across research, policy, and practice in support of Camden City and Southern New Jersey residents. Using social science research methods, WRI specializes in transforming data into actionable information across a variety of areas, including workforce development, education, transportation, and public/population health. WRI reinforces and amplifies Rutgers' research, teaching, and service goals by connecting the multidisciplinary expertise of faculty to regional problems, developing research and professional skills in students, and linking the resources of higher education to communities in Southern New Jersey.

About Inspira Health

Inspira Health is a charitable nonprofit health care organization committed to providing an exceptional experience for patients and their loved ones. Tracing its roots to 1899, the system comprises four hospitals, two comprehensive cancer centers, nine multi-specialty health centers and locations throughout South Jersey. Inspira's surgical teams provide a wide array of innovative robotic and minimally invasive surgeries, including nationally accredited bariatric services at Inspira Medical Centers Mullica Hill and Vineland. In partnership with Cooper University Health Care, Inspira provides comprehensive neuroscience and cardiology services throughout the region. Inspira's extensive ambulatory services include urgent care, ambulatory surgery centers, physical and occupational therapy, comprehensive behavioral health care, primary and specialty physician practices and extensive outpatient imaging in partnership with Atlantic Medical Imaging (AMI). Inspira EMS covers communities throughout South Jersey. Inspira's Population Health and Community Impact departments address social drivers of health that impact individuals and families in our region. Inspira's more than 1,400 physicians and advanced practice providers and 8,000 employees provide evidence-based care to help each patient achieve the best possible outcome. As a regional leader in physician training, Inspira Health educates and provides extensive clinical opportunities for more than 310 medical residents and fellows in 18 nationally accredited programs. Accredited by DNV Healthcare, the system's clinical and support staff are focused on providing quality care.

About Rowan-Virtua School of Osteopathic Medicine

The Rowan-Virtua School of Osteopathic Medicine is dedicated to providing excellence in both undergraduate and graduate medical education, research and health care for New Jersey and the nation.

About the South Jersey Institute for Population Health

The South Jersey Institute for Population Health (SJIPH) is focused on advancing collaborative research projects to improve health and wellbeing in southern New Jersey. In 2018, it was established through a state grant received by the Rowan University/Rutgers-Camden Board of Governors (Joint Board) to integrate the region's medical, educational and research assets, to improve health for Southern New Jersey. The Joint Board will include Rowan University and Rutgers University-Camden as partners in these efforts. SJIPH will focus on population health in South Jersey by addressing health disparities among underserved populations in both urban and rural communities. SJIPH will develop and deepen the network of relationships among the many entities, from schools and nonprofits, to government agencies and hospital networks, that work to improve health in the region. By supporting collaborations between this network of community stakeholders and the research expertise at Rowan University and Rutgers University-Camden, SJIPH will lay the groundwork for a robust research and data resource that can inform population health programs, research and policy needs in the future.

Project Team

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Executive Summary

Preventive colorectal cancer (CRC) screening is essential because the disease is highly treatable when detected early, yet barriers such as low health literacy, limited access to care, and cultural factors reduce participation. In New Jersey, screening rates hover around 70%, with women (66%) slightly less likely than men (68%) to be screened (New Jersey Department of Health, 2019). Progress has been made over time across the State, but rates fall below the 80% target set by the American Cancer Society in 2025 (American Cancer Society National Colorectal Cancer Roundtable, 2025). Screening can detect cancer early and prevent it by removing precancerous polyps.

Funded by the South Jersey Institute for Population Health (SJIPH), this project was a collaborative, community-based research initiative designed to improve CRC screening rates among underserved populations in Southern New Jersey—specifically focusing on two rural counties, Cumberland and Salem—and examined both patient and provider perspectives to identify barriers and opportunities for equitable CRC screening access. Using a mixed-methods approach (e.g. surveys, focus groups, and educational interventions to build an understanding of CRC knowledge, attitudes, and behaviors), the study examined patient and provider perspectives among diverse residents, including Black, Hispanic/Latinx, Nanticoke-Lenni Lenape, uninsured, underinsured, undocumented, and low-income populations.

The educational component targeted third-year medical students at Rowan-Virtua School of Osteopathic Medicine, while provider surveys assessed screening practices and perceived barriers. The project united Inspira Health, Rowan-Virtua School of Osteopathic Medicine, Rutgers–Camden School of Nursing, and the Senator Walter Rand Institute for Public Affairs (WRI) as research project partners to capture a comprehensive view of CRC knowledge and behaviors in Southern New Jersey.

Findings showed major gaps in knowledge and awareness: only 13% of Hispanic respondents and 65% of English-speaking respondents knew what CRC screening was, and many believed screening was unnecessary without symptoms. Misconceptions about age guidelines, test procedures, and risk were common, and participants—especially Spanish-speaking, uninsured, and low-income residents—reported that providers seldom initiated screening discussions. Mistrust of the healthcare system further hindered screening, driven by fear of procedures, past negative experiences, discrimination concerns, and lack of insurance. Structural barriers such as transportation, cost, and work schedules reinforced avoidance of preventive care.

