

Published in final edited form as:

*Int J Canc Prev.* 2011 ; 4(4): 307–338.

## Patient and Provider Preferences for Colorectal Cancer Screening: How Does CT Colonography Compare to Other Modalities?

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### Abstract

**Objectives**—Patient and provider preferences toward CT colonography (CTC) remain unclear. The primary goals of this study were 1) to investigate patient preferences for one of the currently recommended CRC screening modalities and 2) to evaluate provider preferences before and after review of updated guidelines.

**Methods**—Cross-sectional survey of ambulatory-care patients and providers in the primary care setting. Providers were surveyed before and after reviewing the 2008 guidelines by the American Cancer Society, US Multisociety Task Force on Colorectal Cancer and the American College of Radiology.

**Results**—Of 100 patients surveyed, 59% preferred colonoscopy, 17% fecal occult blood testing (FOBT), 14% stool DNA (sDNA) testing, and 10% CTC ( $P < 0.001$ ). The majority of those whose first choice was a stool-based test chose the alternate stool-based test as their second choice over CTC or colonoscopy ( $P < 0.0001$ ). Patients who preferred colonoscopy chose accuracy (76%) and frequency of testing (10%) as the most important test features, whereas patients who preferred a stool-based test chose discomfort (52%) and complications (23%). Of 170 providers surveyed, 96% chose colonoscopy, 2% FOBT, and 1% FOBT with flexible sigmoidoscopy (FS) ( $p < 0.0001$ ). No providers chose CTC or sDNA as their preferred option before reviewing guidelines, and 89% kept their preference after review of guidelines. As a default option for patients who declined colonoscopy, 44% of providers chose FOBT, 12% FOBT+FS, 4% CTC, and 37% deferred to patient preference before review of guidelines. Of the 33% of providers who changed their preference after review of guidelines, 46% recommended CTC. Accuracy was the most influential reason for provider test choice.

**Conclusions**—Patients and providers prefer colonoscopy for CRC screening. Revised guidelines endorsing the use of CTC are unlikely to change provider preferences but may influence choice of default strategies for patients who decline colonoscopy.

## Introduction

Colorectal cancer (CRC) is the second leading cause of cancer-related death and the third most commonly diagnosed cancer among men and women in the United States. [1, 2] Screening has been shown to be a cost-effective strategy for reducing both CRC mortality through early detection and CRC incidence through the detection and removal of precancerous adenomatous polyps. Despite its efficacy and widespread endorsement by authoritative groups, [3–5] screening rates among both average- and high- risk groups remain suboptimal [6–10].

Although most providers prefer colonoscopy because of its superior adenoma detection rates, [11, 12] up to 40% of patients choose stool-based testing after learning about the advantages and disadvantages of the various screening tests. [13] The availability of multiple screening modalities with different pros and cons and the lack of consensus regarding the single most cost-effective strategy have led most authoritative groups to advocate a shared decision-making (SDM) approach when selecting a screening strategy. [14–16] SDM is a sequential, interactive process involving information exchange, values clarification, decision-making and mutual agreement. [17]

Inherent in this approach is the need to elicit not only patient but also provider preferences for one of the recommended screening options, since physician recommendation has been shown to be a major determinant of CRC screening uptake among patients. [18–20]

Computed tomography colonography (CTC) and stool-based DNA testing (sDNA) are newer screening modalities that were recently endorsed in guidelines proposed by the joint American Cancer Society (ACS), GI Multi-Society Task Force on Colorectal Cancer (GI-MSTF) and the American College of Radiology (ACR). [15] Neither CTC nor sDNA, however, were included in revised guidelines proposed by the US Preventive Services Task Force (USPSTF), which concluded that there was insufficient evidence to warrant an endorsement. The extent to which the new ACS/GI-MSTF/ACR guidelines will impact provider recommendations or patient acceptance of CTC within the context of SDM is unclear.

We conducted separate surveys of patients and providers to investigate preferences for CRC screening. The primary goals of this study were 1) to investigate patient preferences for one of the currently recommended CRC screening modalities using a decision aid in the primary care setting and 2) to evaluate provider preferences before and after review of updated CRC screening guidelines.

## Methods

We surveyed both patients and providers. This study was approved by the Institutional Review Board at Boston Medical Center (BMC).

### Patient Survey

**Study Population**—Asymptomatic patients aged 50–75 without prior endoscopic or radiologic CRC screening who had an upcoming appointment with their primary care

provider (PCP) were eligible. Patients unable to speak or read English were excluded. Patients with a personal history of colonic neoplasia, inflammatory bowel disease or family history of colorectal neoplasia were also excluded. Subjects were recruited from two internal medicine resident primary care ambulatory clinics at BMC. Eligible subjects were identified prior to their PCP visit and permission to contact the patient was obtained from the PCP. Subjects who completed the interview were compensated for their time with a \$15 gift card.

**Study Design**—We employed a cross-sectional survey design similar to that used in our prior studies on patient preferences for CRC screening. [13, 21] Written consent was obtained prior to initiating the survey. The survey was conducted in a private consultation room in the ambulatory care clinic using a structured interviewer format in which one of two research staff verbally read the educational components of the instrument to the subject who followed along visually. Subjects were encouraged to ask questions.

At the end of each section, staff assessed knowledge and if questions were answered incorrectly, the relevant material was reviewed until the subject could answer the questions correctly. After the educational component, subjects identified a screening preference and test features influencing their choice. The entire interview took approximately 30 minutes.

**Survey Instrument**—Our survey was composed of 3 main parts: (1) decision aid, (2) assessment of patient preferences and factors influencing choices, and (3) demographic information. A complete survey is attached in Appendix 1.

1. *Decision Aid.* Apart from information about CTC, the decision aid was very similar in content and format to previously validated tools. [13, 21] It was comprised of a series of segments that provided a brief overview of the rationale for CRC screening, descriptions of the four relevant screening tests, comparisons between the different tests with respect to individual test features, and a summary of the different test features for each screening strategy.
2. *Patient preferences.* Subjects were asked to rank order preferences for screening modality and features influencing their choice. They were also asked about desire to participate in decision making process, and willingness to pay if preference was not covered by insurance.
3. *Demographic information.* Age, sex, ethnicity, race, education, insurance coverage, prior FOBT testing, and reasons for lack of prior screening were obtained.

