ABSTRACT

Title of Dissertation:	COLORECTAL CANCER SCREENING IN INDIVIDUALS UNDER AGE 50: USING A SHARED-DECISION-MAKING FRAMEWORK TO EXPLORE KNOWLEDGE, PREFERENCES, AND DESIRED ROLE
	Travis Craig Hyams, Doctor of Philosophy, 2020
Dissertation directed by:	Dr. Barbara Curbow, PhD, Behavioral and Community Health

The rates for colon and rectal cancer (CRC) are increasing at an alarming rate in individuals under the age of 50. Because of this, The American Cancer Society gave a qualified recommendation for average risk adults to initiate colorectal cancer screening at age 45. This recommendation challenges the long-standing guidelines to begin screening at age 50. If adopted, this would add approximately 19 million Americans to the eligible screening pool. This shift in thinking is controversial and researchers and guideline recommending organizations have responded with caution. While a large body of literature on CRC screening exists, very few studies have focused on individuals under the age of 50 due to the previous, relative consensus on guidelines. Because the uncertainty and relative equality of screening strategies and outcomes, patients under 50 and clinicians making decisions about screening should consider a shared decision-making framework. In this dissertation, I explored differences in several constructs of the shared decision-making framework by age (<50 & ≥50) using a sample of 579 participants drawn from MTurk, a global crowdsourcing workforce that is often utilized for research studies. In paper 1, I evaluated knowledge of CRC risk factors and symptoms and found that age moderated the relationships between several independent variables including perceived likelihood of getting cancer and numeracy with total knowledge scores. In paper 2, I explored preferences for colorectal cancer screening strategies using a multicriteria decision analysis technique called the Analytic Hierarchy Process and found that participants <50 preferred colonoscopy more often than those ≥50. In paper 3 I used multinomial logistic regression and found that participants <50 preferred the shared and passive role compared to the active role for deciding whether to get screened and deciding which strategy to use more often than participants ≥50. These findings will act as a foundation for future work if it becomes necessary to incorporate younger people into colorectal cancer screening programs.

COLORECTAL CANCER SCREENING IN INDIVIDUALS UNDER AGE 50: USING A SHARED-DECISION-MAKING FRAMEWORK TO EXPLORE KNOWLEDGE, PREFERENCES, AND DESIRED ROLE

by

Travis C. Hyams, MPH

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Advisory committee

Professor Barbara Curbow, PhD Chair

Evelyn King-Marshall, PhD, MPH

Min Qi Wang, PhD

Bruce Golden, PhD

Shahnaz Sultan, MD

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Dedication

I would like to dedicate my thinking to my advisor, dissertation chair and friend Barbara. It was an honor to be one of your final students before your (well-deserved) retirement. I will always value our time working together.

The work is dedicated to my wife Samantha who supported me in time and energy every step of the way. Thank you for being such a supportive partner. Very soon, I hope to do the same for you.

The finish is dedicated to my sister Jen. Your passing during the final stages of this project was so hard but your inspiration was rocket fuel to cross the finish line. I know that you would be proud.

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List of Abbreviations

CRC: Colorectal Cancer

USPSTF: United States Preventive Services Task Force

FIT: Fecal immunochemical test

FOBT: Fecal occult blood test

SEER: Surveillance Epidemiology and End Results

ACS: American Cancer Society

QALY: Quality adjusted life years

NIH: National Institutes of Health

AHP: Analytic Hierarchy Process

SDM: Shared decision making

Chapter 1: Problem Statement

1.1 Problem Statement

Colorectal cancer (CRC) is a leading cancer control priority because it has the third highest incidence of all cancer sites in both sexes.[1,2] The overall incidence of and mortality from colorectal cancer is declining in the United States and across the globe primarily due to the public health effort to improve age appropriate, guideline-based screening.[3–6] Improved treatment modalities and changes in risk factor exposure also account for some of the decreases in CRC incidence and mortality.[4] However, the incidence of colon and rectal cancer is increasing in younger individuals.[7,8] In adults 50 years and younger, there was a 51% increase in CRC incidence between 1994 and 2014. For rectal cancer, incidence rates doubled between 1991 and 2014 in people age 20 to 49 (2.6/100,000 to 5.2/100,000).[3]

Several key papers in the field have called for reconsidering the age to initiate CRC screening for several reasons: (1) the 'upswing' in CRC incidence in younger people (2) the fact that these cancers are often diagnosed at a later stage, (3) misattribution of symptoms that delays diagnosis and (4) the favorable benefits versus burdens of population based screening in people 45-49.[8,9] Most notably, the American Cancer Society (ACS) recently updated their recommendation to initiate screening at 45 years old with a 'qualified' recommendation.[3] A qualified recommendation designates a recommendation where clear evidence for benefit exists but there is less certainty about the balance of the harms, benefits, patient values and preferences.[3] This updated recommendation is based on microsimulation models indicating the effectiveness (benefits versus harms) of screening in younger individuals,[10] epidemiologic data showing the upwards trend in disease burden,[7,8] and the expectation that screening will

perform similarly well in adults ages 45 to 49 as it does in adults 50 years or older. However, guideline recommendations from other sources, such as the United States Preventive Services Task Force (USPSTF), remain supportive of the position to initiate age-based screening at age 50 for average risk adults.† People are considered average risk if they do not have: a personal or family history of CRC, a history of an inflammatory bowel disease, inherited syndrome, or personal history of radiation to the abdomen for other cancer treatment.[11] This shift in thinking about the appropriate age to begin guideline-based screening for CRC is impactful because, if adopted, this recommendation would add approximately 19 million individuals to the eligible screening pool.[12,13] As such, researchers, clinicians, and other experts in the field have debated such a change and have called for more research to be conducted on the consequences of this shift at multiple levels. [3,13–16] Both clear benefits and harms to screening in younger individuals exist indicating the potential need for a shared decision-making process among physicians and patients that takes into account knowledge, preferences for screening tests, desired role in the decision-making process and their self-efficacy for making medical decisions. Research exploring CRC screening in younger people is timely for several reasons: (1) The shifting disease burden of CRC to younger individuals; (2) updated recommendations about screening in people under 50; (3) evidence indicating that there is a high level of misunderstanding in younger people about screening tests for colorectal cancer and knowledge of risk factors for colorectal cancer; and (4) recent calls for additional research in this area by experts.

† This dissertation project was defended on October 19th, 2020. On October 27th, 2020 the USPSTF released a draft recommendation statement incorporating those age 45-49 into their recommendations. This change does not impact the results of this study but all subsequent references to the USPSTF should be interpreted with this update in mind.

1.2 Guiding Model and Conceptual framework

Clearly, the rates of CRC are rising in younger individuals. However, it is also clear that screening in people under the age of 50 is not without uncertainty around potential harms or risks and additional burden. Screening in this younger cohort is i) costly, ii) it could lead to over-screening for individuals who are actually at lower risk or those who have false positive results, iii) it has the potential for harms, especially with colonoscopy (e.g., perforation, bleeding, or infection), and iv) is associated with a high burden with respect to time and potential resources. Shared decision-making[17] is "at its core… an interpersonal, interdependent process in which the health care provider and the patient relate to and influence each other as they collaborate in making decisions about the patient's health care."[18] The USPSTF defines shared decision-making as a process of decision-making by a patient and clinician with the goal of an informed and joint decision in which the patient:

> "…(1) understands the risks or seriousness of the disease or condition to be prevented; (2) understands the preventive service, including the risks, benefits, alternatives, and uncertainties; (3) has weighed his or her values regarding the potential benefits and harms associated with the service; and (4) has engaged in decision-making at a level at which he or she desires and feels comfortable."[19]

Shared decision-making also assumes that both the provider and the patient have access to and an understanding of the available evidence to make informed decisions. Shared decision-making is most appropriate when there is a decision to be made between treatment options with similar outcomes or when there is a condition of high uncertainty

between options and when the decision is highly 'preference-sensitive'.[18,20–22] Colorectal cancer screening in individuals under the age of 50 satisfies these conditions. For such situations, there are two decisions to be made: whether to screen and if so, which screening test to use. The decision of whether to screen takes into account the benefits of both screening (early detection and peace of mind) as well as potential harms of screening (false positives, false negatives, costs, and the potential for injury), patient preferences, and burden or costs. Unique to the younger patient population is the uncertainty and disagreement amongst guidelines about the appropriate timing for when to initiate screening. Furthermore, the patient and provider face the decision of which screening strategy to use. Availability of screening options for CRC are in a unique area of relative equipoise where there is a balance between test-features, risks associated with the procedures, and cancer detection outcomes. This is evidenced by recommendations that any CRC screening is preferred over none and the American Cancer Society explicitly not endorsing a single strategy over others. [3] In this study, I will use the shared decision-making framework with constructs adopted from Christy and Rawl (Figure 1). [22] Because this study is using a sample from the general population, who have not been screened, I will focus on patient factors that may influence the shared decision-making process as well as the antecedents to SDM that are outlined by the SDM literature: knowledge, preference, and desired role in decision making. These three characteristics of an individual could influence a clinical interaction that would occur when a patient is discussing colorectal cancer screening with a doctor. These patient level characteristics are hypothesized to be influenced by each other but also by other patient- variables, such as age. This study recognizes the importance of the provider as well as the medical

system, however, these characteristics would be more appropriate to assess in a setting where a decision is being made.

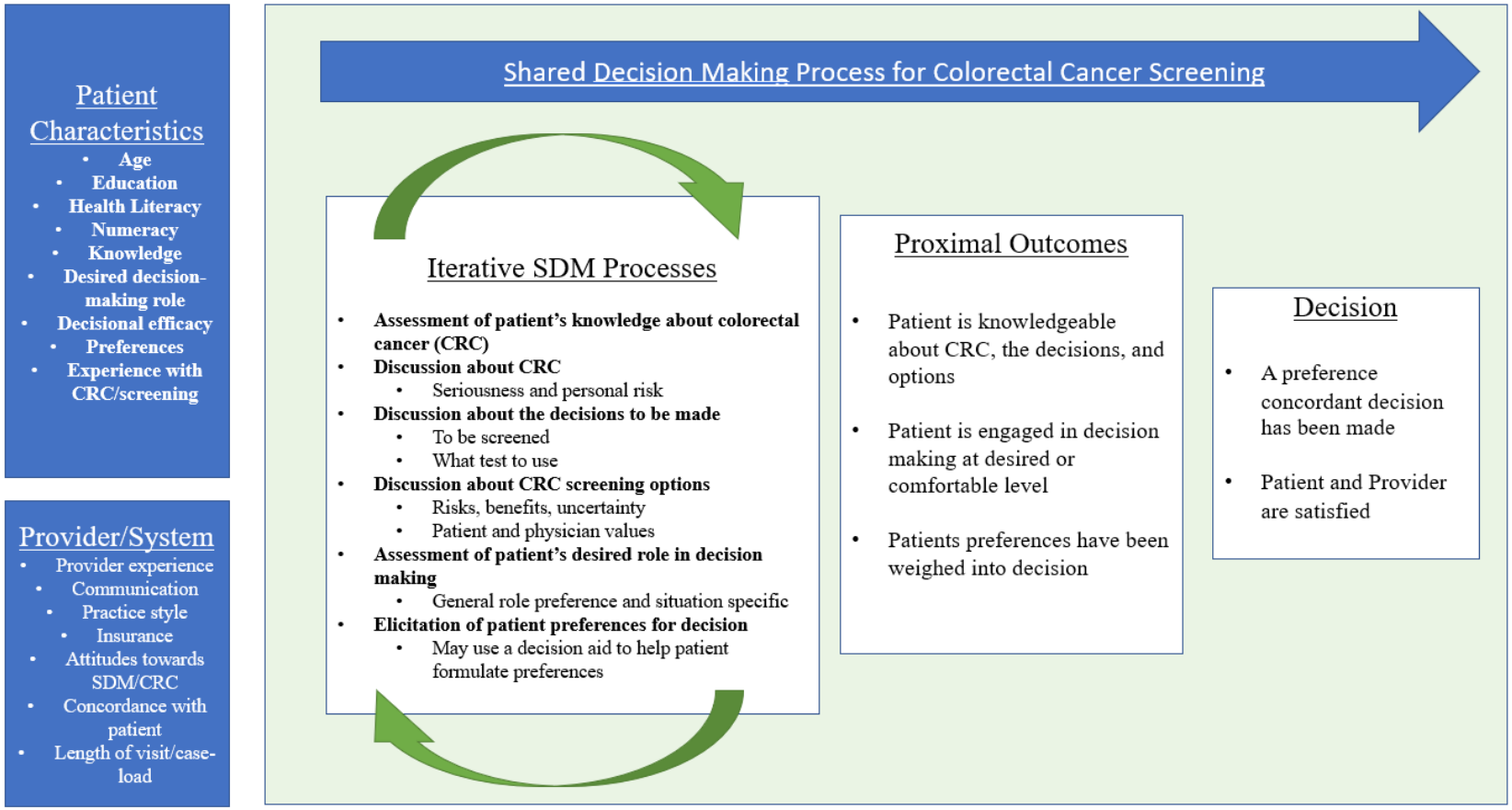


Figure 1: Shared decision making in colorectal cancer screening

1.3 Research Questions

In this dissertation project, I will address the following research questions centered around the shared-decision-making framework for colorectal cancer screening in individuals under 50:

RQ1: Are people under age 50 able to correctly identify risk factors of CRC?

Rationale: To make an informed decision about colorectal cancer screening, a patient must have adequate information to initiate a discussion with their doctor. Additionally, an important part of the shared decision-making process is assessing the patient's current knowledge.[21] Recent work by Mueller et al. (2019)[24] indicates that younger people are confused about the types of screening tests available for CRC and their overall risk of developing the disease. Questions about whether people under 50 can identify risk factors to initiate a discussion with their doctor remain unanswered.

RQ2: What screening strategy do individuals under 50 prefer and on what are these preferences based?

Rationale: A critically important factor to shared decision-making is that the decision is based on preferences. The type of screening test that people prefer fall into 2 major categories: a structural exam (i.e. colonoscopy or flexible sigmoidoscopy), or a stool-based exam. Preferences for these tests are highly dependent and the literature on which test is preferred by individuals 50+ is inconsistent. Almost no work has been done to explore preferences in people under the age of 50. Understanding which tests people under the age of 50 prefer will reveal whether there are strongly held preferences that clinicians should be aware of when working within the shared decision-making

framework. Also, an understanding of what the factors affecting these preferences are will give clinicians more information when describing, highlighting, and creating tools to facilitate decision-making in patients, by focusing on the most important strategy attributes.

RQ3: When making CRC screening decisions, what level of control (role preference) do people under 50 prefer and do they feel confident in their ability to make decisions?

Rationale: When considering decision-making for colorectal cancer screening, it is important to consider that some individuals may not be receptive to shared decision-making and want to follow a paternalistic approach where the doctor leads or guides decisions based on their own preferences and clinical experience. Or, vice versa, some patients may prefer to be the primary driver of decisions. Reviews on the topic show variable interest by patients in desire to participate in shared decision-making.[25] Evidence suggests that these preferences may vary by features including age, education, health literacy, and income.[25] Evidence for these preferences among younger people to engage in shared decision-making in this context, and whether these preferences are related to other patient-level variables will allow clinicians to engage patients at their desired level.