Medical student surveys showed significant gains in CRC knowledge after training, particularly regarding updated screening age guidelines. Remaining gaps highlight the need for continued curriculum emphasis. Provider survey results showed strong reliance on reimbursement and clinical evidence but also revealed that 44% still recommended screening beginning at age 50 instead of 45.

Participants viewed the focus groups as effective and empowering educational experiences, highlighting that face-to-face, community-based sessions led by trusted local organizations are working to build knowledge, trust, and immediate screening uptake. Overall, the study underscores the need for culturally responsive education, stronger provider–patient communication, and community-centered strategies to address CRC screening disparities in rural Southern New Jersey counties.

Introduction

There are more than 20 million Americans eligible for colorectal screenings who have not been screened (Davidson et al., 2021). The American Cancer Society (ACS) estimates that colorectal cancers will result in the death of 55,230 people in 2026 (McDowell, 2026). The incidence of colorectal cancer and the rate of mortality is highest among Black men and women (Giaquinto et al., 2022). Colorectal cancer (CRC) is the third most diagnosed cancer in New Jersey (Selvakumar et al., 2023). Providers, navigators, and support staff are critical components of the screening process for colorectal cancer. Raz et al. (2018) suggest that educational training for healthcare providers should be sought to improve adherence to recommendations. In this study, we examined the impact of patient navigation and provider education on CRC screening completion rates, and the screening barriers among minority populations, including Black, Hispanic/Latinx, Nanticoke-Lenni Lenape (NLL), undocumented, uninsured, low-income, and those with language barriers.

Southern New Jersey counties, including Cumberland and Salem, rank highest in the Area Deprivation Index and have lower cancer screening rates and higher obesity prevalence compared to other counties in the State (Kind & Buckingham, 2018). The Area Deprivation Index is a tool that displays the relative socioeconomic conditions of neighborhoods when compared to the overall nation's average, which exposes vulnerable areas in a standardized method. Cumberland and Salem counties also rank among New Jersey's most rural areas, where healthcare service delivery is challenging, and health status ranks among the poorest in the State. Several types of CRC preventive screenings can be performed at home. The most common tests besides the traditional colonoscopy are the Fecal Immunochemical Test (FIT) and the Fecal Occult Blood Test (FOBT). The stool DNA test (Cologuard/FOBT) detects microscopic amounts of blood in stool and looks for specific DNA changes associated with cancerous tumors or precancerous polyps by searching for DNA biomarkers in stool (American Cancer Society, 2025; Colorectal Cancer Alliance, 2025). A fecal immune test (FIT) is an FDA-approved at-home colon cancer screening test that a doctor may recommend for detecting blood in the stool. This test can detect signs of precancerous polyps or cancer (American Cancer Society, 2025; Colorectal Cancer Alliance, 2025). While colonoscopy remains the standard, a FIT test is a practical alternative for those in rural or low-income settings, those facing social or logistical barriers, or individuals who are not considered high risk.

Previous recommendations from the American College of Gastroenterology advised initiating colorectal cancer (CRC) screening at age 50. In 2021, these guidelines were updated to lower the recommended starting age to 45 for all adults at average risk for CRC (Shaukat et al., 2021). For individuals younger than 45, earlier screening is recommended for those who meet high-risk criteria, including a family history of colorectal cancer or advanced adenomas, a personal history of colorectal polyps, or a history of inflammatory bowel disease, such as Crohn disease or ulcerative colitis (CDC, 2024). In addition, evaluation and possible earlier screening may be warranted in younger individuals who develop concerning symptoms, including rectal bleeding, unexplained iron-deficiency anemia, persistent changes in bowel habits, unexplained weight loss, or chronic abdominal pain. For patients considered at increased risk, healthcare providers may recommend initiating colonoscopy at a younger age and performing screening at more frequent intervals than for average-risk individuals (Hoff & Hudson, 2026).

Project Background

This project, funded by the South Jersey Institute for Population Health, was a collaboration between Inspira Health, Rowan-Virtua School of Osteopathic Medicine, Rutgers University–Camden School of Nursing, and the Senator Walter Rand Institute for Public Affairs at Rutgers-Camden (WRI). It was designed to examine colorectal cancer knowledge, screening behaviors, and barriers to care among community members, healthcare providers, and medical students in Cumberland and Salem counties in Southern New Jersey.

The study was guided by three central research questions: (1) what impact patient navigation and provider education have on CRC screening completion rates among uninsured and underinsured community members; (2) what level of knowledge exists regarding the availability of CRC screening services among healthcare providers and minority populations; and (3) what barriers to CRC screening are experienced by populations that are historically underserved, including Black, Hispanic/Latinx, Nanticoke Lenni-Lenape, undocumented, uninsured or underinsured, low-income individuals, and those with language barriers.