**Sample Size and Power Calculation**—Our analyses focused on patient screening preferences and identification of patient characteristics and attitudes associated with screening preferences. Existing data suggests that 50–60% of patients prefer colonoscopy [21] and 25–45% prefer stool based tests. [13] Data on patient preferences for CTC were unknown at the time. We determined that a sample of 200 subjects would provide >80% power of detecting a 20% difference in preference between colonoscopy and CTC and 98% power of detecting a 25% difference in preference between CTC and stool-based tests at the two-tailed  $P < 0.05$  level.

An interim analysis was performed after recruitment of 100 patients. Based on the results of these first 100 patients and assuming that observed trends reflected the true differences between test preferences, we calculated the conditional power for observing significant pairwise differences in preferences for FOBT, sDNA, and CTC given an additional 100 patients (total n=200). [22] Each of these strategies was preferred by a minority of patients compared to colonoscopy (59%). If the 100 additional patients were recruited, the study would have less than 10% power of showing a difference between FOBT and either sDNA or CTC, and less than 30% power of showing a difference between sDNA or CTC. This projection suggested that further enrollment was unlikely to demonstrate a significance difference between FOBT, sDNA and CTC. Hence, enrollment was stopped at n=100 patients.

**Statistical Analysis**—Descriptive statistics were performed to characterize the study population, screening preferences and important test features associated with preferences. The percentages of patients preferring each screening option were compared using chi-square goodness-of-fit test for equal percentages. Chi-square tests of independence were used to assess associations between outcome variables and demographic factors including age (50–59, 60), sex, ethnicity, race (white, black, other), education (high school degree or less, some college and above), insurance status (private, Medicare, Medicaid, Freecare, none), and prior FOBT testing (yes, no). Similar analyses were used to evaluate associations between decision making autonomy, role of insurance coverage and patient characteristics. Significance was defined at the  $P < 0.05$  level. All analyses were performed using SAS version 9.3 (SAS Institute Inc, Cary, NC).

## Provider Survey

**Study Population and Design**—Surveys were randomly distributed to a convenience sample of general internal medicine and family medicine residents, physicians, physician assistants and nurse practitioners working in the outpatient primary care clinics at Boston Medical Center and its 5-affiliate community health centers (Codman Square, Dorchester House, East Boston Neighborhood, South Boston, South End). The survey took approximately 10 minutes. Obtainment of informed consent had been waived by the IRB at BMC.

**Survey Instrument**—A 19-item close-ended questionnaire was developed to assess provider screening test preferences among recommended options (CTC, colonoscopy, sDNA, and FOBT with flexible sigmoidoscopy (FS)) as well as non-recommended options (barium enema, FOBT, FS alone) before and after reviewing recent guidelines on CRC cancer screening by the ACS/GI-MSTF/ACR and USPSTF (Appendix 2). Providers were also asked about factors influencing their preferences, the guidelines to which they adhere, and demographic information.

**Sample Size and Power Calculations**—A sample size estimate of 200 was determined based on the number of practitioners who met eligibility requirements at participating sites.

**Statistical Analysis**—Descriptive statistics were performed to characterize the practitioners, their preferences, and influencing factors. Chi-square analysis was used to compare associations between outcome variables and provider factors. McNemar's test for paired categorical data was used to evaluate change in provider preferences before and after reviewing guidelines. For our analysis of change in default screening option before and after reviewing guidelines, those who selected “defer to patient preference” were excluded.

## Results

### Patient Survey

**Sample Characteristics**—A total of 121 subjects were consecutively enrolled between October 2008 and February 2010 of which 100 met eligibility criteria and agreed to participate. Of the excluded subjects, six had already had CRC screening not documented in our records, 10 refused due to time constraints, and 5 had immediate competing medical issues. Table 1 summarizes the sample demographics. The patients were predominantly aged 50–59, black, with high school education or less, and Medicaid or free care insurance.

Reasons for not having had prior CRC screening were assessed on a 5-point Likert scale, where 0=not important and 5=very important. “I don't need one because I feel fine” was found to be the most important reason with a mean score (standard deviation) of  $1.8 \pm 1.6$ , followed by “The test(s) are painful,” ( $1.7 \pm 1.6$ ), “No one in my family has/had colorectal cancer,” ( $1.7 \pm 1.6$ ), “My doctor never recommended screening,” ( $1.7 \pm 1.7$ ), “I might get injured by the testing,” ( $1.6 \pm 1.7$ ), “The test(s) are too embarrassing,” ( $0.9 \pm 1.3$ ), “I'm not sure I want to know if I have cancer,” ( $0.9 \pm 1.5$ ), “I am worried that the doctor might find that I have colorectal cancer” ( $0.8 \pm 1.2$ ), “I don't want to use an enema or laxative,” ( $0.8 \pm 1.3$ ), and “I don't want to handle my stool” ( $0.4 \pm 0.98$ ).

**Screening Test Preference and Features Influencing Choice**—Overall, patients were significantly ( $P < 0.001$ ) more likely to chose colonoscopy (59%) than FOBT (17%), sDNA (14%) and CTC (10%); the differences between the other screening tests were non-significant (Figure 1). Eight-seven percent (27 of 31) of those whose first choice was a stool-based test chose the alternate stool-based test over CTC or colonoscopy ( $P < 0.0001$ ) and 13% (4 of 31) chose either CTC or colonoscopy. Moreover, of those who preferred stool-based testing, 68% (21 of 31) preferred CTC over colonoscopy as their next choice ( $P = 0.07$ ).

Table 2 shows the association between test feature and screening preferences. Combined data for the two stool-based tests is shown because results were similar when FOBT and sDNA were analyzed separately. Patients who preferred colonoscopy chose accuracy (76%) followed by frequency of testing (10%) as the most important test features influencing their choice. Conversely, those who preferred one of the stool-based tests were more concerned about discomfort (52%), followed by complications (23%). Patients who preferred CTC were more likely to choose accuracy (40% vs. 13%) than those who preferred one of the stool-based tests, but also more likely to choose concerns about discomfort (20%).

Subgroup comparisons were performed to assess whether screening preferences varied by demographic factors or prior FOBT (Table 3). Sex and education were associated with test preference. Compared to men, women more frequently ( $P=0.04$ ) preferred colonoscopy (70 vs. 52%) and CTC (14 vs. 8%).

Compared to those with a high school degree or less education, those with some college or more frequently ( $P=0.003$ ) preferred colonoscopy (86 vs. 49%). Those with a high school degree or less choose CTC more often than those with higher education (13 vs. 4%,  $P=0.17$ ). Though not significant, all of those who chose CTC were black ( $n=10$ ). Age, ethnicity, race, insurance, and prior FOBT were not associated with test preference.