1.4 Definition of Terms

Colorectal cancer	For this dissertation colorectal cancer (CRC) will be considered any primary cancer originating in the colon or rectum. While these two cancers are distinguishable, mortality statistics are often grouped together [26] due to misclassification on death certificates, similar symptom profile and similar detection methods.
Colorectal cancer screening	Colorectal cancer screening refers to systematic screening of the asymptomatic, general public. This is distinct from diagnostic colonoscopy, which is used in individuals who are symptomatic or otherwise displaying signs of disease and surveillance colonoscopy, which is used to follow-up previously diagnosed CRC. Colorectal cancer screening is usually initiated beginning at a specific age, according to guidelines outlined by professional and government entities (see section 2.7). There are several colorectal cancer screening tests that are recommended and commonly used (see section 2.5)
Decisional Self-Efficacy	Self-efficacy is a health behavior construct that represents one's confidence in their ability to perform a behavior.[27] In this dissertation, self-efficacy is for decision-making, or one's ability to carry out the necessary steps to perform a behavior. For operationalization of decisional self-efficacy see Appendix A (pg. 85): Decision Self Efficacy Scale (DSES).[28]
Patient activation or activated patients	Activated patients "are patients who have the motivation, knowledge, skills, and confidence to make effective decisions about their health"[29]. Higher levels of patient activation are associated with improved health and health related behaviors such as screening.
Shared decision-making	See section 1.2 for a full discussion of shared decision-making. USPSTF defines shared decision-making as a process of decision-making by a patient and clinician with the goal of an informed and joint decision in which the patient "…(1) understands the risks or seriousness of the disease or condition to be prevented; (2) understands the preventive service, including the risks, benefits, alternatives, and uncertainties; (3) has weighed his or her values regarding the potential benefits and harms associated with the service; and (4) has engaged in decision-making at a level at which he or she desires and feels comfortable."[19]

Chapter 2 Literature Review

2.1 Colorectal Cancer as a Public Health Issue

Colorectal cancer is a cancer of the bowel that occurs in either the large intestine (the colon) or the rectum. The lifetime risk of developing CRC is approximately 1/23 (4.4%) for men and 1/25 (4.1%) for women.[30] Currently, within the United States there are around 1.3 million people living with CRC.[31] CRC accounts for approximately 8.3% of new cancer cases and 8.4% of all cancer deaths in the United States.[30] Between 2008-2014, the overall 5 year survival rate for CRC was 65%. For the 39% of people diagnosed with localized disease, the 5 year survival is 90%. [30,32]

Reduction of CRC incidence and mortality is a priority for the United States public health system. Several public health entities have set goals for CRC. For this decade, Healthy People 2030 set goals to reduce the CRC death rate from 13.4/100,000, measured in 2018, to 8.9/100,000[33] and to increase the proportion of adults who receive colorectal cancer screening based on the most recent guidelines from 65.2% to 74.4%.[34] The National Colorectal Cancer Roundtable has set a goal for 80% of adults aged 50 and older to be getting regular screenings for CRC referred to as the "80% Pledge".[35] Reaching this goal would achieve a reduction in incidence by 33% and mortality by 22% by 2030.[36] Overall, this would lead to avoiding 21,000 CRC deaths per year for a total of over 200,000 deaths avoided by 2030. However, the costs of achieving this goal were not calculated for this study, rather, the authors focused on only incidence and mortality reduction of the 80% goal.

Significant progress has been made in the last decade towards tackling CRC as a public health issue and several goals have been achieved. The Healthy People 2020 objectives to reduce the CRC death rate from 17.1 deaths/100,000 population to 14.5 was

achieved. Nationwide, more people are being screened for CRC every year. In 2018, 65.2% of people over the age of 50 were up-to-date with their colorectal cancer screening.[37] However, there are many issues and research questions surrounding screening for colorectal cancer that have yet to be unraveled.

2.2 Etiology

Polyps

Similar to other cancers, the hallmark feature of CRC is unregulated and uncontrolled cell growth and division. Colorectal cancer occurs from malignant cell overgrowth in the parts of the large intestine known as the colon or rectum. Development of CRC begins as noncancerous growth or a precancerous lesion, called a polyp.[38] Precancerous polyps, also known as adenomas or adenomatous polyps, arising from glandular cells found in the colon and rectum, are the most common precursor to CRC.[38,39] Colonic polyps are found in up to 30 to 40% of people by age 60 but only ~10% of polyps progress to cancer.[40,41] However, over 95% of colorectal cancers begin as adenomatous polyps.[41] Polyps under 10mm in size are considered 'small' and polyps <5mm are considered diminutive or minute.[42] Polyps of greater size generally confer an increased risk of CRC compared to smaller polyps and advanced polyps generally grow more rapidly than non-advanced.[43] Polyps are often asymptomatic but can cause rectal bleeding, and rarely, symptoms of partial bowel obstruction.[41]

Development of polyps into colorectal cancer

Adenomatous polyps can develop into cancer over a period of 10 to 20 years. [2,39] Colorectal cancer can be found in both the proximal colon (ascending or transverse colon) or in the distal colon (descending and sigmoid colon).[38] Colorectal cancer is often staged using the American Joint Committee on Cancer (AJCC) system that assesses the size of

the tumor and whether and how far the tumor has grown into the colon or rectal wall (T); whether the cancer has spread to nearby lymph nodes (N); and whether the cancer has metastasized to distal lymph nodes or other organs (M). This system is often referred to as the TMN system. [44]

2.3 Colorectal Cancer Epidemiology

CRC Incidence and Mortality

Colorectal Cancer (CRC) has the third highest incidence of all cancer sites with a projected estimate of 104,610 cases of colon and 43,340 cases of rectal cancer to be diagnosed in 2020. [1,2,7] Most cases of CRC occur in individuals over the age of 50 and the median age that people are diagnosed is 68.[45] Incidence for colon cancer are similar for both men and women with a 2020 projected estimate of 52,340 cases in men and 52,270 cases in women.[1,26,46] However, incidence is markedly higher for rectal cancer in men with 25,960 projected cases in 2020 versus 17,380 in women.[1,26,46] For mortality, colorectal cancer is the second leading cause of cancer death in the United States and, in 2020, 53,200 individuals are projected to die from CRC.[1] Data for colon and rectal cancer mortality are often combined because a large proportion of rectal cancer cases are misclassified as colon cancer.[2,26] Significant disparities exist by race for colorectal cancer incidence and mortality by race and ethnicity. Black men have the highest incidence (58.3/100,000) and mortality rates (25.9/100,000) compared to Asian women who have the lowest incidence (27.8/100,000) and mortality (8.8/100,000). CRC incidence and mortality varies widely by state and region in the United States. Between 2010-2014 Kentucky had the highest age adjusted incidence rate for CRC of 50/100,000 whereas Utah had the lowest at 31.4/100,000. Incidence and mortality rates for CRC have steadily decreased[47] since the

mid-1970s due to increased awareness of the disease, screening uptake, changing of risk factors and improved treatment.[3,4]

2.4 Screening Modalities

Several methods are used to screen for CRC. Some of these strategies are also used for surveillance for colorectal polyps or for diagnosis and workup of symptoms. Generally, these methods can be thought of as stool-based tests and structural exams that allows for direct visualization, such as colonoscopy or flexible sigmoidoscopy. The American Cancer Society recommendations include offering patients the opportunity to choose which strategy they prefer based on availability and preference for test features.[3] Each strategy has a specified screening interval, or the length of time that an average risk individual should repeat testing after a 'normal' screening result. **A 'positive' result for a screening test that is a non-colonoscopy exam is generally followed up with a colonoscopy exam, that allows for therapy of colon polyps or confirmation of CRC.**[48] In the following sections, I will review only tests that are endorsed by the American Cancer Society's 2018 guidelines (Section 2.7), however, lesser used tests are available and generally have less evidence to support their use or are explicitly *not* recommended.

Stool-Based Strategies

Fecal Occult Blood Test (FOBT)

FOBT, also known as gFOBT detects hidden blood in the feces that can come from the upper or lower GI tract.[48] This test is simple to use and has been shown to reduce CRC mortality. [49] In one randomized study of 46,551 participants, annual FOBT reduced 13-year CRC mortality by 33%[50] However, a positive result requires a moderate amount of blood and so the FOBT is not a very sensitive test, especially for advanced

adenomas.[51,52] One-time FOBT testing may have sensitivity lower than 50% so **the screening interval for this strategy is one year**. [51,52] Because of the low sensitivity of FOBT, its poor ability to detect advanced adenomas, and sensitivity to dietary and medication restrictions such as vitamin C, red meats, and anti-inflammatory drugs, it has been replaced by FIT tests in many clinical settings. [53]

Fecal Immunochemical Test (FIT) (iFOBT)

The fecal immunochemical test (FIT) identifies hemoglobin in the stool that could indicate bleeding from a polyp or from CRC. It is more specific than FOBT to hemoglobin arising from the lower gastrointestinal (GI) tract making it a better test for detecting CRC.[54] In a study conducted in Taiwan, Chiu, et al. (2015) estimated a 62% mortality reduction in those participating in biennial FIT testing versus those who received no screening when participants were followed up for a maximum of 6 years. [55]FIT is also advantageous over FOBT because there are no dietary or drug restrictions and it has higher rates of participation and patient acceptance.[53,56,57] Like FOBT, **the screening interval for the FIT strategy is every year.**

Pooled data presented in one study from 113,360 participants with 437 confirmed CRC cases indicated that the sensitivity of FIT was approximately .79 (95% CI: 0.69-0.86) and specificity was .94 (95% CI:0.92-0.95).[58] Another, more recent, meta-analysis found that CRC sensitivity values for FIT tests ranged from .71 to .91 and specificity values ranged from .90 to .95. For advanced adenomas, sensitivity estimates ranged from .25 to .40 and specificity estimates from .90 to.95.[59] However, the authors noted that true sensitivity and specificity values are difficult to estimate due to the multiple FIT tests available on the market and different thresholds for positive results that can be used.[59]

Fecal/Stool DNA (Cologuard)

Like most cancers, CRC begins as an accumulation of genetic changes. DNA markers for these changes can be detected by fecal DNA tests when they are shed by the cancerous or precancerous lesions into the colorectal tract. [54,59,60] Cologuard is currently the only stool DNA test to be approved by the FDA. Cologuard works by detecting fecal blood using FIT in addition to DNA biomarkers related to 3 genes (KRAS, BP3, and NDRG3).

Imperiale and colleagues (2014) reported that fecal DNA testing using Cologuard significantly improved testing sensitivity for CRC when compared to a FIT group (92.3% vs 73.8%) as well as for those with advanced precancerous lesions (42.4% vs 23.8%).[59] This increase in sensitivity significantly reduced specificity thus increasing the false positive rate. Specificity for the Cologuard group, confirmed by negative results on a colonoscopy, was 89.8% compared to 96.4% in the FIT group. [59] Because of the increased sensitivity, **The American Cancer Society recommends the screening interval to follow up normal screening to be every 3 years when using a stool DNA**.[3] However, when compared to colonoscopy every 10 years, stool DNA test every 3 years was not recommended for individuals under 50 by modeling studies that were conducted to inform the American Cancer Society recommendations (Section 2.7) based on the benefits (life years gained) versus burdens (number of colonoscopies due to false positives) of this screening strategy.[10]

According to the Cologuard website, for individuals ages 50 to 85, 94% of patients have no out of pocket costs for screening. [61] However, the most recent list price

of Cologuard is $649, which would likely be the out of pocket costs for an individual under the age of 50 who seeks screening.[62]

Structural Exams

Sigmoidoscopy and Colonoscopy

Sigmoidoscopy and colonoscopy are both structural visualization exams during which an endoscopist inserts a scope through the anus to view the rectum and colon. During both exams, cancerous lesions and polyps can be visualized and biopsied or removed. There are several key differences between sigmoidoscopy and colonoscopy. (1) A colonoscopy can visualize the entire colon and rectum, while sigmoidoscopy can only visualize the rectum and the lower sigmoid colon. (2) Flexible sigmoidoscopy requires less complicated bowel preparation and can often be completed with a laxative or enema. (3) Sigmoidoscopy is a less invasive procedure and thus does not usually require as much sedation for patients to tolerate the procedure as colonoscopy. (4) **The screening interval for sigmoidoscopy is 5 years while normal colonoscopy screenings should be followed up every 10 years**.[48] There are risks associated with both procedures including bleeding, pain, and perforation of the colon, which can lead to death. The risk of bowel perforation is approximately double in colonoscopy (1.96/1,000) than in sigmoidoscopy (.88/1000).[63] Despite these risks, the use of sigmoidoscopy has declined significantly, and as of 2010, only 2.5% of US adults age 50 to 75 report sigmoidoscopy screening within the recommended interval while 60% report colonoscopy screening. [3]

Both sigmoidoscopy and colonoscopy are associated with reduction of colorectal cancer mortality. Pooled data from the 2016 USPSTF† evidence report (pooled n=458,002) indicated that sigmoidoscopy was associated with an approximately 27%

reduction in 11 to 12 year CRC mortality compared to no screening, however, this mortality reduction was limited to CRC in the distal colon due to the visualization range of sigmoidoscopy.[64] Mortality reduction for CRC is even greater for colonoscopy. One study, by Nishihara, et al. reports hazard ratios of .47 (95% CI: .29-.76) for proximal cancer, .18 (95% CI: .10-.31) for distal cancer, and an overall hazard ratio of .32 (95% CI: .24-.45) over 24 years for the group receiving one or more colonoscopy versus no screening.[65] Ko and colleagues (2019) conducted a retrospective study using the SEER database and found that sigmoidoscopy was associated with a 35% reduction in CRC mortality while screening colonoscopy was associated with a 74% reduction in mortality.[66] Similar to other studies in the literature, they also found that reduction in mortality for sigmoidoscopy was only for cancers in the distal colon.

Computed Tomography Colonography (CTC) (Virtual Colonoscopy)

CTC screening is a procedure that utilizes an x-ray to take pictures of the colon and rectum. The compilation of these images allows a physician to visualize the inside of the colorectal tract and see polyps or cancerous lesions.[67] CTC procedures are generally performed in outpatient radiology settings but can be performed selectively in hospital settings for individuals who are considered high risk for colonoscopy.[68] CTC use in the United States is becoming more common, although use varies by geographical location with rates as low as 2.38/100,000 in rural areas and as high as 6.67/100,000 in urban areas.[69] CTC does not require the patient to be sedated and has very low risk because it is noninvasive; however, it does require bowel preparation similar to a standard colonoscopy for proper visualization of the colon.[67] An abnormal result is followed up

with a colonoscopy so that polyps or other lesions can be removed and diagnosed. **The recommended screening interval for a strategy utilizing CTC is 5 years.**[3]

Evidence for CTC effectiveness as a screening strategy is low compared to other screening strategies but growing. One meta-analysis that included 49 studies with a cumulative sample size of 11,151 concluded that sensitivity for CTC to detect colorectal cancer was as high as 96.1%. [70] Specificity values were not calculated in this review because, in many studies, benign polyps are included as true-positives making it impossible to estimate the true negative, and false positive values required for specificity calculations.[70] However, other studies indicate that CTC has a specificity of between 89-91%.[64] Sensitivity values for polyps have been calculated in a large multi-center study as approximately 94% for polyps >10mm, 94% for >8mm, and 89% for polyps >6mm. Corresponding specificity values for these polyp measurements were 96%, 92%, and 80%.[71]

2.5 The Rising Risk for CRC in Younger People

Population-based analyses indicate that 11-12% of incident CRC cases in the United States occur in individuals under age 50.[72] Recent, epidemiologic studies using the Surveillance, Epidemiology, and End Results Program (SEER) database indicate that the incidence of both colon and rectal cancers in the United States is rising at a concerning rate in individuals under the age of 50.[8,73–75] This program is supported by the National Cancer Institute and collects data from all cancer cases reported in a nationally representative sample that spans 19 geographic regions and 12 states in the United States.[76]

A study conducted by Siegel et al (2017)[8] is unique in presenting these findings because of her use of age-period-cohort modeling (Figure 2). This technique allowed her