To address these questions, the project employed a mixed-methods research design that integrated quantitative surveys, qualitative focus groups, and educational interventions. Data collection occurred collaboratively across all partners. Quantitative data were gathered through surveys administered to community members, healthcare providers, and medical students, while qualitative data were obtained through in-person focus groups with targeted community populations. The combination of methods allowed for triangulation of findings, ensuring that numerical trends observed in surveys could be contextualized through lived experiences and participant narratives.

The community-based component of the study used purposeful sampling to recruit underrepresented residents across Cumberland and Salem counties. Recruitment occurred through direct outreach at community centers, public events, healthcare offices, and neighborhood flyers, as well as through online dissemination of survey links via Inspira Health's organizational networks. Surveys were made available in both English and Spanish to maximize accessibility. A total of 57 community surveys were completed, including 21 English-language surveys and 36 Spanish-language surveys.

To deepen understanding beyond survey responses, three in-person focus groups were conducted, engaging a total of 89 participants. Each focus group reflected a specific demographic composition, including a racially diverse group of Black and White residents, a group of members from the Nanticoke Lenni-Lenape Tribal Nation, and a Spanish-speaking group composed of Hispanic community members. This research aimed to capture perceptions of screening recommendations across all age groups, particularly because screening may be initiated at any age due to factors such as family history, symptom onset, or the presence of related conditions.

The educational component of the project focused on medical students enrolled at Rowan-Virtua School of Osteopathic Medicine. Across the Fall 2024 and Spring 2025 semesters, Inspira Health delivered colorectal cancer education lectures covering screening guidelines, regional cancer patterns, and related topics. Medical students completed pre-test surveys prior to the lectures and post-test surveys following the sessions to assess knowledge acquisition. In total, 158 students completed pre-tests and 140 completed post-tests. In addition, nine healthcare providers affiliated with Inspira Health completed provider surveys that explored screening recommendation practices and perceived barriers within clinical settings.

Together, these components created a comprehensive assessment of CRC knowledge, behaviors, and barriers across multiple levels of healthcare in Southern New Jersey. While some survey sample sizes were smaller than anticipated, the findings remain informative and reveal critical gaps in knowledge, communication, and access that can inform future intervention efforts.

All collaborators played integral roles in the data collection process. Rutgers University partners (WRI and Rutgers-Camden School of Nursing) coordinated survey administration, focus group facilitation, and provided research evaluation expertise while supporting direct data collection. Inspira Health directed outreach to community members, facilitated survey recruitment, and coordinated with participants for focus groups.

Additionally, Inspira Health partners delivered the cancer prevention lectures that served as a foundation for pre- and post-surveys with Rowan medical students. Rowan-Virtua School of Osteopathic Medicine partners ensured the participation of medical students in the research by incorporating pre- and post-testing within the Family Medicine Clerkship curriculum.

These collaborators contributed expertise in recruitment, data collection, community engagement, and professional education, ensuring data across all the desired populations.

Quantitative Survey Findings

Pre- and Post-Survey Findings Among Medical Students: Training Effective but Reveals Need for Continuous Awareness of Guideline Updates

The medical student component of the study sought to assess baseline knowledge of colorectal cancer screening guidelines and to evaluate the immediate impact of structured educational lectures delivered by Inspira Health. A total of 158 students completed pre-test surveys prior to the educational intervention and 140 students completed post-test surveys following the lecture. The difference in response counts reflects normal attrition associated with survey-based educational assessments.

Pre-test findings indicated variability in students' baseline understanding of colorectal cancer screening guidelines, risk factors, and regional disparities. Many students demonstrated foundational knowledge regarding colorectal cancer as a significant public health issue. Gaps were observed in awareness of updated screening recommendations, particularly regarding the recommended age to initiate screening for average-risk individuals. This finding aligns with national trends showing lag time between guideline updates and widespread adoption among trainees (Read et al., 2021).

Post-test results demonstrated overall improvements in knowledge following educational intervention. Students showed increased recognition of the importance of early and routine screening, and greater familiarity with screening modalities beyond colonoscopy. The post-test findings suggest that focused educational programming can effectively enhance medical student preparedness to discuss colorectal cancer screening with future patients, particularly those from high-risk or underserved communities.

Do you think colorectal cancer screening procedures should be routinely ordered or performed on asymptomatic, average-risk patients?	Pre-test (N = 161)	Post-test (N = 143)
Yes	93% (150)	99% (142)
No	7% (11)	1% (1)

There was an increase in understanding of screening guidelines for asymptomatic, average-risk individuals, with support for routine screening increasing from 93% to 99%. This suggests that the educational session successfully corrected misconceptions about symptom-based testing and emphasized proactive screening as a best practice.