### Impact of Insurance Coverage

When asked if they would still pick their first choice screening test if it was not covered by their insurance company and they had to pay out-of-pocket, 24% said yes regardless of the cost, 25% said maybe depending on the cost, 29% said no, and 22% were not sure. Subjects who preferred stool based tests were more likely to respond “no” in their willingness to pay out of pocket compared to colonoscopy or CTC (42 vs. 25 vs. 10%,  $P=0.01$ ). Age, sex, race, education, insurance, prior FOBT and most influential test feature were not associated with willingness to pay.

**Decision Making Autonomy**—When asked about who should decide what test to pursue, 53% said the doctor and patient equally, 20% said the patient alone, 13% said the doctor alone, 7% each said mostly the patient and mostly the doctor. Compared with subjects with high school degree or above, those with less than high school education were more likely to favor a doctor-dominant (doctor alone or mostly the doctor) or shared process (96% vs. 64%,  $P < 0.0001$ ). This trend also occurred when education was compared dichotomously at high school education or below versus above high school ( $P=0.06$ ).

Decision making autonomy did not vary by age, sex, race, insurance, prior FOBT or first choice test. When asked whether it is important that the doctor know their preferences for CRC screening test, 95% either agreed ( $n=36$ ) or strongly agreed ( $n=58$ ) and 5% were neutral.

When asked if they would complete a CRC screening test if the test recommended by their doctor was the same as the one they prefer, 96% said yes, 1% said no and 3% were not sure. When asked if they would complete a CRC screening test if the test recommended by their doctor was different from the one they prefer, 49% said yes, 21% said no and 30% were not sure. There was no association between response choice and demographic variables.

### Provider Survey

**Sample Characteristics and CRC Screening Preferences**—A total of 170 providers completed the survey between January and June 2009. Table 4 lists their characteristics. Overall, 96% of providers chose colonoscopy, 2% FOBT, and 1% FOBT with flex sig as their preferred option before reviewing guidelines. No providers selected CTC, barium enema, flex sig alone or stool DNA. After review of guidelines, 89% of providers kept their initial screening preference, with the majority (99%) still preferring

colonoscopy (Figure 2). Of the 11% who changed their first-line screening test after reviewing guidelines, 42% now preferred FOBT+FS, 32% FOBT, 21% CTC, and 5% colonoscopy.

There was a significant decrease in colonoscopy as the first-line screening choice before and after guidelines (96 vs. 89%,  $P=0.001$ ).

When asked to identify a default option for patients who declined colonoscopy, 44% of providers chose FOBT, 12% FOBT+FS, 4% CTC, and 37% deferred to patient preference before review of guidelines.

Among the 107 providers who did not defer to patient preference, 67% kept their default screening preference after review of guidelines with the majority (69%) still favoring FOBT alone (Figure 3); of the 33% of providers who changed, 46% now recommended CTC, 23% FOBT+FS, 11% barium enema, 9% FOBT, 6% colonoscopy, and 6% FS. Both the increase in CTC (6 vs. 18%,  $P=0.004$ ) and decrease in FOBT (70 vs. 49%,  $P<0.0001$ ) were significant.

Choice of default screening method differed by level of training ( $P=0.03$ ). Compared with attendings, residents were more likely to recommend FOBT+FS (17 vs. 6%) or comply with patient preference (42 vs. 32%) and less likely to recommend FOBT alone (35 vs. 54%). Both residents and attendings were equally likely to recommend CTC (3 vs. 4%).

Gender was associated with default test recommendation such that female practitioners were more likely to recommend CTC (25 vs. 19%) and less likely to recommend FOBT alone (29 vs. 45%) compared to males ( $P=0.05$ ). In terms of practice type, hospital-based practitioners were less likely to recommend FOBT testing (37 vs. 61%) and more likely to defer to patient preference (46 vs. 26%) than community based practitioners ( $P=0.02$ ). After review of guidelines, academic practitioners were less likely to recommend FOBT testing (30 vs. 52%) and more likely to recommend CTC (27 vs. 12%) than community based practitioners ( $P=0.04$ ). Number of years in practice, personal CRC screening experiences, and predominant practice insurance type were not associated with screening recommendations in any scenario.

**Access to CTC**—Of the 143 providers who answered, 54% had access to CTC and 46% did not. Of the 170 providers who answered, only 11% said they had ever referred a patient for CTC. Before guidelines, more providers with access to CTC would recommend it as a default screening option (6 vs. 0%,  $P=0.02$ ). Choice of first line and default screening test after review of guidelines did not differ by access to CTC.

**Guidelines**—When asked to which guidelines they were most likely to adhere, 43% of providers choose USPSTF, 25% ACS/GI-MSTF/ACR, 31% both and 1% neither.

**Reason for Test Recommendation**—Providers strongly valued accuracy in their recommendation of test choice with 67% listing this as the most influential reason compared to 8% who listed frequency of testing, 8% patient discomfort, 7% patient comorbidities, 5% complication rates, 2% cost of test, 2% liability, 1% patient demographics and 1%

educational level ( $P < 0.0001$ ). Since providers overwhelmingly choose colonoscopy as their preferred screening method, analysis between association between most influential reason and primary test was not performed.

## Conclusion

In this study of 100 primary care patients using a decision-aid tool explaining CRC screening options, we confirmed that patients have distinct preferences for one of several available CRC screening tests and that their choice reflects the relative value they place on test features. The majority of patients preferred colonoscopy followed by stool-based testing. Among those who preferred colonoscopy, accuracy was the most important test feature whereas among those who preferred stool-based testing, discomfort was the most important test feature, which is consistent with prior studies. [11, 13] Relatively few patients selected CTC as their preferred test; however, among patients who preferred stool-based tests, CTC was preferred over colonoscopy as a default screening option. Women and those with higher education preferred colonoscopy. We also found that a majority of patients want to play an active role in decision making, although those with less education wanted more provider input.