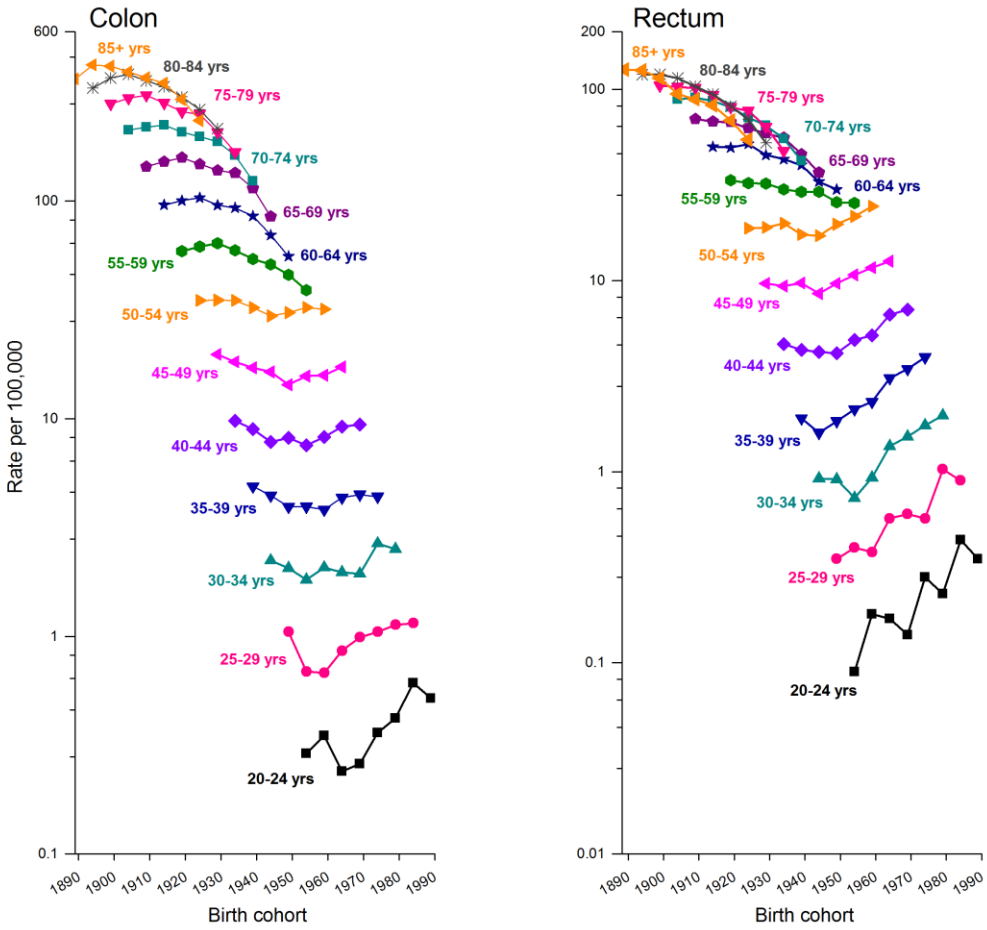


Figure 2: Age adjusted incidence trends for colon and rectal cancer drawn from Siegel, et al. 2017 supplemental materials

to show that the differences seen in both colon and rectal cancer are due primarily to *cohort effects*, described by Siegel as changes that vary by generation like health behaviors, rather than *period effects* which are factors that influence all ages such as changes in medical practice.[8] She found age adjusted relative risks for those born in the 1991 birth cohort were 2.40 for colon and 4.32 for rectal cancer when comparted to the lowest risk birth cohort, or those born circa 1950.[8] This study also found that between approximately 1985 to 2013, rates of colon cancer decreased in adults 55+, but increased

by 2.4% per year in adults age 20 to 29, and by 1% per year in adults age 30 to 39. In adults age 40 to 49, rates of colon cancer started to increase by about 1.3% per year starting in the mid-1990s. These increasing rates were accounted for primarily by tumors in the distal colon. Incidence rates for rectal cancer are increasing even more rapidly than for colon cancer. Rates increased by 3.2% per year for adults age 20 to 29 between 1974-2013 and similarly from 1980 for adults 30 to 39. For adults age 40 to 49, rates increased by 2.3% per year starting in the mid-1990s. Rates of rectal cancer have been steadily decreasing in adults 55+ since around 1980. Additionally, Siegal argues that the increasing rates in younger cohorts are inconsistent with screening or lead time biases. These biases are seen when incidence rates are skewed by increased uptake in screening, which enables us to detect cancers at younger ages. She notes that rates are increasing most rapidly for the youngest cohorts who are also those that are least likely to be screened. Moreover, rates have risen similarly for both early and late stage cancers.[8] Interestingly, increases in both colon and rectal cancer have been documented in other countries across the globe.[5,77]

2.6 Guidelines on When to Initiate Age-Based CRC Screening

A number of policy recommending organizations have released evidence-based guidelines and recommendations for colorectal cancer screening. These recommendations provide guidance for clinicians, researchers, and patients as to the most effective strategies and ages for colorectal cancer screening. A summary table of guidelines, drawn from Robertson and Ladabaum (2019) can be found in Table 1[78]

Table 1: Summary of Current US Colorectal Cancer Screening Guidelines adapted from Robertson and Ladabaum (2019)

Guideline	Year	Starting Age	Stopping age	Sex	Race	Endorsed Tests	Preferred test
ACS[3]	2018	45 (qualified) 50 (strong)	"discourage over age 85"	No tailoring	--	FIT, high-sensitivity FOBT, mtDNA, colonoscopy, CTC, Flex-sigmoid	None
US Multi-Society Task Force[79]	2017	50	"potentially beneficial up to age 86"	No tailoring	AA start at 45	FIT, colonoscopy, CTC, mtDNA, Flex-sigmoid, capsule colonoscopy	Tier 1 Colonoscopy FIT
USPSTF[80]†	2016	50†	Through 75 (grade A) 76-85 (individualized)	No tailoring	--	FIT, high sensitivity FOBT, mtDNA, colonoscopy, CTC, flex-sigmoid, flex sigmoid+FIT	None
American College of Physicians[81]	2012	50	Adults over 75	No tailoring	AA start at 40	FIT, FOBT, mtDNA, colonoscopy, CTC, flex-sigmoid	Stool based test, flexible sigmoidoscopy, or optical colonoscopy
American College of Gastroenterology[82]	2010	50	Not explicit	No tailoring	AA start at 45	FIT, high sensitivity FOBT, mtDNA, colonoscopy, CTC, flex-sigmoid	Colonoscopy

Updated American Cancer Society (ACS) Recommendations

In 2018, the American Cancer Society (ACS) updated their guidelines for CRC screening. In contrast with most guidelines, the ACS recommended that adults aged 45 or older with average risk of CRC begin regular screening with either a high sensitivity stool-based strategy or a structural (visual) exam depending on the individual's preference and test availability. [3] The recommendation to begin screening at age 45 was made because of the upswing in CRC incidence in younger age groups previously

mentioned. **This recommendation is deemed as a qualified recommendation due to the lack of direct empirical data pertaining to screening in individuals under age 50.** [3] However, modeling studies indicate a favorable benefit-burden balance in that the

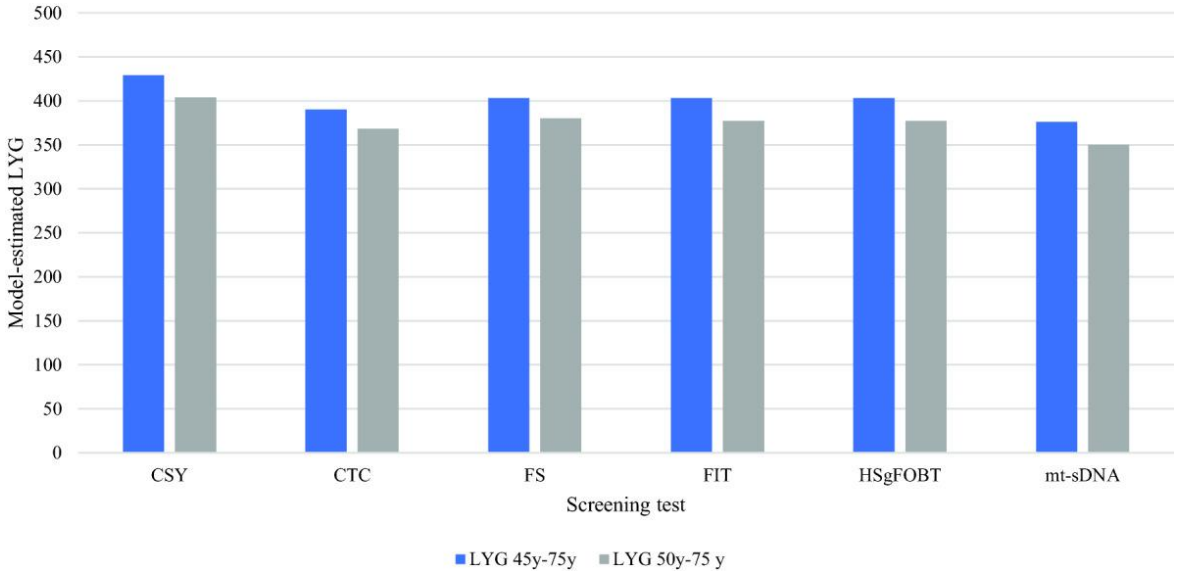


Figure 3: Life years gained for available screening tests at different ages of initiation

number of life years gained through reduced CRC incidence and mortality by beginning screening at age 45 was acceptable when compared to the increase in overall number of colonoscopies performed by beginning at the younger age (Figure 3).

2.7 Debate Over Recommendations

Since the qualified recommendation from the American Cancer Society to lower the age to initiate screening to 45 in May of 2018, several commentaries, editorials, and empirical research articles have been published that debate this shift. The contrasting viewpoints from researchers and practitioners that are summarized in the following sections are essential to state so that the controversy in the field is recognized and future research can address these issues.

The cost of shifting recommendations

Much of the concern that experts in the field have noted focuses on the costs associated with adding approximately 19 million people between the ages of 45 to 49 into the eligible screening pool. In an editorial written by Bretthauer, et al. the authors estimated this cost using CRC incidence and mortality metrics[3,31] and the assumptions that screening in this age group will reduce CRC risk by 50% with a cost of $250 per person using a mix of colonoscopy and FOBT. Roughly, the cost to prevent 900 CRC deaths annually would be approximately $5.5 billion or $6.1 million dollars per death averted through universal screening in this age group. [83] While these assumptions are overly simplifying, this puts into perspective how costly a push towards universal screening in this age group might be. Some authors argue that some of these costs could be mitigated through precision screening, rather than universal screening. Precision screening would involve using genetic, lifestyle, and environmental factors, along with previous screening experience, to categorize people into appropriate risk categories for early screening.[84]

Related to this, some researchers worry that important and limited resources may be diverted away from older groups who remain at the highest risk, regardless of the groups' overall decline in incidence and mortality.[13] A recent cost-effectiveness analysis estimated the costs of changing recommendations from 50 to 45 required an additional 758 colonoscopies and averted approximately 4 CRC cases and 2 CRC deaths in 1000 people, for a total gain of 14 quality of life years (QALYs) costing $33,900 for each QALY gained. While this was deemed cost effective by the authors, for the same number of additional colonoscopies, 231 unscreened 55-year-olds or 342 unscreened 65 to 75-

year-olds could have been tested for 13 to 14 averted CRC cases and 6 to 7 CRC deaths. The researchers estimated that this would be net cost saving to the degree of 163,700-445,800 total dollars per 1000 people from decreased cancer expenditures that are greater than costs of screening, surveillance, and complications.[85]

Lack of evidence for benefits, risks, and epidemiologic shift

Experts in the field have argued that there is a lack of empirical evidence for changing guidelines when considering the weighing of benefits, risks, and costs associated with such a change. This is evidenced by the American Cancer Society's own designation of these recommendations as qualified, rather than strong.[3] Much of this concern stems from the lack of empirical data and evidence for screening in individuals under the age of 50 due to the long standing consensus on recommendations to initiate screening starting at age 50.[3] Because of this, the ACS reliance on modeling studies to guide their recommendation has come under scrutiny and calls for more research to collect direct evidence in this area to be released.[15] Some authors have speculated whether the upwards trends in incidence, while mortality remains steady, may be due to increase in screening utilization detecting more polyps (lead-time bias) rather than an actual increase in disease burden.[86] However, authors such as Siegel, et al. argue that the most steep incidence trends are found in the youngest age groups or those that are least likely to be getting colonoscopies.[8]

Shifting Guidelines and Insurance Coverage

Insurance coverage for preventive services such as screening for colorectal cancer is mandated for non-grandfathered private health plans[87] by the Patient Protection and Affordable Care Act (ACA) (2010).[88,89] The ACA requires Medicare and private

insurance to cover these services with no out-of-pocket costs. The ACA stipulates that only services given an A (high) or B (moderate) rating by the USPSTF are covered by this provision, however, this does not exclude individual insurance companies from deciding to cover CRC screening.[88] Because the USPSTF has kept its current recommendation at 50, rather than 45, individuals under 50 who seek screening may be subject to the costs associated with this service. The previous 2016 recommendation from the USPSTF, released prior to the updated ACS recommendation, concluded that the evidence supports screening beginning at age 50 because of the uncertainty around benefits and risks of screening in younger people. This statement also references the increasing risk in younger individuals as a current research gap. The USPSTF is currently acting in the 'review the evidence and develop a draft recommendation' stage of updating their guidelines for colorectal cancer screening. [90] Shedding light on issues surrounding screening in younger people, such as the ones addressed in this study, could provide more certainty around the potential benefits and risks and bolster evidence for the USPSTF and other policy organizations to also shift their recommendations. Shifts in these guidelines will eventually lead to shifts in insurance coverage and thus changes in practice.

Other considerations

Other unintended consequences that are noted in the literature are important to consider when substantially shifting guidelines for CRC screening. Liang et al. explained that, as previously mentioned, resources to promote and deliver screening for the people at highest risk may be diverted to lower risk populations rather than where they are needed the most. [13] These authors also argue that lowering the recommended age for

screening could increase disparities in CRC because people of higher socioeconomic status, who have more money and knowledge, are more likely to benefit from innovation and new health interventions. [13]

While there is much controversy surrounding the new ACS recommendation, this shift in thinking has opened doors for new lines of inquiry related to screening for colorectal cancer in younger individuals. This literature remains sparse because most studies focus on people within the window of recommended screening. The following sections will summarize the existing literature as it relates to the corresponding research questions that I will explore.

2.8 Evidence for the Association Between Age and Colorectal Cancer Screening Disparities/Outcomes

The necessity to explore research questions related to younger age and colorectal cancer screening extends beyond the epidemiologic shift towards higher risk in younger individuals. ACS recommendations for individuals under 50 are qualified and other professional organizations have been hesitant to endorse screening in younger populations because of the lack of direct evidence for the benefits and risks. In our research program, we have consistently identified younger age as a predictor of screening variables. Findings from these studies add credence to the research questions and hypothesis explored in this dissertation project because, if these outcomes are a consistent trend, additional considerations for this group must be factored into screening programs.

Briefly, in a sample of 1492 pre-colonoscopy patients and their caregivers, younger individuals reported experiencing more social and practical problems when attaining colonoscopy.[91] Problems that younger individuals identified more often than older included difficulty finding time off work, difficulty in finding a driver who is able

to take time off of work, costs associated with the procedure, and finding care for children or elders. Younger patients were also more likely to experience financial strain when attaining colonoscopy as well as having sought colonoscopy because they were symptomatic. [92] Younger patients were more likely to experience poor colonoscopy preparation than their older, screening-aged, counterparts. In recent work by Mueller and colleagues, 96% of the sample age 25-46 were able to identify colonoscopy as a CRC screening tool, however, < 60% identified FOBT, <40% identified stool DNA, and only 20% identified sigmoidoscopy as tools used to screen for CRC. In the same sample, over half of participants were not able to identify that risk for CRC was increasing in people under the age of 50.[24]

2.9 Shared Decision-making and Colorectal Cancer

The shared decision-making framework is appropriate given the evidence of the rising CRC rates, the shifting landscape of CRC recommendations, and the uncertainty about the benefits versus the costs and risks. There are at least 2 decisions that patients and their doctors must make: whether to initiate screening and which screening strategy to complete.[23] These decisions can be complex due to the uncertainty about risks and benefits in this age group and the numerous testing options that exist that each have unique features, schedules, advantages, and disadvantages.