Most people should start colorectal screening at age 50.	Pre-test (N = 160)	Post-test (N = 141)
True	38% (61)	37% (52)
False	62% (99)	63% (89)

However, there was no significant change in participants' understanding of the updated screening guidelines. Around one-third of respondents continued to believe that age 50 is the correct starting point, despite the updated recommendation being age 45 for average-risk individuals. This result highlights a persistent knowledge gap that may require clearer emphasis in future training around the updated guidelines, especially through updated visual aids or updated guideline handouts.

Are average-risk adults aged 50+ eligible for FREE Colorectal Screenings?	Pre-test (N = 160)	Post-test (N = 143)
Yes	66% (105)	82% (117)
No	34% (55)	18% (26)

Importantly, the pre- and post-test design highlighted the role of formal education in addressing inconsistencies in guideline awareness. There was a significant improvement in awareness after training, with recognition of free CRC screening eligibility increasing from 66% to 82%. This reflects a positive shift in knowledge about insurance coverage and public health policy, which is essential for improving screening rates in underserved populations. The observed knowledge gains reinforce the value of incorporating targeted cancer prevention education into medical curricula, especially as future providers will play a critical role in initiating screening conversations and addressing patient concerns.

Effectiveness of Screening Procedures	Pre-test (N = 160)	Post-test (N = 143)
Very effective	75% (120)	92% (132)
Somewhat effective	24% (38)	7% (10)
Not effective enough	1% (2)	1% (1)

There was a notable increase in the number of participants who believe CRC screening is “very effective,” rising from 75% to 92%. The percentage of those who thought it was only “somewhat effective” dropped from 24% to 7%, suggesting the training improved confidence in the proven efficacy of CRC screening. This shift reflects a successful reinforcement of evidence-based outcomes from early detection efforts.

The pre- and post-training survey results demonstrate a positive increase in the medical students’ knowledge of CRC screening guidelines and the importance of addressing health disparities. More education is recommended for future providers to ensure that providers are up-to-date with current age recommendations for cancer screenings. The remaining knowledge gaps, particularly for a small percentage of students who were still unaware of the screening age, indicate an opportunity for continued emphasis on these topics in medical school curricula to ensure future providers are fully equipped to address CRC screening barriers.

Health Provider Survey Findings: Strong Knowledge Base Identified

The healthcare provider survey component included responses from nine professionals affiliated with Inspira Health. These surveys explored provider knowledge of CRC screening guidelines, perceptions of screening barriers, and clinical practices related to screening recommendations.

Overall, providers demonstrated strong foundational knowledge regarding CRC prevention. A large majority of respondents correctly identified that colorectal cancer can often be prevented, reflecting alignment with evidence-based public health messaging emphasizing early detection and lifestyle modification. One respondent disagreed with this statement, suggesting a need for continued reinforcement of prevention principles to ensure consistent patient messaging across clinical teams.

All provider respondents unanimously rejected the misconception that colorectal cancer is not a serious public health issue in the United States, indicating universal recognition of the disease’s significance. Similarly, all respondents correctly disagreed with the statement that patients only need to be tested when symptoms appear, demonstrating strong awareness of the importance of routine, proactive screening for asymptomatic individuals.

Providers also showed unanimous agreement that lifestyle factors such as alcohol use, physical activity, and smoking influence colorectal cancer risk. This finding underscores providers' readiness to engage in prevention-focused counseling that integrates behavioral risk reduction with screening promotion.

Most people should start colorectal screening at age 50.	Percentage	Count
True	56%	5
False	44%	4

Variation emerged regarding knowledge of screening initiation age. Slightly more than half of respondents believed screening should begin at age 50, while the remainder answered "false," likely reflecting their awareness of updated guidelines recommending initiation at age 45 for average-risk individuals. This split highlights an important knowledge gap and reinforces the need for ongoing provider education to ensure guideline updates are uniformly understood and implemented.

Providers identified several major patient-level and system-level barriers to screening. The most frequently cited major barriers included patient embarrassment or anxiety about screening tests, fear of discovering cancer, lack of awareness or underestimation of colorectal cancer risk, and concerns related to cost or insurance coverage. These barriers were each identified as major by six out of nine respondents. Additional noted challenges included inconsistent provider recommendation practices, shortages of trained providers for follow-up invasive procedures, and limited availability of trained personnel for screening modalities beyond fecal occult blood testing.

The provider survey findings illustrate significant alignment between clinical knowledge and the qualitative experiences described by community members below. Providers recognize key barriers,and the persistence of low screening uptake suggests that awareness alone is insufficient without structural support, consistent recommendations, and patient-centered navigation strategies.

Community Member Surveys: English-Speaking & Hispanic Participants—Gaps between Knowledge and Action

Community member surveys were completed by 57 individuals across Cumberland and Salem counties, including 21 English-speaking respondents and 36 Spanish-speaking respondents. The two groups differed markedly in demographic characteristics, health literacy, and perceived barriers, highlighting the importance of culturally and linguistically tailored approaches to colorectal cancer outreach.