Understanding the available CRC screening options, weighing their attributes, and ultimately selecting the test that is most aligned with individual preferences can be a time-consuming and challenging process for patients and practitioners alike. Different methods have been used previously in the research setting to help with CRC screening decisions. Explicit techniques ask patients to compare the relative importance of relevant characteristics of a decision and include rating and ranking, [23] maximal differential scaling, [24] and conjoint analysis (aka choice-format or discrete choice experiments). [11, 23, 25] In rating and ranking, patients rate on a Likert scale the importance of different decision attributes, whereas in maximal differential scaling, respondents make choices among a series of sets of items from master list in lieu of rating. In conjoint analysis, which has been used in marketing, economics and psychology, [26] multiple sets of two hypothetical options with different attributes are presented to the patient who must pick their preferred options or state they have no preferences. In all of these approaches, the results can be used to help the patient select the test which is most congruous with their answers. In this study, we used a more direct technique, in which patients received detailed information about choices and considered their potential value on their own. This approach has been used previously in CRC screening decision aids [13, 27] and has the benefit of providing more thorough information on test choices as part of an informed decision making process. It also is intuitively more practical for clinical use.

To our knowledge, this is the first study to elicit patient preferences for CTC among the menu of other recommended modalities in asymptomatic patients who were previously unscreened. A survey of 68 patients previously non-adherent with recommendations for CRC screening found that 80% were willing to undergo CTC but 70% would not be willing to pay. [28] This study was limited by a lack of a comparison modality and in its generalizability given the homogeneity of the population, which was mostly white. Studies among patients who have been previously screened are conflicting and highlight potential



racial differences in preferences. A survey of 205 ethnically diverse patients found no significant difference in ratings for colonoscopy, CTC, or fecal immunochemical testing (FIT). [11] However, blacks were more likely to prefer FS and colonoscopy, which was not fully explained by elicited values. They also found that the less educated were less likely to prefer colonoscopy and choose FOBT, consistent with our findings. A convenience sample of 323 patients at a video rental store found that after hearing about test choices, 60% preferred CTC because it is noninvasive and does not require sedation compared to 26% colonoscopy. [29] Those with higher income preferred CTC. Of note, only 20% of respondents were aged  $\geq 50$ . A theoretical choice format survey of 547 Canadians found that test accuracy followed by test process were valued highly, however based on overall attributes, CTC would be preferred over colonoscopy because it is non-invasive. [25] Thirty percent of respondents preferred no screening. In contrast, a survey of 92 Veterans using a computer based decision aid to compare FOBT, FS, colonoscopy, CTC, and colon capsule endoscopy found that 62% prefer colonoscopy, 23% capsule, and 10% CTC. [24] The study must be interpreted with caution as 85% of these patients had prior screening of which 78% had had colonoscopy.

Preferences for CTC and colonoscopy among patients who have experienced both remain mixed, [29–31] with some studies favoring CTC [32–36] and others favoring colonoscopy. [37–40] A study of ethnically diverse patients found that racial and ethnic minorities were less likely than whites to prefer CTC over colonoscopy (66% white, 45% black, 36% Hispanic). [39] Overall, minorities were less satisfied with CTC and less willing to undergo it again. In our study, although not statistically significant, all patients who preferred CTC were black. Our new findings highlight that while CTC may not be preferred to colonoscopy, it may have a role as a default screening strategy in patients who prefer stool blood testing.

In our survey of 170 primary care providers, we found that providers overwhelmingly value accuracy and promote colonoscopy as their first choice screening test and did not change after review of new ACS/GI-MSTF/ACR guidelines. After review of guidelines, however, providers were more like to consider CTC as a default screening strategy for patients who decline colonoscopy though they still preferred FOBT for this group. There were some differences by level of training, gender, and practice setting. In a different web-based survey designed to assess knowledge of CTC, only 12% of providers were aware of CRC screening guidelines including CTC. [41] While our study explicitly reviewed guidelines that included CTC, we still found that provider behavior is unlikely to change despite new guidelines. Our findings are consistent with existing literature on the secular trends of providers preferring colonoscopy and valuing accuracy most. [13, 21, 27, 29] Interestingly, previous work suggests that while providers and patients both value accuracy highly, providers perceive that patients may value discomfort the most, which may influence their discussion. [21] Most providers seem to have a preferred option and one default option and do not routinely discuss entire menu of screening options, [42, 43] which our current work supports given how patients dichotomize into those who value accuracy and those that value discomfort.

While our study's main strengths are its inclusion of CTC among the CRC screening options as well as the participation of both patients and providers, we acknowledge certain

limitations. First, we did not evaluate CTC with non-cathartic bowel preparation, which may increase the appeal of CTC and change patient preferences.

A previous survey of 212 patients showed that preparation was a low attribute in test selection; [11] however, another survey conducted in Australia among patients with symptoms suspicious for CRC found that while colonoscopy was preferred to CTC, as the need for second procedure and accuracy increased and cost of CTC rose, CTC would be preferred to colonoscopy if no bowel preparation was needed.[44]

In a recent randomized control trial of over 8000 patients evaluating participation and yield of colonoscopy versus non-cathartic CTC in the Netherlands, Stoop et al. found that when no bowel preparation is needed, patients are more likely to adhere to CTC (34%) than colonoscopy (22%). [45] Colonoscopy, however, yielded more adenomas. We did not discuss other subtleties with CTC such as discovery of incidental findings, which may have changed responses but was outside the scope of this study.

Our study did not include newer FIT and therefore, we can not draw conclusions, although there is some evidence that FIT may be better accepted than FS or colonoscopy. [46, 47] In a study of ethnically diverse patients using conjoint analysis, both FIT and CTC were preferred over older tests such as FS and FOBT, though colonoscopy was still the most preferred [11].

Those who ranked discomfort and accuracy highly tended to prefer FIT, compared with those who ranked accuracy and test frequency highly who tended to prefer CTC. A recent large randomized controlled trial of FIT versus colonoscopy in Spain showed greater adherence with biannual FIT (34%) compared to colonoscopy (25%). [48]

We did not include specific information on cost in our decision aid, which may impact choices; however, the extent to which cost considerations influence patient preferences is unclear. Two studies found that cost was not a significant determinant of patient preferences for CRC screening strategy, [49, 50] whereas one study comparing FOBT and FS found that patient preferences were sensitive to out-of-pocket expenses. [51]

We did ask patients about their willingness to pay for their preferred screening test if not covered by insurance, but in the absence of cost information, conclusions can not be drawn. Another limitation is that our study does not address whether or not eliciting patient and provider preferences changes behavior, such as type of screening test ordered, adherence or other outcomes.

There is some evidence to suggest that despite the use of decision aids, such as ours, the overall effectiveness depends on the extent to which providers comply with patient preferences. [52] Lastly, despite the racial diversity in our sample, our findings may have limited generalizability beyond an urban, socioeconomically disadvantaged referral center.