There is evidence in the literature that shared decision-making leads to higher intention to be screened and higher satisfaction with the decision-making process,[93] however, evidence for individuals getting their preferred test is inconsistent.[94,95] Moreover, in some clinical sites, shared decision-making procedures in the context of colorectal cancer screening may not be conducted at all. Wunderlich et al. found that

while 70% of their patient sample seeking screening preferred shared decision-making, only 47% reported that their decision for screening was shared with their physician, and only 1/363 primary care visits contained all four elements of shared decision-making that the authors were assessing.[96] Ling and colleagues (2008) found that over 50% of clinical interactions that they studied did not include any of 9 elements of shared decision-making conversations that they were assessing[97] In some scenarios, such as when a patient is symptomatic, a shared decision may not be appropriate, because diagnostic colonoscopy is the most appropriate decision. Studies containing samples under age 50 are sparse so a number of questions about shared decision initiation, process, and outcomes remain unanswered in the literature. [23] In this dissertation, I addressed three research questions related to shared decision-making for colorectal cancer screening in individuals under 50. These questions descriptively explore antecedents to making a shared decision in individual under age 50. This study will also test differences between individuals who have not been screened <50 age group and the 50+ age group to examine important differences that must be considered when building screening programs that incorporate younger people.

2.10 Remaining Questions: Literature review and rationale for research questions

RQ1: Are people under age 50 able to correctly identify risk factors of CRC?

Research exploring colorectal cancer in younger individuals points to a higher risk for younger patients to present with later stage CRC than their older counterparts. [98,99] For example, in a study conducted in 2016 using a large sample drawn from the SEER database, a multinomial logistic regression controlling for sex, race, marital status, tumor location, and year of diagnosis, indicated that younger patients (<50) compared to older

patients (>50) had a 1.37 relative risk ratio (RRR) for developing regional (Stage III) disease when compared to local disease (Stage I or II), and a 1.58 RRR for distant disease (Stage IV) than localized disease.

Reasons for this phenomenon are explained in several ways in the published literature. **First,** it is likely that many of these cancers are not caught by the routine, guideline-based screening that is generally recommended for individuals over the age of 50. **Second,** patients and their doctors may misattribute symptoms or ascribe less severity to these symptoms in younger individuals, thus increasing time to workup and diagnosis. In 2015, Dozois, et al. found that the majority of patients under the age of 50 (mean age=42) at their institution presented with late stage disease (Stage III or IV) and were symptomatic at the time of diagnosis.[100] Symptoms seen in this population were most commonly rectal bleeding (51%), abdominal pain (32%), change in bowel habits (18%), and weight loss (13%). Chen and colleagues (2018) found that the median time to CRC diagnosis in their setting for people under the age of 50 was 128 days versus 79 days for those over 50 and the mean time to diagnosis was 152 days versus 87.[101] Multivariable analysis support these findings, time to diagnosis in those under 50 was 1.4 times longer than their older counterparts. While at a population level, the clinical relevance of a 60 day differential in time to diagnosis is not certain, the differential may be driven by a select number of individuals whose symptoms were misattributed, and thus, those at the extreme of the time to diagnosis range may suffer the most from any delays in diagnosis. In the above sample, this is evidenced by the maximum time to diagnosis for both age groups. For the under 50 age group the maximum time to diagnosis was 265 days while for the older group the maximum was only 184 days. **Third,** Younger people may

encounter more challenges that delay screening or diagnostic procedures when navigating the CRC screening system.[91] These challenges could present as social problems such as difficulty finding somebody to come to the appointment or practical such as arranging childcare or paying for procedure. **Finally**, key biological differences may exist between cancers that are occurring in younger individuals than those found in older populations.[101,102]

Risk factor identification.

The ability to identify risk factors associated with CRC would be a valuable tool for initiating screening at an age under what is generally recommended for screening. If a patient has one or more risk factors, this may influence their decision to seek or proceed with screening. Further, the patient having adequate knowledge of the decision at hand and the ability to assess that knowledge are important components in shared decision-making. [18] However, the recent dissertation work by Mueller et al.[24] indicates that younger individuals' knowledge of increasing risk and screening tests is low. This is consistent with the hypothesis that CRC is likely not on younger people's 'radar'.[103] It follows that younger people may also have less knowledge of important and potentially compounding risk factors

A number of studies have been conducted that explore CRC risk factor identification in the United Kingdom[104,105], Ireland[106], Hong-Kong[107], Kuwait[108], and Bahrain;[109] however, little published work on this subject in the United States could be identified and none of these studies focused specifically on younger people. However, a 2019 Master's thesis, published online, provided additional evidence for age effects in CRC knowledge. The author found that higher knowledge of risk factors was

significantly associated with being less than 27 years old compared to over 27 in a sample of individuals age 20 to 40. This study did not explore this relationship in a multivariable model.[110] Additionally, this study was limited in its external validity as it recruited only employed millennials between age 20 to 40.

In the United Kingdom, Power et al. sought to create and validate a scale called the Cancer Awareness Measure for Colorectal Cancer to assess people's ability to identify both risk factors and symptoms of bowel disease.[104] This 'scale' utilized both unprompted qualitative responses as well as a prompted checklist to assess knowledge of risk factors. This study found that knowledge of risk factors was low in this population and multivariable analysis indicated that higher social status and white race were related to higher knowledge, however, other ethnicities scored higher for identifying risk factors such as eating processed meats and low physical activity.

There is a distinct gap in the literature around younger people's knowledge of risk factors for CRC, especially in the United States. Additionally, these gaps in knowledge may be related to demographic and literacy/activation variables that could be leveraged when creating, tailoring, and targeting educational interventions.

RQ2: What screening strategy do individuals under 50 prefer and on what are these preferences based?

Patient Preferences for Screening Tests

The second remaining question relates to people's preferences for testing, which is an essential component of the shared decision-making process. In fact, a 2010 NIH state-of-the-science conference statement included patient preferences as a key question to be answered and a priority for research stating:

> *"The effect of patient preferences on colorectal cancer screening rates has not been well studied. We know very little about how preferences for screening modalities are formed; how they are related to knowledge, beliefs, and cultural norms; and whether these preferences vary across sociodemographic groups. It is also unknown whether patient preferences change [or] vary over time; it is also unknown what factors may influence that change. Given the multiple options for colorectal cancer screening, interventions that provide decision support and incorporate patient preferences may be effective at increasing colorectal cancer screening rates across diverse populations."* [111]

While some research has explored preferences (summarized below), the 2018 ACS recommendation statement notes that *consistent* evidence for patient preferences for screening strategies has not yet been established and very little evidence exists for individuals under the age of 50. While people generally prefer one strategy over another when given a choice, we know little about what the features of tests are that lead to these preferences in individuals under age 50.

Descriptive preferences and predictors of strategy preference

Several studies have descriptively explored patient preferences for tests that screen for CRC. A systematic review of preferences in vulnerable populations including racial and ethnic minorities, veterans, rural and low income individuals shows large variability in preferences for screening modality and strategy attributes.[112] The authors of this review found 43 articles that explored patient preferences for screening that contained samples with a high proportion of vulnerable individuals in their sample. The

authors also highlighted the small number of studies that explored how preferences are formed around strategy attributes. A sample of the studies that represents the lack of consensus on this topic is summarized below:

In 2014, Ruffin and colleagues explored this question by conducting 10 focus groups and surveying 93 previously unscreened participants between ages 50 and 70 (mean 60). [113] Participants in focus groups were presented basic information (purpose, process, preparation, pain, test accuracy, frequency, and follow up testing) about colonoscopy, FOBT, double contrast barium enema, and flexible sigmoidoscopy**.** In this sample, **49% of participants preferred colonoscopy, 39% of participants preferred FOBT, 7% preferred barium enema, and 5% preferred flexible sigmoidoscopy.** Participants identified thoroughness and accuracy of information provided, not needing follow up testing for 10 years, and relative painlessness because of anesthesia as reasons for colonoscopy preference. Reasons for FOBT preference were identified as simplicity, convenience, privacy, and the annual testing interval. No statistically significant differences were found for demographic subgroups but, descriptively, more Caucasians than African Americans preferred FOBT (46% vs 30%) and more African Americans preferred colonoscopy (55% vs 44%).

A 2011 3-arm randomized control trial of a computer-based decision aid for CRC screening explored this question in 666 primary care patients age 50 to 75 (mean 57) who had never been screened.[93] In both intervention arms, **the majority (59%) of patients preferred colonoscopy, 26% preferred FOBT** and a small minority of patients preferred the other screening modalities. Patients who selected colonoscopy as their primary choice identified accuracy as the most important test feature. In those that chose

FOBT, inconvenience, discomfort, and bowel preparation were the most noted concerns. When the authors tested demographic features including age, sex, race/ethnicity, education, and insurance status, no significant associations were found for preference of FOBT or colonoscopy.

Only one study in the literature explicitly assessed preferences in individuals in the 40 to 49 age group[114] (besides one that included individuals 49+[115]). This study, conducted in 2008, recruited 323 previously unscreened (with colonoscopy) supermarket participants, of whom, the majority (63%) were below the age of recommended screening (age 40 to 49).[114] When presented with side by side information about FOBT and colonoscopy "nature", "safety", "frequency", "convenience", "accuracy", "cost", and "follow-up testing", **53% preferred FOBT and 47% preferred colonoscopy.** Demographic features associated with FOBT preference included Latino ethnicity (compared to non-Latino whites), and lower education. Family history of CRC and previous experience with sigmoidoscopy were associated with preference for colonoscopy. While age was not significantly associated with test preference, 44.9% of people in the under 50 age group preferred colonoscopy while 49% and 63.6% in the 50 to 64 and 65 to 79 age groups, respectively, preferred colonoscopy. This study may have been underpowered to detect these differences because the sample was primarily under the age of 50. Like other studies, test accuracy and convenience were noted as the most important reasons for preferences for colonoscopy and FOBT, respectively.

Decision Models

Some work has explored these preferences using the Analytic Hierarchy Process (AHP) (Table 2). This method focuses on exploring criteria that people prioritize when making decisions involving multiple options with differing features (see Chapter 4 for

details). In adults age 50 to 85, Dolan, et al. found that patients recruited from primary care practices weighted the most important criteria for assigning priorities as preventing cancer (mean priority score 54%), avoiding side effects (18%), minimizing false positives (15%), and logistics (12%) when comparing these criteria among 10 CRC screening modalities.[116]

A study by Xu and colleagues[117] performed a similar decision-making study in a unique sample of patients age 40 to 75. These individuals were already scheduled for screening or surveillance colonoscopy. Recruitment included sending FIT kits with recruitment materials and data-collection surveys were completed the following day after their completed colonoscopy. In this sample, results indicated that patients who had completed both tests **slightly preferred FIT over colonoscopy with aggregated priority scores of .517 and .483 respectively**. The rank for importance of criteria identified by this study were test accuracy (45.7%), complications (32.1%), and finally test preparation (22.3%). While this study's inclusion criteria included individuals age 40+, the average age of the analytic sample was 56.7 and no subgroup analysis was presented for participants under the age of 50.

Finally, a Dutch AHP study conducted by Hummel et al. in individuals 55 to 75 found that preference weights were **.26 for sensitivity, .26 for safety, .24 for specificity, .15 for frequency, and .09 for convenience** choosing between FIT, colonoscopy, sigmoidoscopy, and computerized tomographic colonography. [118]

Table 2: Summary of AHP for CRC screening in the literature

First Author (Year)	Setting	Population	Alternatives	Criteria (1…) Sub criteria (a…)	Subsamples	Preference for screening test
Dolan [116](2013)	Primary care practices (USA)	People at average risk (50+)	10 screening options/ intervals	(1) Prevent cancer (2) Reduce Side Effects (3) Minimize False positives (4) logistics (a. Frequency; b. preparation; c. procedure)	**Criteria preference clusters tested by:** Age, gender, race, education, marital, lit., num., knowledge, income	Not tested
Xu [117](2015)	University affiliated hospital clinic (USA)	People completed both colonoscopy and FIT just prior to survey (age 40-75 m=56.7).	(1) Colonoscopy (2) FIT	(1) Accuracy (2) Complications (3) Test prep, frequency, and procedure	Race, marital status, insurance, rural vs urban, gender, education, income	.483 colonoscopy .517 FIT
Hummel [118](2013)	National survey (Dutch)	Nationally representative sample online (55-75)	(1) FIT (2) Sigmoid (3) colonoscopy (4) CTC	(1) Sensitivity (2) Specificity (3)Safety (3) Comfort (a. convenience; b. frequency)	None tested	.26 FIT .17 sigmoid .22 colonoscopy .36 CTC

Preferences for screening tests are inconsistent in the literature, and very little is known about preferences for people who generally fall outside of the range for initiation of age-based screening. Additional work must be conducted in this age group to determine what the preferences for CRC screening are, what these preferences are based on, and whether these preferences are related to any key sociodemographic features that providers could leverage to help patients make informed decisions about screening. This information can be utilized to create and enhance existing decision-making tools used in clinical settings to encourage adherence to a preferred screening strategy.

RQ3: When making CRC screening decisions, what level of control (role preference) do people under 50 prefer and do they feel confident in their ability to make decisions?

Patient willingness to participate in shared decision-making is a critical component of the process.[19,119] However, there may be considerable variation in an individual's desired role.[25] It follows that if a patient prefers a shared or patient driven role in decision-making, their self-efficacy for making that decision must also be high. A seminal review on shared decision-making by Fosch and Kaplan indicated that willingness to participate in shared decision-making ranged from 19% to 63% depending on the sample and health concern being studied.[25] They also found that younger and more highly educated individuals tended to desire more involvement in making medical decisions. A 2012 systematic review of 115 studies on shared decision-making preferences in patients found that, in 63% of studies assessed, shared decision-making was the majority preference while, in 21% of studies, physician delegated decision-making was preferred by the majority of participants.[120] The authors of this study found variation in desire for shared decision-making between samples that were drawn from cancer decision- (77% preferred SDM) and general population- studies (53%) indicating that role preference could be contextual.

For colorectal cancer screening there is not as strong a consensus on when to initiate screening and no screening method is recommended consistently above others. In this instance, people may be more likely to want to defer the screening decision to their physician, or alternatively, they may want more involvement when uncertainty is involved. This issue is complicated because patients may be unaware of or confused by

current guidelines,[121] especially when long-standing guidelines become part of patients' general knowledge through public health and media messaging (i.e. 'get your colonoscopy at age 50'), and when physicians have reservations or disagree with new guidelines.[122]

Measuring patient's desired role in colorectal cancer screening decisions

Previous work on a primarily African- American, female sample of primary care patients (mean age 56.4) indicated that approximately 10% of their sample preferred physician based decision-making while 48% preferred patient based and 41% preferred shared decision-making.[93] In another sample, consisting of primarily white individuals, 45% preferred decision-making to be shared with the doctor, 25% desired to be the primary decision maker (after considering the doctor's opinion), 16% preferred the doctor to make the decision, and 15% preferred to make the decision on their own. [94] Several demographic features were associated with preferences in this sample including black race preferring shared decision-making and lower education preferring doctors to make the decision. Finally, in a primarily Hispanic sample, a collaborative role was preferred by 53.3% of participants while passive was preferred by 26.4%.[123] However, none of these studies included individuals who were under the age of 50, so very little information is available in the literature regarding these individuals' preferences for participating in the colorectal cancer screening decision-making process. Unanswered questions remain about individuals in younger age groups desired role in decision-making about colorectal cancer and whether they have confidence in their ability to perform this role. On the one hand, younger age may play a role in increased desire to be more engaged, while on the other, uncertainty and lack of clarity on guidelines and

screening modalities may influence these people to defer decisions to their doctors. If younger patients want patient driven or shared decision-making for CRC screening, they must also have the self-efficacy necessary to carry out those decisions. If decisional self-efficacy and desired role are mismatched, tools can be built to increase self-efficacy for making decisions, thus, empowering patients and improving satisfaction with the process and adherence to screening plans.