English-Speaking Community Members

Among English-speaking respondents, ages ranged from 24 to 62 years, with an average age of 44.5 years and a median age of 45. The sample was predominantly White, with smaller proportions identifying as Hispanic/Latinx, Black or African American, American Indian or Alaska Native, and Native Hawaiian or Pacific Islander. Nearly all respondents reported English as their primary language spoken at home.

English Community Member Age Summary	Value
Minimum Age	24
Maximum Age	62
Average (Mean) Age	44.5
Median Age	45
Mode	34, 44, 48
Age Range	38
Total Respondents	**21**

The majority of English-speaking respondents were married, and most identified as women. Educational attainment was relatively high, with most participants reporting completion of a college degree. Employment status reflected a largely working population, with most respondents employed full-time. Household income levels varied widely, reflecting a mix of higher-income households and individuals with more limited financial resources.

Despite relatively high levels of education and healthcare engagement, screening uptake remained low. Only 37 percent of English-speaking respondents reported ever completing a colorectal cancer screening, while 63 percent had never been screened. Among those who had been screened, most reported recent screenings occurring between 2019 and 2023, with one individual scheduled for screening in late 2024. One respondent reported having undergone two colonoscopies, suggesting high-risk monitoring or adherence to follow-up recommendations. While 65% of community members reported knowing what colorectal cancer screening is, a significant 35% did not, indicating a critical knowledge gap. This highlights an opportunity for basic education and outreach to explain what CRC screening involves, who needs it, and why it matters.

Use of non-invasive screening methods was particularly low. Only one out of eight English respondents reported completing a fecal blood test within the past three years, while the vast majority had not. Among respondents who had been screened, colonoscopy was the sole method reported. This narrow reliance on colonoscopy suggests limited awareness or availability of alternative screening options such as FIT or FOBT. Further, only 1 in 5 community members reported being informed about their eligibility for free colorectal cancer screenings, while 65% had never been told, and 15% were unsure. This reflects a major gap in outreach and communication, especially considering cost is a known barrier. Expanding education on free or low-cost screening programs could significantly improve uptake, particularly among uninsured or underinsured populations.

Provider engagement was inconsistent. Only 40 percent of respondents reported that a doctor had advised them to obtain colorectal cancer screening, while 60 percent reported never receiving such a recommendation. Among those who received advice but did not follow through, inability to take time off work was cited as the primary barrier. Additionally, only one in five respondents reported being informed that they might be eligible for free colorectal cancer screening services, highlighting a significant gap in communication about cost-reducing resources.

Overall, the English-speaking community demonstrated relatively high awareness of colorectal cancer risk factors and prevention but continued to experience a gap between knowledge and action. Structural barriers, inconsistent provider recommendations, and limited system-level support appear to contribute to persistently low screening rates.

Hispanic Community Members

All Hispanic respondents reported Spanish as the primary language spoken at home, underscoring the importance of Spanish-language communication strategies. Many respondents were married and identified as women. Educational attainment was notably lower, with nearly all respondents reporting education at the elementary school level. Most participants were employed full-time, yet household income levels were uniformly low, with all respondents reporting annual incomes below $30,000.

Hispanic Community Member Age Summary	Value
Minimum Age	23
Maximum Age	60
Average (Mean) Age	44.13
Median Age	46
Mode	47
Age Range	37
Total Respondents	**36**

Misconceptions about colorectal cancer prevalence were also present. Over one-third of respondents believed that colorectal cancer is not a major problem in the United States, indicating a need for broader public health education emphasizing disease burden and disparities.

Most reported at least one healthcare visit in the past year, and relatively few reported frequent interactions with the healthcare system. Knowledge assessments revealed substantial gaps and misconceptions. For example, only half of respondents correctly believed that colorectal cancer can often be prevented, while the other half believed it could not.

I Only Need to Get Tested for Colorectal Cancer If Something Seems Wrong	Percentage	Count
True	69.4%	25
False	30.5%	11

Most Hispanic respondents (69%) incorrectly agreed with the question that screening is only necessary when symptoms appear, demonstrating a gap in understanding the importance of routine and preventive screening.

Lifestyle Choices Impact Colorectal Cancer Risk	Percentage	Count
True	44.4%	16
False	55.5%	20

Approximately (55%) of Hispanic community members did not recognize that lifestyle choices, such as smoking, exercise, and alcohol use, can affect colorectal cancer risk. This reflects a generally limited level of health literacy. This population may benefit from targeted education on risk factors, empowering them to take preventive action in their daily habits.

Has anyone ever told you that you may be eligible for FREE colorectal cancer screenings?	Percentage	Count
Yes	16.6%	6
No	77.7%	28
Not sure	5.5%	2

Only 16% of Hispanic community members reported being informed about their eligibility for free colorectal cancer screenings, while 77% had never been told, and 5% were unsure. This reflects a major gap in outreach and communication, especially considering cost is a known barrier. Expanding education on free or low-cost screening programs could significantly improve uptake.