In summary, our study finds that both primary care providers and patients prefer colonoscopy and that recent guidelines endorsing CTC as a screening option are unlikely to

change provider preferences. Still, CTC may have a role as a default strategy in those who decline colonoscopy.

Our work contributes to the growing body of literature regarding the importance of employing a shared decision-making approach when selecting an appropriate screening strategy.

Future studies are needed to determine whether the elicitation of patient preferences within the context of shared-decision making improve CRC screening participation.

## APPENDIX A

Subject # \_\_\_\_\_

### COLORECTAL CANCER SCREENING DECISION AID AND PATIENT PREFERENCE QUESTIONNAIRE

Colorectal cancer is the second leading cause of cancer-related death and the third most commonly diagnosed cancer among men and women in the United States.

Screening has been shown to reduce mortality through the detection and subsequent removal of precancerous adenomatous polyps, but many patients are still not being screened.

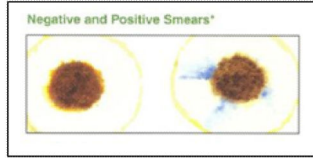
There are at least 4 possible ways to screen for colon cancer:

- Stool card test (fecal occult blood test)
- Stool DNA test
- CT colonography (virtual colonoscopy)
- Colonoscopy

#### DESCRIPTION OF SCREENING TESTS

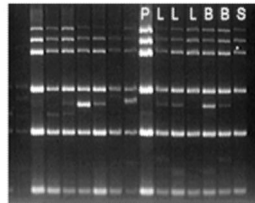
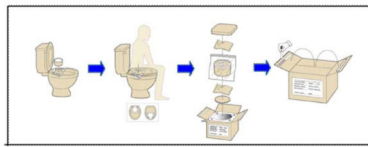
##### I. Stool card test

Involves placing a small amount of stool onto a cardboard slide with a small wooden stick. It is done at home and involves three consecutive bowel movements onto three separate cards. These cards are then brought to your doctor's office or mailed in.



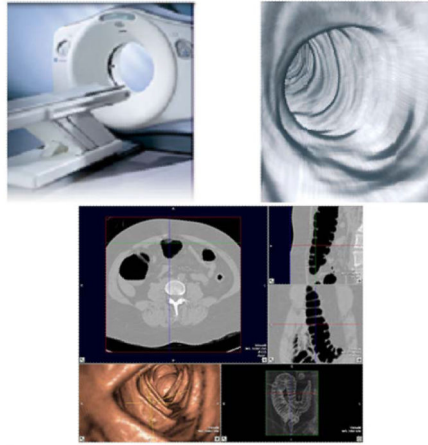
## II. Stool DNA Test

Involves placing a collection bucket directly under the toilet seat to collect a single whole stool sample. The bucket is then placed in the preaddressed packing, and shipped to the laboratory for analysis. You will not have to handle the stool material.



### III. CT Colonography

Involves lying down on a table that moves into and out of a large tunnel. A small flexible tube is inserted into the rectum to allow air to be pumped into the colon. The machine then uses x-rays to produce multiple images of the inside of the body that are then linked together to create 3D images that are examined on a computer monitor.







### IV. Colonoscopy

Involves the insertion of a flexible rubber tube into the rectum that is advanced to directly look at the walls of the entire colon.









Frequency that each test needs to be performed

			
<b>Stool Card Test</b>	<b>Stool DNA Test</b>	<b>CT Colonography</b>	<b>Colonoscopy</b>
Needs to be done once a year. In 10 years it would be done 10 times.	Needs to be done once every 2 to 5 years. In 10 years, it would be done 2 to 5 times.	Needs to be done once every 5 years. In 10 years, it would be done 2 times.	Needs to be done once every 10 years. In 10 years, it would be done 1 time.

(1) Based upon this information, over 10 years which test is done the least number of times?

- Stool card testing
- Stool DNA test
- CT colonography
- Colonoscopy





Discomfort from Each Test

			
<b>Stool Card Test</b>	<b>Stool DNA Test</b>	<b>CT Colonography</b>	<b>Colonoscopy</b>
None	None	Causes stomach pain.	Causes stomach pain and pressure. May be minimized with sedation.
Unpleasant nature of placing stool onto a card.	Unpleasant nature of collecting stool sample		

(2) Based upon this information, which test do you think has the most discomfort?

- Stool card testing
- Stool DNA test
- CT colonography
- Colonoscopy





*Possible Complications Associated with Each Test*

			
Stool Card Test	Stool DNA Test	CT Colonography	Colonoscopy
None.	None.	Tears in the bowel: occurs in 1 patient per 20,000 exams (0.005%)  Potential long term harm associated with radiation dose effects.	Tears in the bowel or bleeding: occurs in 10-30 patients per 10,000 exams (0.1-0.3%) Death: occurs in 1-3 patients per 10,000 exams (0.01-0.03%)

(3) Based upon this information, which test do you think has the least number of complications?

- Stool card testing
- Stool DNA test
- CT colonography
- Colonoscopy





*What Needs to Be Done Before Each Test Is Performed*

			
Stool Card Test	Stool DNA Test	CT Colonography	Colonoscopy
Best results while on a restricted diet which involves avoiding red meat, and certain fruits and vegetables for two days before doing the test and until the test is finished.	Nothing.	Liquid diet on day before exam. Ingest 1 gallon (128 oz) of special drink or a strong laxative in liquid (3 oz.) or pill form causing bowel movements throughout the evening. No food after midnight the night before. No escort needed.	Liquid diet on day before exam. Ingest 1 gallon (128 oz) of special drink or a strong laxative in liquid (3 oz.) or pill form causing bowel movements throughout the evening. No food after midnight the night before. Must come with an escort because sedation given.

(4) Based upon this information, which test do you think is the least inconvenient in terms of preparation?

- Stool card testing
- Stool DNA test
- CT colonography
- Colonoscopy

*Amount Of Time Needed To Perform The Test*





			
Stool Card Test	Stool DNA Test	CT Colonography	Colonoscopy
The time to collect stool from 3 consecutive bowel movements.	The time to collect a single bowel movement.	The time spent in the CT scanner is 15 minutes.	The entire process is about 2-3 hours. The actual test takes 15-30 minutes to perform.

(5) Based upon this information, which test do you think takes the least amount of time?