Conclusions:

With shifting guidelines about when to initiate screening for colorectal cancer, new doors for scientific inquiry have opened. Almost no work in the colorectal cancer literature has included samples of individuals who are under the age of 50 due to the long-standing guidelines that recommend initiating age-based screening at 50. While only the American Cancer Society has currently recommended shifting the age to 45, there is growing evidence for increasing risk in younger individuals. As evidence accumulates, other policy recommending entities may follow suit and begin advising people under 50 to be screened. When guidelines change, especially those issued by the USPSTF, insurance coverage for the tests will shift and so will practice. However, varying protocols, uncertainty and lack of consensus make using a shared decision-making framework appropriate for individuals under the age of 50. The aims of this project will fill gaps in the current literature by exploring several components of the shared decision-making process. Within these areas, there is a distinct lack of literature that can be used to build tools to guide clinicians and their patients when navigating these decisions. In this dissertation I explored 3 key questions about: (1) knowledge of CRC risk factors; (2) preferences for screening tests; and (3) desire and self-efficacy to engage in decision-

making in this context. This study is innovative because most previous work on this topic has included individuals within the previously agreed upon guidelines for appropriate initiation of screening and has not included individuals below age 50. However, 19 million people may now be in the age group that would benefit from screening. Answering these questions will be essential for improving clinical interactions, ensuring screening when appropriate, and continuing to reduce CRC incidence and mortality.

Chapter 3: Is Colorectal Cancer on their Radar? Symptom and Risk Factor Identification and the Moderating Role of Age

Is Colorectal Cancer on their Radar? Symptom and Risk Factor Identification and the Moderating Role of Age

T. Hyams[1,2], B. Golden[3], S. Sultan[4], E. King-Marshall[1], M. Wang[1], B. Curbow[1]

1. University of Maryland, College Park, School of Public Health, Department of Behavioral and Community Health; 2. National Cancer Institute, Division of Cancer Control and Population Sciences, Office of the Director; 3. University of Maryland, College Park, Robert H. Smith School of Business, Department of Decision, Operations, and Information Technologies; 4. University of Minnesota, Department of Medicine, Division of Gastroenterology, Hepatology, and Nutrition

Introduction: Colorectal cancer is an essential cancer control priority and improvements in uptake of screening have reduced mortality from the disease. However, in individuals under 50, the incidence of colorectal cancer is increasing and cancers in this population are often found at a later stage. In order for younger people to make informed decisions about colorectal cancer, they must be knowledgeable about the disease. Little work has been conducted in the United States evaluating younger people's knowledge of risk factors and symptoms of colorectal cancer. In this study, we investigate individuals under age 50 and their knowledge of colorectal cancer, predictors of symptom and risk factor knowledge and the moderating role of age on these associations. **Methods:** We recruited 579 participants from Amazon Mechanical Turk (MTurk) for a survey on perceptions about colorectal cancer screening. We assessed risk factor knowledge by creating an index of 8 true risk factors and 2 false risk factors and we assessed symptoms using 5 'true' symptoms and 3 'false' symptoms. Scores on each index were scored and analyzed separately and in aggregate. We used linear regression models to evaluate demographic and cancer experience variables as predictors of total index scores. We split the sample into two groups (<50 years old and ≥50) to test the moderating role of age. **Results:** Knowledge of both symptoms and risk factors was adequate and did not differ by age group. However, we found evidence for the moderating role of age. In the <50 age group, subjective numeracy (p=.008), knowing somebody close who was tested for CRC (p=.006), and commitment to testing (p=.048) were significant predictors of risk factor knowledge. For symptoms, female gender (p=.039), knowing somebody close who was tested(p<.000), and perceived likelihood of getting cancer (p=.033) were moderated by age. **Discussion:** Results of this study indicate that age will be an important factor to consider for future research. As risk continues to rise in younger populations, we must address knowledge of the disease to ensure that younger people are able to make informed decisions about their healthcare.

Colorectal Cancer in younger people

The overall burden of colorectal cancer (CRC) is declining in the United States, however, it still represents the third highest mortality of cancer sites for both sexes.[2,8,26] Population-based analyses also indicate increasing rates of CRC among individuals under age 50.[72] Currently, 11-12% of colorectal cancers are identified in people under age 50 and yearly increases in incidence for people under 50 range from approximately 1.3-2.4% in colon cancer and 2.3-3.2% for rectal cancer.[8,72] Steep increases in incidence when data are analyzed year-by-year also show that many cancers in people age 45-49 remain undetected until they initiate screening at age 50.[124] In response to this epidemiologic shift and an evaluation of benefits versus burdens, the American Cancer Society reevaluated their recommendation to initiate screening in average risk individuals at age 50.[3] In the updated guideline statement, they gave a qualified recommendation for people age 45-49 to consider initiating screening. If the lowered screening age were widely adopted by the United States Preventive Services Task Force (USPSTF), approximately 19 million individuals would be added to the eligible screening should they seek screening.[88,89,125] Despite this increasing risk and potentially changing guidelines on when to initiate screening, colorectal cancer may not be on younger people's 'radar'.[103] This could be due, in part, to younger people's thoughts of cancer as a disease that older people get and the consistent messaging that CRC, in particular, is not something to think about until they turn fifty.[8,103]

Risk factor and Symptom identification

An individual's ability to identify risk factors associated with CRC could influence their decision to initiate screening at a younger age than recommended. Young-onset CRC patients are also at higher risk of presenting with later stage CRC than their

older counterparts and may be symptomatic at the time of diagnosis. [98,99] Reasons for worse clinical manifestation are likely part biological[100,102] but could be associated with doctor and patient misattributing or ascribing less severity to symptoms of possible cancer. In 2015, Dozois, et al. found that the majority of patients under the age of 50 (mean age =42) at their institution presented with late stage disease (Stage III or IV) and were symptomatic at the time of diagnosis.[100] Symptoms seen in this population were most commonly rectal bleeding (51%), abdominal pain (32%), change in bowel habits (18%), and weight loss (13%). When symptoms do arise, younger patients may also encounter different challenges than older individuals when navigating the colonoscopy procedure used for diagnosis.[91] For example, younger people experience more social and practical problems like difficulty finding somebody to come to the appointment, arranging childcare or paying for procedure. These factors can increase time for a patient to visit a provider, increase work-up time, lead providers down an incorrect treatment path, or otherwise increase the amount of time from symptom onset to diagnosis.[100,101] Knowledge of CRC symptoms could empower individuals to seek care and advocate for more testing, especially when multiple factors are present.

A number of studies have been conducted that explore CRC risk factor and symptom identification with varying results[104–109]. Knowledge of risk factors and symptoms vary by demographic features of participants. For example, in a representative sample conducted in Great Britain, awareness of risk factors was independently associated with white ethnicity and higher socioeconomic group while awareness of symptoms was associated with being female, white ethnicity, higher socioeconomic group, and familiarity with cancer.[104] However, little work has been published in the

United States and these studies have not focused specifically on the moderating role of age for an individual's ability to identify risk factors and symptoms of CRC.

As our knowledge of increasing CRC risk in younger people grows, it is prudent to build on the existing literature around younger individuals' understanding of CRC risk factors and symptoms. However, the overwhelming body of literature on colorectal cancer has focused on people over 50. This has left a distinct gap in our understanding about how younger people perceive CRC and their knowledge about the risk factors for the disease. Recent work supports that younger people are confused about the types of CRC screening tests available and they may be unaware of their increased risk of developing the disease.[24] Given the uncertainty surrounding screening for colorectal cancer, the rising risk in younger people, and the relative equality in effectiveness of screening options, CRC related screening and diagnosis decisions should also consider a shared decision-making framework. A shared decision-making framework stipulates that an individual is knowledgeable about the disease, their individual risk, and the different options available to them so that they can make an informed choice.[19] As a next step, we aim to classify differences around risk factor and symptom awareness for colorectal cancer by age groups. Additionally, we explore how gaps in knowledge related to demographic, cancer experience, and psychological variables are moderated by age. This information can be leveraged when creating, tailoring, and targeting educational interventions for younger people, when considering how to best incorporate younger people into screening programs, or, when developing research agendas to fill gaps in colorectal cancer knowledge in individuals under 50.

Methods:

Study Sample:

This study was part of a larger study on perceptions about colorectal cancer in individuals under age 50. Survey data were collected using Qualtrics[126] after participants self-selected to participate from Amazon Mechanical Turk (mTurk). MTurk describes itself as a crowdsourcing global workforce for individuals that complete a variety of tasks, including research tasks.[127] MTurk workers (Turkers) represent diverse individuals from across the globe and previous work with Turkers has shown that they produce high quality research data, even when presented with complex behavioral tasks that are traditionally conducted in-person.[128] We took best- practice measures to ensure high quality data including requiring workers to have completed tasks with a high approval rating and including qualitative responses to screen for 'bots' or automated responses. Initial inclusion criteria related to participant characteristics for this study included being ages 45-55, living in the United States, and never having been screened for colorectal cancer. After initial collection of 482 participants, we then released the survey to all individuals over 18 who met these criteria.

Knowledge Index of CRC Risk Factors:

We assessed risk factor knowledge by creating an index of 8 true risk factors and 2 false risk factors. Eight true risk factors were: increased age[3]; higher body mass index (BMI) (obesity)[129]; smoking cigarettes or using other tobacco products[130]; heavy alcohol consumption[131]; a family member with colon or rectal cancer[132]; inflammatory bowel disease such as irritable bowel disorder (IBD), Crohn's disease, or ulcerative colitis[133]; diabetes,[134] and diet high in red meat or processed meat.[135] False risk factors included exposure to violent video games and exposure to the sun without sunscreen. Each

question was phrased: “Which of the following would increase the risk for somebody to get colon or rectal cancer?” Participants were given the option to respond “yes”, “no” or “I don’t know”. Scores for the index were calculated as a sum of correctly identified (“yes”) true risk factors (range: 0-8). ‘I don’t know’ was not considered to be a correct response for true risk factors. False risk factors were also assessed using ‘yes’ responses for false risk factors (range 0-2). For analysis, false risk factors were dichotomized to 0=no false risk factors identified, 1= 1 or more false risk factors identified.

Knowledge Index of CRC Symptoms:

Symptoms were assessed in a similar manner using 5 ‘true’ symptoms and 3 ‘false’ symptoms. Questions were phrased “which of the following are likely symptoms of colon or rectal cancer?” and response options included “yes”, “no”, and “I don’t know”. True symptoms included: blood when you wipe after using the bathroom; persistent abdominal pain; anemia (paleness, weakness, fatigue); unexplained weight loss; and change in bowel habits. False symptoms were indigestion or heartburn; persistent headaches, the urge to urinate often. Scores for correctly identified true symptoms (range 0-5) and identified false symptoms (range 0-3) were also calculated using “yes” responses. For analysis, we collapsed false symptoms into 0= no false symptoms identified, 1= 1 false symptom identified, 2= 2 or more false symptom identified.

Independent Variables

Demographic variables included age (1= <50, 2= ≥50); education (1= High school or less, 2= some college, 3= college completion, 4=higher than college); household income (1= <30k, 2=30-59,999, 3=60-89,999, 4= >90k); gender identity (1=man,

2=woman), self-identified primary race (recoded as 1=white, 2=other); type of insurance coverage (recoded as 0=no, 1=public, 2=private for regression and 0=no, 1= yes for false risk factor analysis), relationship status (recoded as 1=single, 2=dating or cohabitating but not married, 3=married). We also assessed general health (continuous 1=Poor, 5=excellent); health literacy[136] (continuous 4-20); subjective numeracy[137] (continuous 1-6); confidence in seeking advice on medical topics (continuous 1= not confident at all, 5=completely confident); and having a regular medical provider (0=no, 1=yes) as independent variables. Finally, we included independent variables related to cancer experience: having somebody close who has died of cancer (0=no, 1=yes); family, spouse, or anybody else close having been tested for CRC (recoded 0=no/don't know, 1=yes); self being diagnosed with cancer (0=no, 1=yes); worry about cancer (continuous 1=not at all, 5=extremely); perceived likelihood of getting cancer (1= very unlikely, 5= very likely); and stage of commitment to CRC testing (1=have not thought about getting tested-5=committed to getting tested) .

Analysis:

We calculated descriptive statistics for demographics, individual symptom and index items, and overall index scores. We also used ANOVA to determine differences in the mean index scores of the two age groups (<50, ≥ 50). We used multivariable linear regression models to test independent predictors of total index scores in the full sample and in each age group. To contextualize the associations found in linear regression models, we also performed ANOVA and χ^2 tests to determine if significant variables were also associated with higher false symptom and risk factor scores in the overall

sample in age subgroups. We calculated 2 sided Fishers exact statistics for categorical variables when cell sizes were less than 5. All analyses were conducted using SPSS v26.

Results:

Sample demographics

The demographic features of the sample can be found in Table 1. The sample was majority women, white/Caucasian, English speaking, born in the United States, and married. Approximately 54.9% of the sample had completed a college degree or above and most participants were insured with either private (67.9%) or public insurance (15.5%).

Individual and combined knowledge scores

Knowledge of individual risk factors and symptoms can be found in Table 2. Participants' ability to identify risk factors ranged from 44.2% for diabetes to 88.9% for family history of CRC. On average, participants scored 5.5/8 on the risk factor index (range 0-8). About 9.1% of the sample identified 1 or more false risk factors as a true risk factor. Participants' ability to identify symptoms varied from 59.8% correctly identifying persistent anemia to 85.8% correctly identifying blood when you wipe after using the bathroom. The average score for symptom identification was 3.7/5 (range: 0-5). A number of participants (38.3%) identified one or more of the false symptoms. For both true risk factors and true symptoms, participants were much more likely to respond 'I don't know' rather than correctly identifying a false symptoms and risk factors as such.

ANOVA results indicated that participants <50 and 50 and older scored similarly on both the symptom and risk factor index. Mean symptom scores for the <50 age group

were 3.6 and 3.8 for ≥ 50 (F=1.808, p=.179). For risk factors, the mean scores were 5.6 (<50) and 5.5 (≥50) (F=.361, p=.548).

Multivariable linear regression Risk factors:

Regression results for risk factors can be found in Table 3. In the full sample, higher scores on the risk factor index were associated with higher levels of cancer worry (B=.182, p=.035) and perceived likelihood of getting cancer (B=.207, p=.05); public insurance vs private (B=.586, p=.031); having a family member, spouse, or other anybody else close who has been screened for CRC (B=.601, p=.001); higher subjective numeracy (B=.284, p=.003), and higher commitment to getting tested for CRC (B=.160, p=.016). In the subgroup analysis, for individuals under age 50, higher subjective numeracy (B=.336, p=.008); family, spouse, or anybody else close screened for CRC (B=.639, p=.006); and commitment to getting tested (B=.167, p=.048) remained significantly associated with higher risk factor index scores. In those over 50, having been previously diagnosed with cancer emerged as predictive of lower index scores (B= -.921, p=.044) and public vs private insurance remained significantly associated with higher index scores (B=1.243, p=.007). None of the variables that were significant in the full models or age subgroup models were associated with false risk factor identification at the bivariate level.