Family history awareness was limited, with most respondents reporting no known family history of colorectal cancer or polyps, and a notable proportion indicating uncertainty. Moreover, provider recommendation rates were low, mirroring patterns seen in the English-speaking group.

Taken together, the Hispanic community survey findings highlight compounded considerations related to language, education, income, health literacy, and healthcare access. These factors intersect to create significant challenges in awareness, engagement, and screening uptake, underscoring the need for culturally responsive, linguistically appropriate, and low-barrier screening interventions.

Qualitative Focus Group Findings

The qualitative findings presented in this section are drawn from in-person focus groups conducted with community members in Cumberland and Salem counties. These focus groups were intentionally designed to explore firsthand experiences, perceptions, beliefs, and emotional responses related to colorectal cancer and its screening process. While the quantitative surveys provided measurable trends in knowledge and behavior, the qualitative data offer critical contextual depth, revealing how structural, cultural, and personal factors intersect to influence screening decisions. The themes that emerged illuminate knowledge gaps, misinformation, emotional resistance, and systemic barriers that were not fully captured through survey instruments alone.

Across all focus groups, participants initially demonstrated hesitation and discomfort, particularly when discussions involved medical systems, bodily functions, and cancer diagnoses. However, as conversations progressed, participants became increasingly engaged, candid, and reflective, allowing for the emergence of consistent thematic patterns across groups.

Knowledge Gaps and Misinformation

Focus group discussions revealed widespread gaps in knowledge and persistent misinformation related to colorectal cancer, its risk factors, recommended screening ages, and available screening methods. Many participants demonstrated limited understanding of the purpose of routine screening and were unfamiliar with the concept of preventive screening altogether. Several participants believed that colorectal cancer screening was only necessary when symptoms were present, reflecting a misunderstanding that screening is reactive rather than proactive.

In many cases, participants were unaware of recommended screening ages or had outdated information. During discussions, facilitators often encountered uncertainty or silence when asking direct questions about screening timelines. One facilitator asked, *"Do you know how old you should be to check your colon?"* prompting visible confusion among participants and reinforcing the extent of the knowledge gap.

> *"Do you know what they are looking for when you do a stool test? What do you think they're looking for in the stool?" - Focus Group Facilitator.*
>
> *"Diseases." - Focus Group Participant.*
>
> *"Blood, that's what he's looking for. Because sometimes there is blood in the stool, but it does not show up in the eyes, but when we look at it under the microscope, there is blood. That is what he is looking for." - Focus Group Facilitator.*

Participants also demonstrated limited awareness of colorectal cancer symptoms and risk factors, including hereditary risk and lifestyle influences. Some participants shared information that was inaccurate or outdated, indicating that prior health messaging may have been inconsistent, inaccessible, or insufficiently reinforced over time. This lack of foundational knowledge appeared to contribute directly to delayed screening, avoidance of healthcare conversations, and heightened anxiety surrounding testing.

Commonly noted amongst focus group participants was the lack of familiarity with medical terminology as it relates to the names of colorectal cancer tests and procedures. There were quite a few instances of respondents not remembering or realizing that they had tests done when they had been asked if they had completed the procedure by name. However, when said procedure had been described to them, they were able to recognize that they had completed it. For instance, asking focus group participants if they had ever been screened for colorectal cancer or completed a FIT test produced limited responses, vs. describing a FIT test in detail yielded multiple responses from individuals stating they had completed the procedure.

Additionally, it was a common occurrence that once participants were provided with information and descriptions relating to testing procedures, they were able to make personal, real-life connections. For some, this meant newly discovering the name and/or purpose of a medical procedure they had completed. However, others learned during the focus group that, despite likely being eligible for screening(s), they had not received them.

> *"[interpreted in real time] They [Participant] said that they had taken a FIT test before they did a stool test. They have never had a colonoscopy, though they didn't realize that they should have had one." - Focus Group Participant.*
>
> *"Was that easily accessible? Was it easy to do?" - Focus Group Facilitator.*
>
> *"Oh yeah, it was easy, but he didn't realize that he should have had one done (colonoscopy). He's never had one, and he's 45." - Focus Group Facilitator on behalf of the participant, interpreting in real time.*

Notably, knowledge gaps were not confined to one demographic group. Across English-speaking, Spanish-speaking, and Indigenous focus groups, participants expressed similar uncertainty regarding screening eligibility and processes. In several instances, participants learned for the first time during the focus groups that they may have already qualified for screening based on age or risk profile. This realization often occurred alongside expressions of frustration or disbelief that such information had not been communicated earlier by healthcare providers.

Personal and Emotional Barriers to Screening

In addition to informational gaps, focus groups revealed deeply rooted personal and emotional barriers that strongly influenced participants' willingness to seek colorectal cancer screening. These barriers included fear, anxiety, embarrassment, distrust, competing responsibilities, and discomfort with medical procedures.