- Stool card testing
- Stool DNA test
- CT Colonography
- Colonoscopy

*Accuracy of the Test for Detecting Cancers*

This is how good the test is in finding colon cancer. Some of the tests are better than others. Some of the tests may be positive even if a cancer is not there (false positive) which then requires further testing, usually with a colonoscopy. Sometimes the test is negative when a cancer may really be there (false negative). The best possible test would be able to find all the cancers that are really there and avoid being positive when the cancer is not really there.

			
Stool Card Test	Stool DNA Test	CT Colonography	Colonoscopy
Low-Medium	Medium-High	High - Highest	Highest





(6) Based upon this information, which test do you think is the best at finding colon cancers?



- Stool card testing
- Stool DNA test
- CT Colonography
- Colonoscopy

*Accuracy of the Test for Detecting Precancerous Polyps (Adenomas)*





This is how good the test is in finding precancerous growths called adenomatous polyps. Some of the tests are better than others. Some of the tests may be positive even if a polyp is not there (false positive) which then requires further testing usually a colonoscopy. Sometimes the test is negative when a polyp may really be there (false negative). The best possible test would be able to find all significant precancerous adenomas.

			
Stool Card Test	Stool DNA Test	CT Colonography	Colonoscopy
Low	Medium-High	High	Highest

(7) Based upon this information, which test do you think is the best at finding precancerous polyps?

- Stool card testing
- Stool DNA test
- CT colonography
- Colonoscopy

*What Is Done If the Test Is Abnormal*

			
Stool Card Test	Stool DNA Test	CT Colonography	Colonoscopy
If test is abnormal, a colonoscopy is performed.	If test is abnormal, a colonoscopy is performed.	If test is abnormal, a colonoscopy is performed.	Diagnosis is made with this test. No further testing is needed

(8) Based upon this information, which test, if abnormal, do you think has the least complicated follow up?

- Stool card testing
- Stool DNA test
- CT Colonography
- Colonoscopy

REVIEW



**Stool Card Test**

Frequency: Once a year  
Discomfort: None  
Complications: None  
Preparation: Restricted diet  
Time: 3 bowel movements  
Accuracy: Low-Medium for cancers; Low for polyps  
Follow-up: Colonoscopy



**Stool DNA test**

Frequency: Once every 2 to 5 years.  
Discomfort: None.  
Complications: None.  
Preparation: None.  
Time: A single bowel movement.  
Accuracy: Medium-High for cancers; Medium-High for polyps  
Follow-up: Colonoscopy



**CT Colonography**

Frequency: Once every 5 years.  
 Discomfort: Causes stomach pain.  
 Complications: Tears in bowel – occurs in 0.005% of patients. Potential long-term harm from radiation dose effects.  
 Preparation: Liquid diet on day prior to exam. Ingest 1 gallon (128 oz) of special drink or a strong laxative in liquid (3 oz.) or pill form causing bowel movements throughout the evening. No food after midnight the night before  
 Time: 15 minutes for test.  
 Accuracy: High – highest for cancers; high for polyps  
 Follow-up: Colonoscopy

**Colonoscopy**

Frequency: Once every 10 years  
 Discomfort: Stomach pain and pressure. Minimized with sedation.  
 Complications: Tears in bowel or bleeding- occur in 10 to 30 patients per 10,000 exams (0.1-0.3%), Death- 1 to 3 patients per 10,000 exams (0.01-0.03%)  
 Preparation: Liquid diet on day prior to exam. Ingest 1 gallon (128 oz) of special drink or a strong laxative in liquid (3 oz.) or pill form causing bowel movements throughout the evening. No food after midnight the night before. Must come with an escort because sedation given.  
 Time: 15-30 minutes for the test. Entire process- 2-3 hours.  
 Accuracy: Highest for cancers and polyps  
 Follow-up: None

(9) With the help of the information you have read, which testing type would you choose if given a choice by your doctor? Please rank the alternatives 1,2,3,4,5,6 with 1 being the most preferable and 6 the least preferred. Use each number only once.

- Stool card testing
- Stool DNA testing
- CT Colonography
- Colonoscopy

(10) Summary of important test characteristics involved with choosing a particular test:

Please select the three most important qualities of a test from the list below that influenced your decision on choosing a particular test. Once this is done, please rank them 1,2, and 3 with 1 being the most important, 2 the next most important, and 3 the third most important quality.

- How often the test needs to be done
- Discomfort associated with the test

- Complications associated with the test
- What needs to be done in preparing for the test
- How long it takes to do the test
- Accuracy of the test
- Further testing for abnormal results

(11) Medical insurers may not pay for all of the different screening tests. Would you still pick the screening test you rate #1 in question 8 if your insurance company did not cover it and you had to pay out-of-pocket?

- Yes, regardless of the cost
- Maybe, depending on the cost
- No
- Not sure

(12) Your doctor presents the four different screening options which we have discussed today at your upcoming visit. At that time you will:

- Have your doctor decide which test should be done.
- Have your doctor decide which test should be done only after he/she hears your opinions on the topic.
- Like for your doctor and you to decide together which test should be done.
- You will decide which test to have done after hearing your doctor's opinion on the topic.
- You will decide which test to have done using all you know or have learned about the different tests.

(13) Please respond to the following: It is important that my doctor know what my preferences are in deciding on a test for colon cancer screening.

Strongly Agree	<b>Agree</b>	Neither agree or disagree	<b>Disagree</b>	Strongly disagree
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(14) Would you have the screening test for colon cancer if the test recommended by your doctor is the same as the one you prefer?

- Yes  No

(15) Would you have the screening test for colon cancer done if the test recommended by your doctor is different from the one you prefer?

- Yes  No

(16) Which of the screening tests would you have done if recommended by your doctor?

Stool card test  Stool DNA test  CT Colonography  Colonoscopy

(17) Which of the screening tests would you not have done even if recommended by your doctor?

Stool card test  Stool DNA test  CT Colonography  Colonoscopy

(18) Has your doctor ever discussed colon cancer screening with you?

Yes  No

(19) Have you ever had any of the following tests done in the past (may check more than one)?

Stool card testing  
 Stool DNA testing  
 CT Colonography  
 Colonoscopy  
 Never been tested for colorectal cancer

(20) Background information

Your age

40-49  
 50-59  
 60-69  
 70 and older

Your sex

Male  
 Female

Race/

White  
 Ethnicity  
 Black  
 Hispanic  
 Asian

Other- please specify \_\_\_\_\_

Family history of colon cancer

yes  
 no  
 don't know

Highest level of education

No school completed  
 Less than 9<sup>th</sup> grade  
 High school- not completed

High school degree or equivalency  
 College- not completed  
 College degree  
 Graduate degree

Household Income

Less than \$25,000  
 \$25,000-\$49,999  
 \$50,000-\$99,999  
 \$100,000-\$149,999  
 \$150,000-\$199,999  
 \$200,000 or more

Health Insurance

uninsured  
 insured

Thank you for your time and effort. Your participation in this study has been greatly appreciated.