Multivariable linear regression Symptoms:

Results of the multivariable linear regression results for symptom index scores can be found in table 4. Results for the full sample show significant associations between higher symptom knowledge and female gender identity (B=.354, p=.007); having

somebody close that has died of cancer (B=.301, p=.022); and family, spouse, or anybody else close that has been tested for CRC (B=.397, p=.003). In the under 50 age group, associations remained for female gender identity (B=.348, p=.039) and family, spouse, or anybody else close tested for CRC (B=.608, p <.000) and perceived likelihood of getting cancer (B=.216, p=.033). In the ≥50 age group, only having somebody close that has died from cancer remained associated with higher symptom knowledge scores (B=.648, p=.003). None of the significant variables in the full model or age subgroup models were significantly associated with false symptom identification at the bivariate level. However, the association between higher false symptom scores and perceived likelihood of getting cancer approached significance for the ≥50 age group (mean range: 3.07-3.47, F=2.93, p=.055).

Discussion:

Participants' ability to identify risk factors was generally high (range: 44.2%-88.9%). However, lower levels of knowledge pertaining to modifiable risk factors such a tobacco use (47%), and heavy alcohol consumption (52.8%) are important to note as these behaviors are related to multiple cancers and other health conditions. Participants' ability to identify individual symptoms was also high (range: 59.8%-85.8%) but identification of the symptoms that are related to general cancer (persistent anemia and unexplained weight loss) were lower than symptoms specific to colorectal cancer (blood in stool, abdominal pain, and changes in bowel habits). This could be explained by participants using context clues about gastrointestinal symptoms, rather than actual knowledge about the symptom's association with colorectal cancer. Consistent with this, Power and colleagues (2011) explored knowledge using unprompted assessments and

found that their sample had very low knowledge of symptoms when not provided a list of possibilities.[104] When prompted, participants in their sample had much higher knowledge of symptoms, similar to this study. The distinction between prompted and unprompted responses is important when considering the measurement of knowledge in community samples and a multi-step approach could more accurately classify an individual's baseline knowledge about both symptoms and risk factors. Furthermore, providing information about risk factors and symptoms specific to CRC and generally to cancer should be considered when designing interventions to improve knowledge.

In this sample, participants in both age groups had similar knowledge about risk factors and symptoms of colorectal cancer. While we did not find differences in the overall scores for each index between age groups, we did find that the overall scores were associated with different participant characteristics. This is evidence that an individual's age moderates these relationships. For younger people, having a family member, spouse, or anybody else close who has been tested for CRC was predictive of higher scores on both the risk factor and symptom index. Personal experience with colorectal cancer screening is likely important when considering the best way to improve knowledge about the disease. Individuals with higher baseline experience with colorectal cancer testing might benefit less from interventions that aim to increase knowledge of CRC risk factors and symptoms. Unique to the under 50 age group, male gender was associated with lower knowledge scores on symptom identification and those with lower numeracy scored lower on risk factor identification. Additionally, individuals under 50 that were less committed to getting tested for CRC were more likely to have lower risk factor identification scores. These features warrant further study and can be used to identify

younger people who are at higher risk of having lower knowledge and thus benefit from educational interventions or targeted public health messaging.

We found that perceived likelihood of getting cancer and cancer worry were associated with higher risk factor index scores in the overall sample. It is possible that those who worry more about cancer or perceive their likelihood of getting cancer as higher are more likely to identify more risk factors, regardless of whether they are 'true' or not. However, we did not find evidence that participants in the overall group and in each age subgroup were erroneously identifying all of the presented risk factors and symptoms as 'true'. This adds evidence to the predictive associations for index scores found in this study. To our knowledge, this is the first study to test whether false knowledge was associated with participant characteristics.

Limitations:

There are several limitations to this study that must be noted. First, our sample lacked racial and ethnic diversity. This limitation is consistent with other studies that use mTurk as a platform to collect data.[138] Future studies using targeted recruitment can reveal whether similar issues persist in groups disproportionately burdened by colorectal cancer. Second, due to survey administration restraints, we were not able to assess participants unprompted responses to symptoms and risk factors. Unprompted responses have been used elsewhere in the literature[104,109] and may more closely represent actual knowledge.

Strengths

Strengths of this study include a large sample size that allowed us to test multivariable associations. The large sample that we studied allowed us to assess the moderating role of

age on these associations. Knowledge, especially of a complex disease like CRC, can be difficult to contextualize when considering the many participant characteristics that could be associated with higher levels of knowledge. Another strength of this study is the robust collection of cancer experience and psychological variables. We found that these variables remained significantly associated in multivariable models while demographic variables did not. Finally, we included false symptoms and risk factors allowing us to test whether index scores were true to actual knowledge rather than representing participant identification of presented survey items.

Conclusion

A large body of literature related to perceptions about colorectal cancer and screening exists for individuals age 50+. We show that age is an important factor to consider when assessing predictors of CRC symptom and risk factor knowledge. Because no participants in our sample have been screened for colon or rectal cancer before, these differences offer some evidence that unscreened people under 50 years old should be considered differently than those over 50 in both research and clinical practice. As researchers, practitioners, and the public grapple with increasing risk for CRC in younger people, we must preemptively build our knowledge around other important constructs in younger cohorts of people. In fact, an early impact analysis indicated that there has been significant increases in testing in those age 45-49 after the ACS guideline statement was released in 2018.[139] It is currently difficult for people under 50 to obtain screening that is covered by insurance. If the USPSTF recommends that individuals 45-49 should be screened, the Affordable Care Act mandates that this testing is covered by the patient's insurance.[88,89] Patients even younger than age 45 could potentially seek screening should

they choose, leading to over screening. There are downstream consequences of over-screening and utilization of healthcare resources to conduct potentially invasive and costly screening on groups of individuals whose risk remains relatively low compared to their older counterparts.[72] Innovative solutions involving stratification based on risk using technologies such as artificial intelligence to identify those who would benefit most from more intensive screening, may help with defining appropriate populations .[140]

If symptoms in younger individuals arise, there must be rapid response from both patients and their providers to conduct diagnostic workup to ensure that the diagnosis of younger-onset colorectal cancers are not delayed. An individual's baseline knowledge about both risk factors and symptoms will be valuable to assess so that they can make an informed decision about the best actions for screening and diagnosis. This study provides a base for future work that unravels the complicated contextual factors that influence somebody's knowledge about CRC risk factors and symptoms.

Paper 1 Tables

Table 1: Participant Demographics (N=579)

Continuous Variables	**Range**	**Mean (SD)**
Age	20-69	48.2 (5.9)
Health Literacy 5-20	8-20	17.8 (2.48)
Subjective Numeracy 1-6	1.38-6	4.6 (.94)

Categorical Variables	**N (%)**
Age	
18-49	358 (61.8)
50+	220 (38)
Gender	
Female	357 (61.7)
Race	
White / Caucasian	480 (82.9)
Not-White/Caucasian	99 (17.1)
Hispanic – Yes	26 (4.5)
Primary Language English—Yes	573 (99)
Education categories	
Highschool or less	96 (16.6)
Some college	164 (28.3)
College Graduate	189 (32.6)
Some Graduate School / Graduate degree	129 (22.3)
Relationship Status	
Single	212 (36.6)
In a relationship / cohabitating	87 (15)
Married	278 (48)
Income	
<30k	112(19.3)
30-59,999	181 (31.3)
60-89,999	136 (23.5)
>90k	149 (25.7)
Insurance	
No	93 (16.1)
Private	393 (67.9)
Public	90 (15.5)

Table 2: Risk Factor and Symptom Identification Full Sample

Risk Factor	**Identified as risk factor N (%)**	**Don't Know N (%)**	**Identified as not a risk factor N (%)**	
Increased Age	514 (88.8)	49 (8.5)	14 (2.4)	
Obesity/ High BMI	441 (76.2)	110 (19)	28 (4.8)	
A diet high in red or processed meats	448 (77.4)	90 (15.5)	39 (6.7)	
Diabetes	256 (44.2)	263 (45.4)	58 (10)	
IBD/Inflammatory bowel disease	450 (77.7)	106 (18.3)	23 (4.0)	
Heavy Alcohol	306 (52.8)	195 (33.7)	77 (13.3)	
Tobacco use	272 (47.0)	198 (34.2)	109 (18.8)	
Family History	515 (88.9)	44 (7.6)	20 (3.5)	
Correctly Identified Risk Factors (0-8) Mean (SD)	5.5 (1.96)			
False Risk Factors				
Exposure to violent video games	13 (2.2)	51 (8.8)	512 (88.4)	
Exposure to sun without sunscreen	44 (7.6)	190 (32.8)	345 (59.6)	
False Risk Factors Identified as risk factors (yes)	**0 identified**	**1 identified**	**2 identified**	
	526 (90.8)	46 (7.9)	7 (1.2)	
Symptom	**Identified as a symptom N (%)**	**Don't Know N (%)**	**Identified as not a symptom N (%)**	
Blood when you wipe after using the bathroom	497 (85.8)	61 (10.5)	21 (3.6)	
Persistent abdominal pain	429 (74.1)	113 (19.5)	35 (6.0)	
Persistent anemia (paleness, weakness, fatigue)	346 (59.8)	180(31.1)	52 (9.0)	
Unexplained weight loss	399 (68.9)	147 (25.4)	31 (5.4)	
Persistent changes in bowel habits	468 (80.8)	90 (15.5)	21 (3.6)	
Correctly Identified Symptoms (0-5) Mean (SD)	3.7 (1.46)			
False Symptoms				
Persistent indigestion or heartburn	152 (26.3)	255 (44)	171 (29.5)	
Frequent urges to urinate	115 (19.9)	252 (43.5)	210 (36.3)	
Frequent headaches	38 (6.6)	281 (48.5)	260 (44.9)	
False Symptoms Identified as symptoms (yes)	**0 identified**	**1 identified**	**2 identified**	**3 identified**
	357 (61.7)	157 (27.1)	47 (8.1)	18 (3.1)

Table 3: Multivariable linear regression for correct risk factors a= significant at .05, b= significant at .01, c= significant at <.001										
		Overall sample Risk factors			<50 risk factors			≥50 risk factors		
Variable	coding	B	95% CI	p value	B	95% CI	p value	B	95% CI	p value
Age	≥50	-.010	-.341-.321	.953						
Education	More than college (ref)									
	College grad	.036	-.401-.472	.873	.024	-.520-.569	.931	.166	-.629-.961	.680
	Some college	-.052	-.519-.414	.826	.002	-.606-.610	.995	.000	-.775-.776	.999
	HS or less	-.043	-.580-.494	.875	-.257	-.981-.466	.485	.199	-.657-1.055	.647
Household Income	GT90k (ref)									
	60-89,999	-.037	-.505-.430	.875	-.091	-.665-.482	.754	.096	-.758-.951	.824
	30-59,999	.024	-.458-.506	.921	-.182	-.790-.427	.558	.409	-.427-1.245	.336
	LT30k	-.297	-.931-.337	.358	-.217	-1.045-.610	.605	-.345	-1.421-.732	.528
Gender	Woman vs Man	.036	-.306-.379	.835	.085	-.357-.527	.706	.092	-.486-.671	.754
Race	Other v. white	-.261	-.695-.173	.238	-.459	-1.047-.130	.126	.059	-.620-.738	.864
Insurance	Private (ref)									
	Public	.586	.055-1.117	**.031**[a]	.102	-.590-.794	.772	1.243	.347-2.140	**.007**[b]
	No	-.186	-.683-.312	.464	-.238	-.946-.470	.509	-.151	-.886-.583	.685
Subjective Numeracy	Cont.	.284	.098-.470	**.003**[b]	.336	.088-.583	**.008**[b]	.142	-.155-.440	.347
Anybody close died of cancer	Yes v no	.170	-.169-.509	.326	.028	-.421-.477	.903	.452	-.107-1.010	.112
Family, spouse, or somebody close tested for CRC	Yes v. no/don't know	.601	.253-.949	**.001**[b]	.639	.189-1.089	**.006**[b]	.510	-.063-1.083	.081
Self ever diagnosed with cancer	Yes v no	-.517	-1.103-.068	.083	-.213	-1.027-.600	.606	-.921	-1.818- -.023	**.044**[a]
Cancer worry	Cont.	.182	.013-.351	**.035**[a]	.166	-.043-.375	.119	.280	-.027-.588	.074
Perceived Likelihood of cancer	Cont.	.207	.001-.415	**.05**[a]	.252	-.012-.517	.062	.070	-.293-.433	.703
Commitment to testing	Cont.	.160	.030-.289	**.016** [a]	.167	.001-.332	**.048** [a]	.176	-.057-.409	.138

Non-significant control variables also included in the model: General health, Health Literacy, Confidence in seeking advice about medical topics, having a regular medical provider, and relationship status

Table 4: Multivariable linear regression for correct symptom scores a= significant at .05, b= significant at .01, c= significant at <.001

		Overall sample symptoms			<50 symptoms			≥50 symptoms		
Variable	coding	B	95% CI	p value	B	95% CI	p value	B	95% CI	p value
Age	≥50	.145	-.105-.395	.256						
Education	More than college (ref)									
	College grad	-.043	-.372-.286	.797	-.204	-.613-.205	.327	.370	-.234-.973	.228
	Some college	.087	-.266-.440	.628	-.023	-.481-.435	.922	.291	-.300-.883	.332
	HS or less	.005	-.401-.411	.981	.009	-.537-.555	.975	.157	-.497-.812	.636
Household Income	GT90k (ref)									
	60-89,999	-.017	-.370-.335	.923	-.126	-.555-.303	.564	.099	-.552-.750	.765
	30-59,999	-.201	-.564-.163	.279	-.179	-.637-.279	.442	-.144	-.781-.492	.656
	LT30k	-.371	-.852-.110	.130	-.360	-.982-.262	.256	-.331	-1.159-.496	.431
Gender	Woman vs Man	.354	.095-.612	**.007[b]**	.348	.018-.677	**.039[a]**	.400	-.044-.843	.077
Race	Other v. white	.133	-.194-.459	.425	-.016	-.459-.426	.942	.316	-.197-.828	.226
Insurance	Private (ref)									
	Public	.094	-.309-.497	.647	.220	-.300-.740	.406	-.039	-.731-.653	.912
	No	-.034	-.410-.341	.857	.214	-.319-.747	.430	-.166	-.725-.393	.558
Subjective Numeracy	Cont.	.098	-.043-.239	.172	.134	-.053-.321	.159	.002	-.226-.231	.983
Anybody close died of cancer	Yes	.301	.044-.558	**.022[a]**	.126	-.210-.463	.461	.648	.217-1.079	**.003[b]**
Family, spouse, or somebody close tested for CRC	Yes v. no/don't know	.397	.134-.660	**.003[b]**	.608	.271-.945	**<.000[c]**	.078	-.361-.517	.725
Self ever diagnosed with cancer	Yes	-.166	-.610-.277	.462	-.109	-.721-.503	.726	-.274	-.963-.415	.434
Cancer worry	Cont.	.052	-.076-.180	.428	.035	-.122-.192	.660	.127	-.110-.363	.293
Perceived Likelihood of cancer	Cont.	.108	-.049-.265	.176	.216	.017-.415	**.033[a]**	-.069	-.346-.209	.625
Commitment to testing	Cont.	.036	-.063-.135	.473	.061	-.063-.186	.334	-.065	-.245-.116	.481

Non-significant Control variables also included in the model: General health, Health Literacy, Confidence in seeking advice about medical topics, having a regular medical provider, and relationship status

Chapter 4: Using the Analytic Hierarchy Process to Evaluate Preferences for Colorectal Cancer Screening Strategies by Age

Using the Analytic Hierarchy Process to Evaluate Preferences for Colorectal Cancer Screening Strategies by Age

T. Hyams[1,2], B. Golden[3], J. Sammarco[4], S. Sultan[5], E. King-Marshall[1], M. Wang[1], B. Curbow[1]

1. University of Maryland, College Park, School of Public Health, Department of Behavioral and Community Health; 2. National Cancer Institute, Division of Cancer Control and Population Sciences, Office of the Director; 3. University of Maryland, College Park, Robert H. Smith School of Business, Department of Decision, Operations, and Information Technologies; 4. Definitive Business Solutions, Inc., 11921 Freedom Drive, Suite 550, Reston, VA 20190; 5. University of Minnesota, Department of Medicine, Division of Gastroenterology, Hepatology, and Nutrition

Abstract:

Introduction: In 2018, the American Cancer Society gave a qualified recommendation for individuals age 45-49 to initiate screening for colorectal cancer (CRC). Because several screening strategies are recommended, making an informed decision involves including an individual's preferences. Few studies have included individuals under age 50 due to guidelines recommending initiation of screening at age 50. In this study, we use the Analytic Hierarchy Process (AHP) to explore preferences for screening strategies and evaluate whether preferences vary by age (<50 and ≥50). **Methods:** Participants evaluated a hierarchy with 3 decision alternatives (colonoscopy, fecal immunochemical test, and computed tomography colonography), 3 criteria (test effectiveness, the screening plan, and features of the test) and 7 sub-criteria. We used the linear fit method to calculate consistency ratios and the eigenvector method to calculate aggregated group preferences. We also conducted sensitivity analysis to assess whether results are robust to change. We tested differences in preferences by participant variables using chi-square and ANOVA. **Results:** Participants that were either white or have lower health literacy were more likely to be excluded due to inconsistency. Colonoscopy was the preferred strategy in those under age 50 and FIT was preferred by those over age 50 (p=.002). Participants rated test effectiveness as the most important criteria for making their decision (weight=.555). Sensitivity analysis showed that our results were robust to shifts in criteria and sub-criteria weights. **Discussion:** The differences that we found by age should be considered if adapting screening programs to include individuals under age 50. AHP activities can also be incorporated into health systems to ensure that patients are making preference-aligned decisions. Costs should be considered when allocating limited resources to colorectal cancer screening programs.