Throughout the focus groups, there was a noticeable group-level unease associated with medical environments and cancer-related discussions. Participants were initially wary of sharing personal experiences and hesitant to engage with facilitators. Conversations involving bodily exposure, invasive procedures, or the possibility of a cancer diagnosis often prompted audible expressions of anxiety. Participants described fear related to making appointments, attending medical visits, and receiving potentially life-altering diagnoses.

One participant shared a personal loss that shaped their avoidance of screening, stating,

> *"Well, my brother-in-law, he died of colon cancer... And we know that in our country, it is not very accessible... Do we ignore it because we are scared? ...We do not go to the doctor when we should go..."*

Fear of discovering cancer emerged as one of the most powerful deterrents. Several participants openly acknowledged avoiding screenings because they did not want to know if something was wrong. This sentiment was echoed repeatedly across groups, particularly in the Spanish-speaking focus group, where interpretation captured the emotional weight of these decisions. One participant explained,

> *"[interpreted in real time] He was scared. He didn't want to know... That's why he never had a colonoscopy."*

This theme was reiterated by another participant, who stated,

> *"[interpreted in real time] They didn't do it because they were scared... They didn't want to know.... They didn't want to go have a test done and find something... They just didn't want to know... That's why he never had a colonoscopy done."*

Anxiety surrounding anesthesia and bodily exposure during colonoscopy procedures was another frequently cited barrier. Some participants expressed fear of medical risks associated with anesthesia, while others voiced discomfort with the idea of losing bodily control while unconscious. One participant articulated this concern by stating,

> *"[interpreted in real time] That's his issue because he's asleep, so he doesn't know what they're doing with his body."*

This concern was further clarified in another interpreted response,

> *"[interpreted in real time] Their issue is that the doctor told them that they would have to get put to sleep, so they would give them anesthesia, and people would be seeing their body. So that's their issue, because they are asleep, so they don't know what they (medical staff) are doing."*

Practical and psychological discomfort related to colonoscopy preparation also emerged as a significant deterrent. Participants described the preparation process as lengthy, unpleasant, and difficult to manage alongside work and caregiving responsibilities. One participant bluntly summarized this barrier by stating,

> *"It's the prep for it – the preparation (is a pain)."*

Others cited the taste of the preparation solution as a deterrent, with one participant stating simply,

> *"The prep tastes awful."*

Gendered caregiving roles further compounded these challenges, particularly among women. One Spanish-speaking participant highlighted how family responsibilities often take precedence over personal health, stating;

> *"Women don't go to the doctor because the women of the house take care of them, the husband, the children, everything and the women are the last ones. And it really shouldn't be like that because you have to take care of me if the others are not well, who is going to take care of the family? And you don't pay attention to the body, the body is saying that something is wrong, but it is not going to check us for many reasons, because you don't have health insurance, you don't have money to pay or a private doctor in colorectal screenings can be expensive."*

These narratives illustrate how emotional, cultural, and logistical factors interact to discourage screening, even when individuals recognize its importance.

Healthcare System Barriers and Provider Engagement

Participants across all focus groups expressed frustration and mistrust related to the healthcare system and provider engagement. Many described feeling unheard, rushed, or dismissed during medical encounters. Several participants shared perceptions that providers do not consistently listen to patient concerns or initiate meaningful conversations about preventive care.

One participant stated plainly,

> *"You can't depend on the doctors,"*

while another remarked,

> *"You have to take your health into your own hands… doctors don't take enough time with you."*

A recurring issue was the absence of provider-initiated conversations about colorectal cancer screening. Many participants reported that they had never discussed screening with their doctor and did not know that such conversations were necessary. In several instances, participants learned during the focus groups that they likely qualified for screening based on age or risk, which contributed to feelings of confusion and skepticism toward the healthcare system.

This lack of communication fostered mistrust and reinforced avoidance behaviors. While some participants acknowledged personal responsibility for managing their health, many emphasized that guidance from trusted medical professionals was essential and often missing. The disconnect between provider knowledge and patient experience mirrored findings from the quantitative provider surveys, where inconsistent recommendation practices were identified as a barrier.

Cost and access barriers further strained trust in the healthcare system. Even when low-cost or free screening options existed, participants were often unaware of them. One participant expressed frustration with perceived costs, stating,

> *"The kit costs $90… for a plastic container and some little bottles of crap."*

This perception of high cost, regardless of actual pricing or eligibility for free programs, served as a powerful deterrent and reinforced the belief that screening was financially out of reach. For many individuals, there are a number of systemic barriers in place that make it very difficult to access care.

Addressing Barriers, Effective Community Messengers, and Focus Groups as Two-Way Learning Spaces

Despite the challenges identified, focus group participants consistently described the sessions themselves as positive and empowering experiences. As discussions progressed, participants increasingly viewed each focus group as an educational opportunity rather than solely a research activity. Many became engaged, curious, and comfortable asking questions, treating the sessions as informal learning seminars.