# APPENDIX B

## COLORECTAL CANCER SCREENING PREFERENCES

(1) Do you recommend colorectal cancer screening to your average risk patients?

Yes  No  Not sure

(2) Which is your preferred screening method for your average-risk patients?

Barium Enema  Colonoscopy  FOBT (in-office)  
 FOBT (take-home)  FOBT + Flex Sig  Flex Sig  
 Stool DNA test  Virtual Colonoscopy

(3) Which of the following is your default option for patients who decline your preferred screening option?

Barium Enema  Colonoscopy  FOBT  
 FOBT + Flex Sig  Flex Sig  Stool DNA test  
 Virtual Colonoscopy  Depends on patient preference

(4) The American Cancer Society, GI Multi-society Task Force on Colorectal cancer, and American College of Radiology have recently modified their guidelines for average risk patients to include flexible sigmoidoscopy, colonoscopy, barium enema, and CT colonography (virtual colonoscopy) as an effective screening option for the detection of colorectal polyps and early cancers. In patients unwilling to pursue the above tests, fecal

occult blood testing, fecal immunochemical tests, and stool DNA tests are endorsed as an effective screening options for the detection of colorectal cancer.

In contrast to these guidelines, the US Preventive Services Task Force (USPSTF) recommends screening for CRC using fecal occult blood testing, sigmoidoscopy, or colonoscopy in adults. They conclude that the evidence is insufficient to assess the benefits and harms of virtual colonoscopy and fecal DNA testing as screening modalities for CRC.

In light of these new guidelines, which of the following would be your preferred screening option for average risk individuals undergoing first-time screening?

Barium Enema  Colonoscopy  FOBT  
 FOBT + Flex Sig  Flex Sig  Stool DNA test  
 Virtual Colonoscopy

(5) In light of the revised guidelines, which of the following would be your default option for patients who decline your preferred option but have no preference of their own?

Barium Enema  Colonoscopy  FOBT  
 FOBT + Flex Sig  Flex Sig  Stool DNA test  
 Virtual Colonoscopy

(6) Do you have access to virtual colonoscopy at your institution?

Yes  No

(7) Have you ever referred a patient for virtual colonoscopy for the purpose of colorectal cancer screening?

Yes  No

(8) Which guidelines are you most likely to adhere to?

American Cancer Society, GI Multi-society Task Force on CRC, & American College of Radiology  
 US Preventive Services Task Force  
 Both  
 Neither

(9) Which of the following attributes most influences your choice when recommending a screening option to your average-risk patients? Please rank order your top 3 choices from 1 to 3.

Complication rates  Cost of test/coverage  
 Frequency required for testing  Liability concerns

Patient discomfort/inconvenience       Patient education level  
 Patient demographics       Test accuracy  
 Patient comorbidities

(10) One recent study suggested that colonoscopy may be much less effective in preventing death from CRC of the right colon compared to the left colon. Have the results of this study influenced your preferences for CRC screening?

Yes       No       I was not aware of the study

#### Background Information

Your sex       Male  
 Female

Your age       <50 years     60-69 years  
 50-59 years     >70 years

Your training       MD  
 Physician Assistant  
 Nurse Practitioner

Years in Practice       <5 years  
 5-10 years  
 >10 years

Practice type       Hospital based (academic)  
 Private practice  
 Hospital based (Private)  
 HMO  
 Community based clinic

Have you been screened for colorectal cancer?       Yes  
 No

If yes, through what method?  
 Barium Enema       Colonoscopy     FOBT  
 FOBT + Flex Sig       Flex Sig     Stool DNA  
 test       Virtual Colonoscopy

Do you have a family history of colorectal cancer?       Yes  
 No

Predominant level of insurance among your patients  
 Private/HMO       Medicare     Medicaid

Military/VA     Free Care     None  
 Don't know

Thank you!!!

## Abbreviations

<b>ACR</b>	American College of Radiology
<b>ACS</b>	American Cancer Society
<b>BMC</b>	Boston Medical Center
<b>CRC</b>	colorectal cancer
<b>CTC</b>	computed tomography colonography
<b>FOBT</b>	fecal occult blood testing
<b>FIT</b>	fecal immunochemical testing
<b>FS</b>	flexible sigmoidoscopy
<b>GI-MSTF</b>	GI Multi-Society Task Force
<b>HMO</b>	health maintenance organization
<b>PCP</b>	primary care provider
<b>sDNA</b>	stool DNA

<b>SDM</b>	shared decision making
<b>USPSTF</b>	United States Preventive Services Task Force

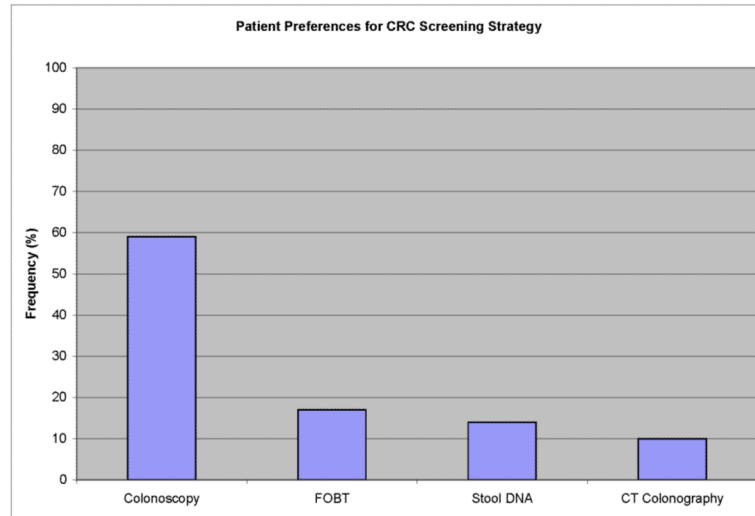
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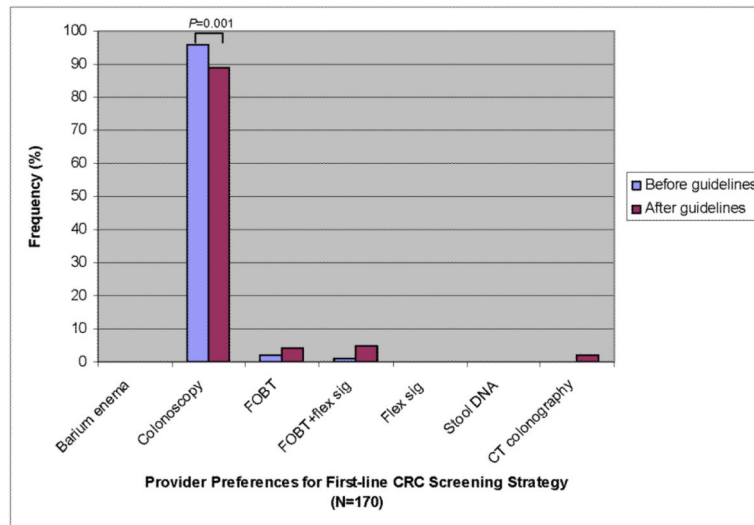