Introduction:

Colorectal Cancer and Screening Guidelines:

Colorectal-cancer (CRC) related incidence and mortality is declining in the United States and across the globe, primarily due to public health efforts to improve age appropriate, guideline-based screening. However, it still remains a leading cancer control priority.[3–5,72] Recent analyses indicate a concerning trend of increasing risk in individuals under age 50.[8,72] In 2018, the American Cancer Society updated it's guidelines for colorectal cancer screening to address this trend in younger individuals and made a 'qualified' recommendation that average-risk adults aged 45 or older should begin regular screening.[3] This is in contrast to other guidelines that primarily endorse CRC screening starting at age 50.[141] If adopted by the United States Preventive Services Task Force (USPSTF), an independent guideline-producing organization whose recommendations influence clinical coverage and policy decisions, approximately 19 million individuals will be added to the eligible CRC screening pool.[125]

Preferences for screening strategies:

There are several effective but different CRC screening strategies that fall broadly into either stool-based or structural, visual exams and are conducted at varying screening intervals. These strategies differ with respect to characteristics that could influence an individual's preference and adherence to that screening strategy. Recommendations state that choice in screening strategy should depend on the individual's preferences, test availability, and the strategy to which the patient is most likely to adhere to and complete.[3,141] There is a robust literature that explores preferences for screening strategies

and it demonstrates high variability in preferences across studies.[112] However, because guidelines only recently began recommending screening starting at age 50, few studies have included younger people and hardly any have explicitly tested differences in preferences by age.

The Analytic Hierarchy Process and Colorectal Cancer Screening

Multicriteria Decision Analysis (MCDA) techniques can be used to help individuals make complex decisions. As a research tool, MCDA is a valuable means to explore underlying preferences on which a decision is based. In a clinical setting, MCDA can facilitate decision-making processes and encourage informed and shared decision-making by helping patients think critically about all available options and their unique characteristics. The Analytic Hierarchy Process (AHP) is a MCDA technique that breaks a decision problem into a hierarchical structure and allows a decision maker to focus on one aspect of a complex decision at a time.[142] The AHP also enables the analyst to quantify preferences for decision alternatives and the criteria on which those preferences are based. The AHP technique can be used in healthcare decision-making research and practice[143] in areas such as shared decision-making, healthcare policy and evaluation, and human resource planning.[144] Individuals are generally willing and able to use AHP for decision-making.[116,145] AHP can be used for individual level decisions and results across individuals can be aggregated into a group decision. Aggregating to the group level allows one to compare hierarchy weights across different subgroups to determine if they are evaluating the hierarchy differently.

Several studies have used AHP to assess preferences for colorectal cancer screening strategies.[116–118] These studies were successful in the implementation of AHP and found that the screening strategy's effectiveness or ability to detect and prevent cancer was paramount in the decision-making process. Of these, only Xu (2015) and colleagues included individuals under age 50.[117] The mean age of the participants in their analytic sample was 56.7 years old but they did not conduct age subgroup analysis to assess differences in preferences by age.

Current Study:

Current guidelines suggest that any evidence-based screening strategy is better than an individual not getting screening and that individuals generally have preferences for CRC screening strategies when given a choice.[112] Therefore, preferences should be assessed and incorporated into the decision-making process to ensure that individuals are receiving preference-aligned care. Research that unravels these preferences will give providers information to focus clinical interactions on the most important issues for younger people. If age differences are found, it could indicate the need to adapt screening programs for younger populations to ensure that they are making preference-concordant decisions.

In the current study, we used the Analytic Hierarchy Process to quantify preferences for colorectal cancer screening strategies and the criteria on which these preferences are based. This study extends the current United States-based AHP work that has recruited from clinic samples and has not explicitly tested whether preferences vary for individuals under the current recommended screening guidelines. We also tested

whether these preferences are related to any key characteristics of participants beyond age, including health literacy and previous experience with cancer.

Methods:

Study Sample:

This study was part of a larger study on perceptions about colorectal cancer in individuals under age 50. We collected a convenience sample whereby participants self-selected to participate from Amazon Mechanical Turk (MTurk). MTurk describes itself as a crowdsourcing marketplace that leverages a global workforce to complete a variety of tasks, including research tasks.[127] MTurk workers (Turkers) represent diverse individuals from across the globe and previous work with Turkers has shown that they produce high quality research data, even when presented with complex behavioral tasks that are traditionally conducted in-person.[128] We took best- practice measures to ensure adequate quality data including requiring workers to have completed tasks with a high approval rating and including qualitative responses to screen for automated responses. Initial inclusion criteria related to participant characteristics for this study included being ages 45-55, living in the United States, and never having been screened for colorectal cancer. After an initial collection of 482 participants, we then released the survey to all individuals over 18 who met these criteria. Survey data were collected using Qualtrics.[126]

Hierarchy Development:

In this paper screening strategy is defined as the test, the subsequent follow-up to an abnormal result, and the regular screening interval for normal results. In subsequent

references, criteria will be in **bold,** sub-criteria will be *italicized*. The AHP hierarchy (Figure 1) was built to include 3 criteria, 6 sub-criteria, and 3 decision alternatives (screening strategies). Criteria and Sub-criteria were selected based on a review of prior AHP studies and the colorectal cancer screening literature. Criteria included **test effectiveness,** the **screening plan,** and **features of the test**. The **screening plan** includes 2 sub-criteria: the *follow-up possibility* and *frequency of testing*. **Features of the test** included 4 sub-criteria: the *possibility of complications, convenience,* the *preparation,* and the *procedure*. We presented 3 distinct screening strategies as decision alternatives: colonoscopy every 10 years (an invasive test that allows for direct visualization of the colon), fecal immunochemical test (FIT) every year (a stool-based test that detects blood in the stool) and computed tomography colonography (CTC) every 5 years (a radiographic test).

AHP assessment

Survey procedures were approved by the University of Maryland IRB. After completing demographic and knowledge survey items, participants read a brief overview of colorectal cancer and the importance of screening (Supplemental materials). They were also informed that the goal of the activity was to choose a preferred screening strategy. Participants then read statements (Supplemental materials) about each strategy related to each criteria/sub-criteria at the lowest level of the hierarchy.

After each description, we asked participants to rank the decision alternative with respect to that criteria from (1) Does not fit to (9) Fits extremely well: *"*When considering the *(***Criteria***/Sub-criteria): On a scale from 1 - 9,* how well does (Decision Alternative) fit your preferences?" Overall, participants made 3 x 7 = 21 direct

comparisons for the 3 decision alternatives and 7 criteria/sub-criteria (**Test effectiveness**, *follow-up possibility, frequency of testing, possibility of complications, convenience, preparation,* and *procedure*). We used direct comparisons on decision alternatives to reduce respondent burden and eliminate the risk of rank reversal.[142] Participants then made pairwise comparisons at each level of the hierarchy to assess which criteria/sub-criteria was more important for their decision: *"*When considering the *(***Criteria/***Sub-criteria):* Which is more important for your decision?*"* Participants were given the option to select "**Criteria**/*Sub-criteria 1*, **Criteria**/*Sub-criteria 2* or 'They are both equal'". Participants then ranked their selection on a scale from 1 (very slightly more important) to 9 (extremely more important). To assess stated preferences, after the AHP procedure, participants were asked: "After completing this exercise, which test for colorectal cancer would you choose?".

Independent Variables

Demographic variables included age (1= <50, 2= ≥50); education (1= high school or less, 2= some college, 3= college completion, 4=higher than college); household income (1= <30k, 2=30k to 59,999, 3=60k to 89,999, 4= >90k); gender identity (1=man, 2=woman), self-identified primary race (recoded as 1=white, 2=other); type of insurance coverage (recoded as 0=no, 1=public, 2=private), relationship status (recoded as 1=single, 2=dating or cohabitating, but not married, 3=married). We also assessed health literacy[136] (continuous 4-20); subjective numeracy[137] (continuous 1-6); decisional self-efficacy (DSES, continuous 0-100), and having a regular medical provider (0=no, 1=yes). Finally, we explored variables related to cancer experience: having somebody close who

has died of cancer (0=no, 1=yes); and family, spouse, or anybody else close having been tested for CRC (recoded 0=no/don't know, 1=yes).

Statistical Analysis

We used the pairwise comparisons at each level of the hierarchy to compute reciprocal matrices for each set of comparisons. We then used the eigenvector method, which relies on the matrices principal eigenvector[146] to calculate a ratio scale of priorities for criteria/sub-criteria. Weight estimates are calculated by solving the equation: $A \bullet \hat{w} = \lambda max \bullet \hat{w}$ where A is the matrix of pairwise comparisons elicited from the participant, $\hat{w}$ is its right eigenvector, and λmax is the largest eigenvalue of A. We calculated consistency ratios at the criteria level using the Alonso and Lamata linear fit method to evaluate how consistently participants were making judgments.[147] Lower consistency ratios represent more consistent judgments. Participants with consistency ratios (CR) higher than 0.18 were excluded from our analysis. To calculate aggregated group decisions for criteria and sub-criteria, we used the row geometric mean method (RGMM). We assigned participants their individual preferences for decision alternatives based on the greatest of the 3 normalized priority weights for decision alternatives. We performed Chi- squared for categorical variables and ANOVA for continuous variables to determine associations. We conducted sensitivity analysis by varying the weights of the criteria and sub-criteria to assess whether observed alternative weightings are sensitive to small changes in the group weighting factors. We conducted statistical analysis using SPSS.[148] For AHP analysis, data were imported into Definitive Pro®[149], a software product designed to help decision-makers comprehensively and consistently assess and prioritize alternatives.

Results:

Of the 579 individuals surveyed, 556 (96%) provided complete responses to the AHP portion of the survey. Of these, 247 (44.4%) participants gave responses consistent enough (CR <0.18) to be included in the final analysis. The demographic features for included and excluded participants can be found in Table 1. Participants who are either white (p=.037) or have lower health literacy (p=.014) were more likely to be excluded from the final analysis due to inconsistency. The spread of consistency ratios <0.18 can be found in Figure 2.

Preferences for screening strategy (decision alternatives)

Group decision

We used the group decision to compare hierarchies in the overall sample and in each age subgroup using the row geometric mean. The aggregated preference for the whole sample (Figure 3, n=247) was for colonoscopy, with a normalized preference of 0.366, followed by FIT (0.335) and CTC (0.299). In the <50 group (n=161), colonoscopy was the preferred test (0.375) followed by FIT (0.321) and CTC (.304). In the ≥50 (n=86), the group preference was for FIT (0.366) followed by colonoscopy (0.345) and CTC (.289).

Individual preferences

To assess whether the differences we found at the group level were driven by participant variables, we assessed individual level preferences for screening tests (Table 2). The AHP procedure revealed preferences for 239 participants. Eight participants (3.2%) scored equally for multiple screening tests or did not prefer any of the tests. Of the participants who had preferences, colonoscopy was preferred by 50.6%, 40.6% preferred

FIT, and 8.8% preferred CTC. In the <50 age group, colonoscopy was the preferred screening test by 57.7% of participants while, in the ≥50 age group, most participants (56.1%) preferred FIT. Chi-square tests revealed significant differences between the proportion of individuals who preferred colonoscopy and FIT in the two age groups (p=.002). Those with lower health literacy (p=.002) and lower decisional self-efficacy (p=.041) were more likely to select the CTC option compared to colonoscopy or FIT. We did not find associations between test selection and any other demographic variables in our sample. The majority (59.8%) of participants stated preferences that were concordant with their AHP-derived preferences.

Criteria and sub-criteria

As a group (Figure 3, n=247), the sample weighed **test effectiveness** as the most important criteria for making their decision (0.555) followed by the **features of the test** (0.280) and the **screening plan** (0.165). For the sub-criteria of the **screening plan**, they rated *frequency of testing* and the *possibility of follow-up as* similarly important, at 0.480 and 0.520 respectively. For **features of the test**, the *procedure* was weighted as most important (0.318), followed by the *possibility of complications* (0.305), the *convenience* (0.224) and the *preparation* (0.153).

In the under 50 and ≥50 age groups, the relative priority order was similar to the larger group for the criteria (**effectiveness, screening plan, features**) and sub-criteria of **features of the test** *(preparation, convenience, complications, procedure).* For the sub-criteria of **screening plan**, the under 50 group weighed *possibility of follow-up* (0.499) and *frequency* (0.501) almost equally, while the ≥ 50 age group weighed the *possibility of follow-up* (0.548) as slightly more important than *frequency of testing* (0.452). Even

though the relative priority order was similar between groups, and **test effectiveness** was most important for both groups, we found differences in the magnitude of priorities. The under 50 age group assigned a relative priority of 0.585 to **test effectiveness** while the ≥50 age group assigned it 0.495. The ≥50 age group assigned higher importance to the **features of the test** (0.340) than younger people (0.250). Both age groups rated **screening plan** at approximately .165.

Ratings of tests by criteria

The results of direct comparisons of screening strategies by criteria/sub-criteria can be found in Table 3. The group (n=247) rated colonoscopy as highest for the criteria **test effectiveness** and **screening plan**, while they rated FIT as highest for the criteria **features of the test**. For the sub-criteria of **screening plan**, colonoscopy was rated most favorably for both *follow-up* and *frequency*. For all 4 sub-criteria of **features of the test** (*complications, convenience, preparation,* and *procedure*), FIT was rated highest. The highest rated criteria/sub-criteria were stable when the sample was split by age.

Sensitivity Analysis

From our prior experience and the colorectal cancer literature, we identified bowel preparation as an important barrier to completion of structural colorectal cancer screening exams for some individuals.[150] To address this, we tested whether increasing the weight of preparation would change the weights of decision alternatives. In the overall group, we increased the priority of *preparation* from .153 to .400 and subsequently, *complications* was reweighted from .305 to .220, *convenience* from .224 to .160, and *procedure* from .318 to .220. These changes had no impact on the order of alternative preferences. In fact, they only changed normalized priority scores of each

alternative by < ± .5%. We also tested whether our findings were robust to small changes in weighting factors at the criteria level. When we tested a 5% reduction in **test effectiveness** (from .555 to .505), with a prorated distribution to the weightings of **features of the test** and **screening plan,** we saw no changes in the rank order of alternatives and minimal (< ±.5%) changes in the normalized priority scores of alternatives.