Participants frequently requested additional information about colorectal cancer and screening opportunities, both during and after the sessions. Several asked facilitators whether they would return and expressed interest in continued engagement. When asked how barriers could be addressed, one participant responded,

> *“You guys coming here like this,”*

while another stated,

> *“Information sessions like this are helpful.”*

Trusted community voices were repeatedly identified as effective messengers. Participants praised local organizations such as the Cumberland County African American Breast Cancer Support Group and NJ Cancer Education and Early Detection (NJCEED) for their outreach and education efforts. One participant shared,

> *“We love that group (Cumberland County African American Breast Cancer Support Group) they explain all kinds of stuff.”*

The immediate impact of these interactions was evident. As a direct result of focus group engagement, six individuals were able to register for NJCEED and received FIT tests to complete independently. Beyond screening participation, some participants expressed a desire to become advocates within their own communities. One participant stated,

> *“Maybe if I get it done, I could turn around and go spread the word and maybe get another person to go. Maybe they can go and just try to get it done.”*

Another participant echoed this sentiment, stating,

> *“[interpreted in real time] He said he would be willing to tell family members because he’s at an age he feels like he doesn’t really need it and probably they wouldn’t do it anyway. But he said his family members that are younger and friends, he would definitely encourage them to have a test done when they’re supposed to have it done.”*

Participants also emphasized the need for age-targeted outreach, particularly for younger individuals perceived as disengaged from their health. One participant remarked,

> *“Young ones need more coaxing… all they care about is the computer.”*

Suggestions for improving communication included more face-to-face conversations with healthcare providers, routine distribution of simple and accessible educational materials, and the use of patient portals such as MyChart for reminders and learning resources. Importantly, participants stressed that materials should be concise and approachable. One participant explained,

> *"I think too that sometimes less information can be better – it's more likely to catch people's eyes. Maybe give something very simple and that way you can pull them in…because sometimes when someone sees something (really long) they're like 'oh no, I'm not reading all that stuff.'"*

The qualitative data from the community focus groups underscores the critical need for person-centered and community-driven outreach. The findings confirmed the existence of significant knowledge gaps and misinformation, highlighting the need for educational materials that are simple, accessible, and culturally appropriate. The participants' desire for more direct, face-to-face conversations with healthcare providers and the value of positive doctor-patient relationships also suggest that relationship-building is a key component of effective screening promotion. Ultimately, the qualitative insights provide a clear directive for future interventions: they must not only provide information but also build trust and address the emotional and social factors that serve as barriers to care. The data affirm that effective interventions must go beyond information dissemination to build trust, address emotional and cultural barriers, and strengthen relationships between patients, providers, and community organizations.

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For more information around free CRC screenings, please click the link below or scan the QR code to learn more about NJ Cancer Education and Early Detection (NJCEED).

Click here

Overarching Recommendations, Takeaways and Future Directions

This project's mixed-methods approach provides a clear picture of the multi-level strengths and barriers around colorectal cancer (CRC) screening in Southern New Jersey. Surveys showed significant knowledge gains among medical students after training, validating the effectiveness of targeted educational sessions. Focus groups offered valuable firsthand insight and helped build trust with both English- and Spanish-speaking community members, many of whom were highly engaged, asked questions, and requested additional sessions. Participants recommended improving public awareness through TV ads, social media, mailers, community events, and expanded educational forums.

Community input emphasized the need to reach younger audiences by integrating CRC education into schools, universities, and local events. Participants also stressed the importance of consistent communication from healthcare providers, including discussing screening ages, symptoms, and family history at routine visits. Clear, multilingual educational materials and increased automated reminders through patient portals could further support screening adherence. Outreach workers and patient navigators remain essential for building trust and guiding patients through the healthcare system, while collaboration among providers, community leaders, and health systems will strengthen ongoing efforts.

Provider survey results highlighted persistent knowledge gaps, supporting the need for continuing education courses focused on updated screening guidelines, patient communication, and navigation services. These should be offered in both in-person and virtual formats. A regional CRC awareness campaign featuring simple, bilingual messaging and clear testing instructions would further extend the project's impact and should be developed with community input to ensure cultural relevance.

The findings of this research have broad implications for future efforts in public health. Future studies should move beyond simply identifying knowledge gaps to testing the efficacy of specific intervention models. This could include comparing the effectiveness of different patient navigation models or evaluating the long-term impact of provider education on patient screening rates.

Policymakers should consider the study's findings when developing policies to improve cancer screening rates. This includes creating or expanding prevention efforts such as reimbursement for patient navigation services, which would incentivize health systems to adopt a proven model. The findings also support the need for public health campaigns that address both knowledge gaps and the emotional barriers to screening. With sustained collaboration and investment, Southern New Jersey can move toward a more proactive approach to CRC prevention, improving outcomes not only for today's patients but for future generations.

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