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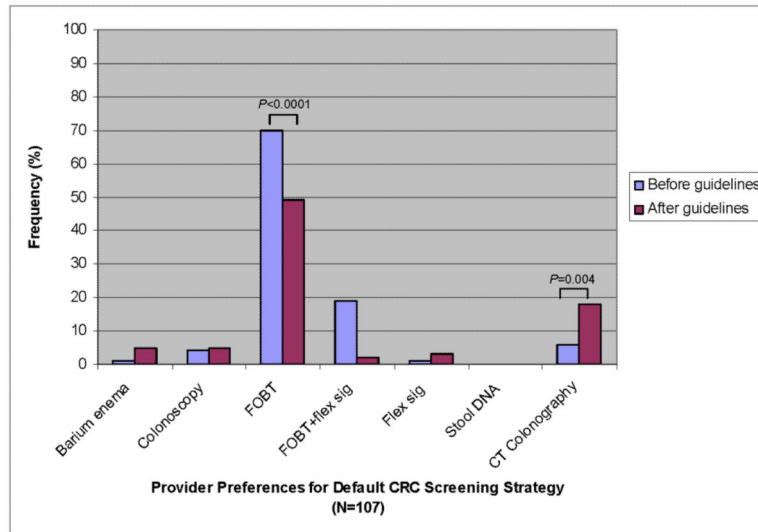
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**Figure 1.**  
Patient preferences for CRC screening strategy.



**Figure 2.** Comparison of first-line CRC screening strategy preferred by providers before and after review of guidelines.



**Figure 3.** Comparison of default CRC screening strategy preferred by providers before and after review of guidelines.

**Table 1**

Description of patient population (N=100)

Characteristic	Number
Age, years	
50–59	75
60–69	24
70+	1
Sex	
Male	63
Female	37
Ethnicity	
Hispanic	3
Non-Hispanic	97
Race	
White	19
Black	73
Asian	1
Other	4
Missing	3
Education	
Less than high school	28
High school degree	44
Some college	12
College degree	9
Graduate degree	7
Health insurance	
Private/HMO	19
Medicare	7
Medicaid	36
Free care	32
None	6
Prior FOBT	32

FOBT = fecal occult blood testing.

HMO = health maintenance organization.

**Table 2**

Test features influencing screening test preference

Most important test feature	Preference, N (%)		
	Any stool test * N =31	CTC N=10	Colonoscopy N= 59
Accuracy	4 (13)	4 (40)	45 (76)
Discomfort	16 (52)	2 (20)	1 (2)
Preparation	4 (13)	0	0
Complications	7 (23)	0	1 (2)
Time	0	1 (10)	1 (2)
Frequency of test	0	0	6 (10)
Further testing for abnormal results	0	3 (30)	5 (8)

Overall comparison significant at  $P < 0.0001$  level.

CTC = CT colonography

\* Any stool test = fecal occult blood testing or stool DNA

**Table 3**

Univariate associations between demographic factors and screening test preference

Characteristic	No.	Preference, N(%)				p*
		FOBT	Stool DNA testing	CTC	Colonoscopy	
Age, years						0.69
50–59	75	15 (20)	10 (13)	7 (9)	43 (57)	
60	25	2 (8)	4 (16)	3 (12)	16 (64)	
Sex						0.04
Male	63	13 (21)	12 (19)	5 (8)	33 (52)	
Female	37	4 (11)	2 (5)	5 (14)	26 (70)	
Ethnicity						0.17
Hispanic	3	2 (67)	0 (0)	0 (0)	1 (33)	
Non-Hispanic	97	15 (15)	14 (14)	10 (10)	58 (60)	
Race						0.42
White	19	4 (21)	1 (5)	0 (0)	14 (74)	
Black	73	9 (12)	13 (18)	10 (14)	41 (56)	
Other	5	2 (40)	0 (0)	0 (0)	3 (60)	
Education						0.003
High school degree	72	17 (24)	11 (15)	9 (13)	35 (49)	
Some college or more	28	0 (0)	3 (11)	1 (4)	24 (86)	
Health insurance						0.19
Private/HMO	19	2 (11)	1 (5)	0 (0)	16 (84)	
Medicare	7	3 (43)	1 (14)	0 (0)	3 (43)	
Medicaid	36	6 (17)	5 (14)	4 (11)	21 (58)	
Free care	32	6 (19)	4 (13)	5 (16)	17 (53)	
None	6	0 (0)	3 (50)	1 (17)	2 (33)	
Prior FOBT						0.28
Yes	32	3 (9)	7 (22)	1 (3)	21 (66)	
No	68	14 (21)	7 (10)	9 (13)	38 (56)	

CTC = CT colonography.

FOBT = fecal occult blood test.

HMO = health maintenance organization.

\* Comparison for any stool test (blood or DNA) vs. CTC vs. colonoscopy.



**Table 4**

## Characteristics of the provider sample

Characteristic	N (%)
Provider type	
Medical doctor	
Resident	88 (52)
Non-resident	68 (40)
Physician assistant	4 (2)
Nurse practitioner	10 (6)
Male	75 (45)
Practice experience, years	
<5	110 (65)
5–10	16 (9)
>10	44 (26)
Practice setting	
Hospital based	119 (70)
Community-based clinic	51 (30)
Personal experience with CRC screening	25 (14)
Predominant level of insurance	
Private	4 (2)
Medicare	21 (12)
Medicaid	59 (35)
VA	6 (4)
Free care	71 (42)
None	1 (1)
Don't know	8 (5)

CRC = colorectal cancer.