Discussion:

Based on our study, colonoscopy was the preferred screening strategy in our overall sample, but we found that CTC was preferred more often by participants who had lower levels of literacy and decisional self-efficacy. This may be explained by these participants defaulting to the 'middle' option (between colonoscopy and FIT) when unsure about **effectiveness**, **features,** and the **screening strategy**. We also found differences in the preferences for screening strategies between the <50 and ≥50 age subgroups. Generally, colonoscopy was the preferred strategy for individuals under 50 and FIT was preferred by those 50 and over. To our knowledge, the only study in the literature that explicitly tested preferences by age was conducted by DeBourcy and colleagues in 2008.[114] In their supermarket sample, they observed a nonsignificant (p=.12) but illustrative trend in preferences for colonoscopy versus FOBT (another stool based test) by age that are similar to the results of this study. In the under 50 age group, 44.9% of people in their sample preferred colonoscopy, while 49% ages 50-64, and 63.6% ages 65-79 preferred colonoscopy. The differences that we found between those ≥50 and people <50 in this sample are explained by the relative priority assignment to the **test effectiveness** and **features of the test** criteria**.** Both age groups rated **test**

effectiveness as most important for making their decision, however, the ≥ 50 age group gave **features of the test** higher priority than the <50 age group. This difference gave FIT a higher priority score than colonoscopy when we applied the criteria weighting factors in the ≥50 age group. Other studies that have used AHP to explore preferences for colorectal cancer screening strategies have similarly found that the test effectiveness is the most important criteria for participant's decisions. Researchers across studies have conceptualized and operationalized this criteria in slightly different ways (i.e., preventing cancer[116], test accuracy[117], and sensitivity/specificity[118]).

Approximately 60% of participants gave a stated preference that was concordant with their AHP derived preference, after completing the AHP exercise. This is similar to what Xu, et al. found (.57) in their 2015 study on individuals that had completed both colonoscopy and FIT tests.[117] The AHP procedure is not created for or intended to replace traditional decision-making processes but to provide additional information that can be used and revisited when thinking through complex decisions.[142] For the remaining 40% of participants who provided discordant preferences, there could be criteria that we did not include in the hierarchy or subconscious thoughts about the screening strategies that were otherwise not factored into our AHP model or participant's judgments that warrant further investigation.

The results of this study can be placed among a body of literature that explores preferences for screening strategies. The variability in the results of these studies is likely due to how researchers design the descriptions of each test that are presented to participants, the population that they recruit including their experience with CRC screening, and the screening strategies that the researchers provide as options.[93,112,113] We

also add to the AHP literature that explores colorectal cancer screening[116–118] in the following unique ways: 1) we recruited a United States based national sample when other US based work has recruited from clinics only; 2) we simultaneously recruited people <50 years and ≥50 years old and tested younger age as a predictor of screening strategy preferences; 3) our results offer insight into criteria preferences for individuals under 50 that is not explored elsewhere in the literature; 4) we conducted sensitivity analysis to determine if results were robust to changes at the criteria and sub-criteria level; 5) we tested whether individual preferences were associated with participant variables; and 6) we developed and tested a new hierarchy that can be considered when incorporating AHP into colorectal cancer screening decision-making.

Strengths and Limitations:

A strength of this study is that we were careful to reduce confounding factors that could act to influence an individual's decision-making process such as only including participants that have never been screened, the length and reading level of descriptions, and the consistency of test characteristics that we described for each strategy (Supplemental material). Using the MTurk platform also allowed us to gather data from a national sample representing diverse perspectives. However, convenience sampling through the MTurk platform is not representative of an average community sample and our sample lacked racial and ethnic diversity. Future studies using targeted or representative sampling methods can be used to assess whether the associations we found remain stable.

Participants also responded to pairwise comparisons with a high level of inconsistency leading to many participants with high consistency ratios warranting exclusion. High consistency ratios are seen in all current AHP work in colorectal cancer screening. Xu and colleagues (2015) excluded 26% for inconsistent judgments in their sample who had already completed both FIT and colonoscopy.[117] Dolan (2012) and Hummel (2013) also report that many participants in their samples were excluded for consistency with 22% and 74% excluded respectively.[116,118] Inconsistency can be explained in several ways. Participants may have never thought about or formulated preferences for choosing a screening strategy for CRC. An individual who is still formulating preferences may not judge comparisons in a highly consistent manner. Alternatively, the online, self-guided nature of the data collection instrument may have made it more difficult for participants to consistently judge a hierarchy with multiple levels. This could be mitigated by using tools that streamline the process by guiding patients through the pairwise comparisons.

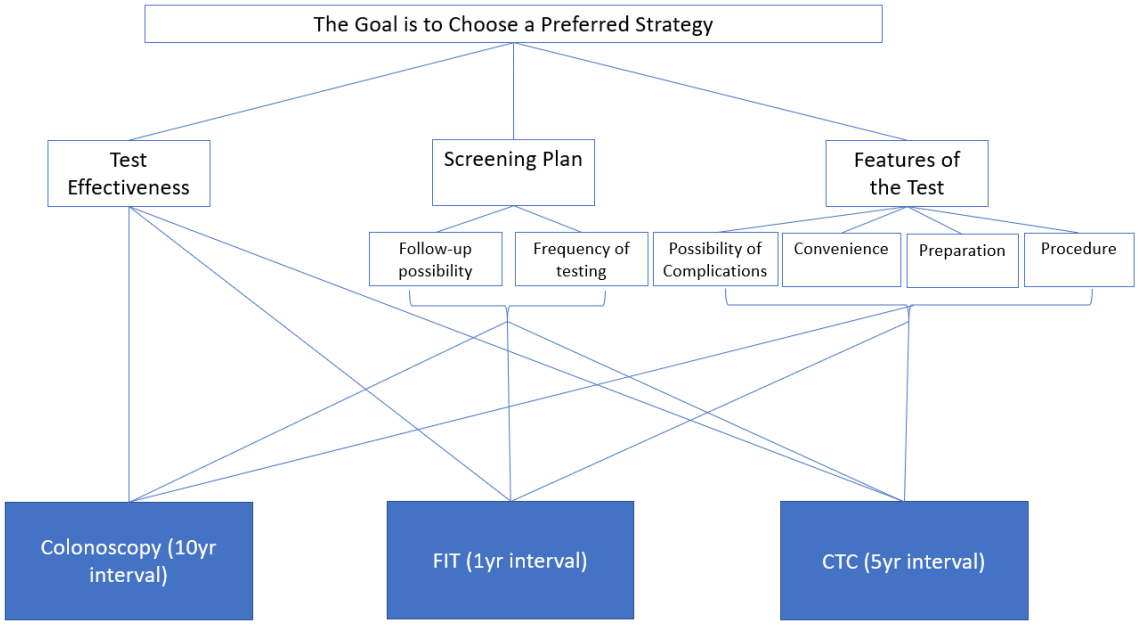
Clinical Implications / Conclusions (future directions)

In this study, we found differences in the preferences for screening strategies by age. To our knowledge, this is the first study designed with the intended purpose of exploring whether people under 50 think differently about CRC screening strategies than their older counterparts. This information has policy implications and, with further evidence, could be used to reevaluate current screening programs to incorporate people under age 50. Of note, participants under the age of 50 in this sample preferred the screening strategy with the highest associated costs even though these individuals have the lowest age-based risk. This finding aligns with the concerns of some opponents of

widening the screening age[13,83] and should be given attention when considering how to allocate limited resources, especially if resources must be diverted from populations with the highest absolute risk (those over 50).[85] Future work can explore other facets of the colorectal cancer screening process that may differ in people under age 50 and whether these differences will influence clinical care.

A key component to shared decision-making is that an individual's preferences are elicited and incorporated into the decision.[23] In a healthcare setting, an AHP activity similar to the one conducted in this study can be used by individuals to assist the formulation of preferences for a particular screening strategy. Doctors or practitioners can use the information derived from such an activity to address patient understanding or target appropriate information to the things that matter most to individuals. Future work should incorporate the lessons learned from this study and previous work using AHP to build tools that can be integrated in a healthcare system to help younger individuals make informed decisions about screening.

Figure 1: Hierarchy structure



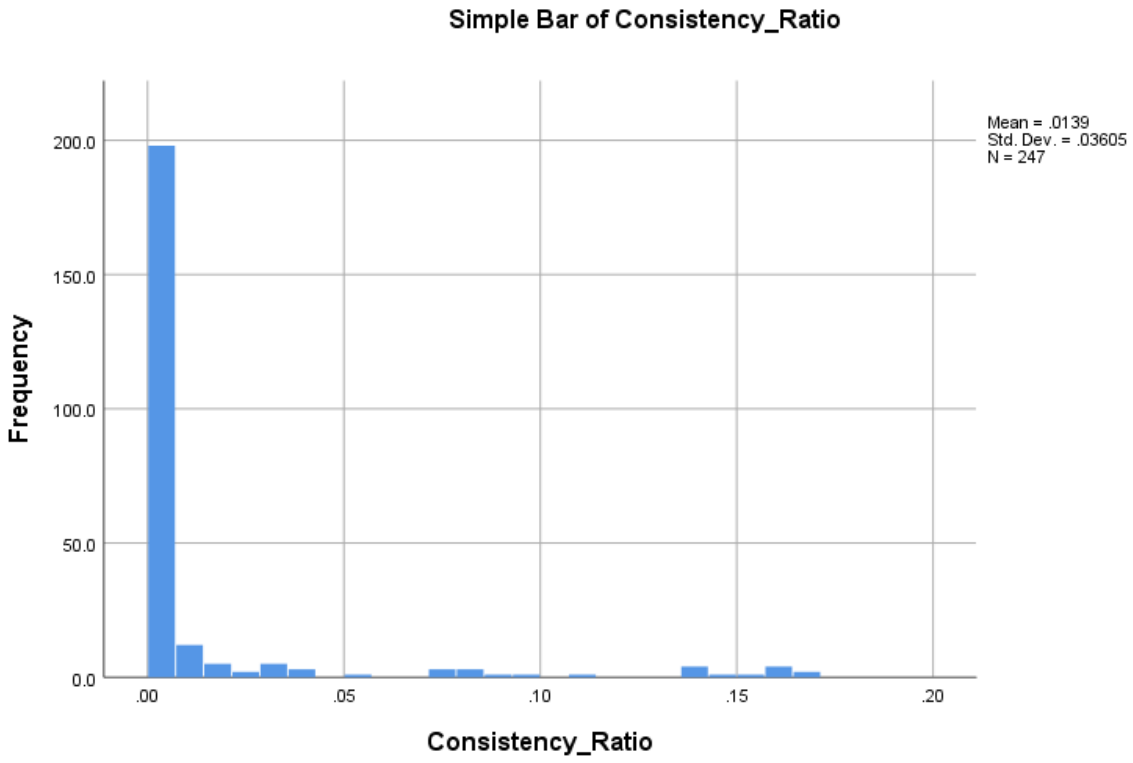


Figure 2: Consistency ratios of included participants

Table 1: Participant demographic characteristics

Categorical Variables		**Included Subjects (CR < .18) N=247 N (%)**	**Excluded Subjects (CR > .18) N=309**	**p-values χ^2**
Age	18-49	160 (65)	190 (61.5)	.389
	50+	86 (35)	119 (38.5)	
Gender	Woman	157 (63.6)	182 (58.9)	.256
	Man	90 (36.4)	127 (41.1)	
Race	White / Caucasian	198 (80.2)	268 (86.7)	.037
	Not white/Caucasian	49 (19.8)	41 (13.3)	
Education categories	HS or less	45 (18.2)	51 (16.6)	.474
	Some college	65 (26.3)	88 (28.6)	
	College graduate	88 (35.6)	95 (30.8)	
	Some graduate school / Graduate degree	49 (19.8)	74 (24.)	
Relationship	Single	93 (37.7)	110 (35.8)	.769
	Relationship / cohabitating	35 (14.2)	50 (16.3)	
	Married	119 (48.2)	147 (47.9)	
Income	<30k	52 (21.1)	54 (17.5)	.472
	30k to 59,999	72 (29.3)	102 (33)	
	60k to 89,999	63 (25.6)	70 (22.7)	
	>90k	59 (24)	83 (26.9)	
Insurance	No	38 (15.4)	48 (15.7)	.751
	Private	166 (67.2)	212 (69.3)	
	Public	43 (17.4)	46 (15.0)	
Continuous Variables		**Mean (SD)**	**Mean (SD)**	**ANOVA**
Health Literacy		18.15 (2.2)	17.63 (2.7)	.014
Subjective Numeracy		4.59 (.97)	4.67 (.90)	.302
Decisional self-efficacy		82.2 (16)	80.0 (15.9)	.107

Table 2: Preferences for screening tests from AHP.

*Individuals that expressed no clear preference (n=8) were excluded from this analysis

		Colonoscopy N (%)	CTC N (%)	FIT N (%)	p-value χ^2
Full Sample with preference (N=239)		121 (50.6)	21 (8.8)	97 (40.6)	
Categorical Variables		N(%)	N(%)	N(%)	
Age	<50	90 (57.7)[a]	15 (9.6)	51 (32.7)[a]	.002
	50+	31 (37.8)[b]	5 (6.1)	46 (56.1)[b]	
Gender	Woman	73 (48.3)	10 (6.6)	68 (45)	.100
	Man	48 (54.5)	11 (12.5)	29 (33)	
Race	White/ Caucasian	100 (51.5)	14 (7.2)	80 (41.2)	.205
	Not white/Caucasian	21 (46.7)	7 (15.6)	17 (37.8)	
Education	HS or less	19 (43.2)	7 (15.9)	18 (40.9)	.581
	Some college	33 (52.4)	3 (4.8)	27 (42.9)	
	College graduate	42 (50.6)	7 (8.4)	34 (41)	
	Some graduate school / Graduate degree	27 (55.1)	4 (8.2)	18 (36.7)	
Relationship	Single	41 (45.6)	10 (11.1)	39 (43.3)	.396
	Relationship/cohabitating	15 (42.9)	3 (8.6)	17 (48.6)	
	Married	65 (57)	8 (7)	41 (36)	
Income	<30k	25 (50)	3 (6)	22 (44)	.548
	30k to 59,999	30 (44.1)	5 (7.4)	33 (48.5)	
	60k to 89,999	32 (52.5)	8 (13.1)	21 (34.4)	
	>90k	33 (55.9)	5 (8.5)	21 (35.6)	
Insurance	No	16 (45.7)	1 (2.9)	18 (51.4)	.277
	Private	88 (54)	15 (9.2)	60 (36.8)	
	Public	17 (41.5)	5 (12.2)	19 (46.3)	
Regular Provider	Yes	79 (54.5)	13 (9.0)	53 (36.6)	.276
	No	42 (44.7)	8 (8.5)	44 (46.8)	
Family, spouse, other close tested for CRC	Yes	86 (51.8)	12 (7.2)	68 (41)	.434
	No	35 (47.9)	9 (12.3)	29 (39.7)	
Anybody close ever died of cancer	Yes	76 (56.7)	11 (8.2)	47 (35.1)	.099
	No	45 (42.9)	10 (9.5)	50 (47.6)	
Continuous Variables		**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**ANOVA**
Health Literacy		18.2 (2.0)	16.6 (3.1)	18.4 (2.0)	.002
Numeracy		4.6 (.96)	4.2 (1.0)	4.6 (.98)	.205
Decisional self-efficacy		82.9 (15.5)	74 (17.4)	83.6 (15.4)	.041

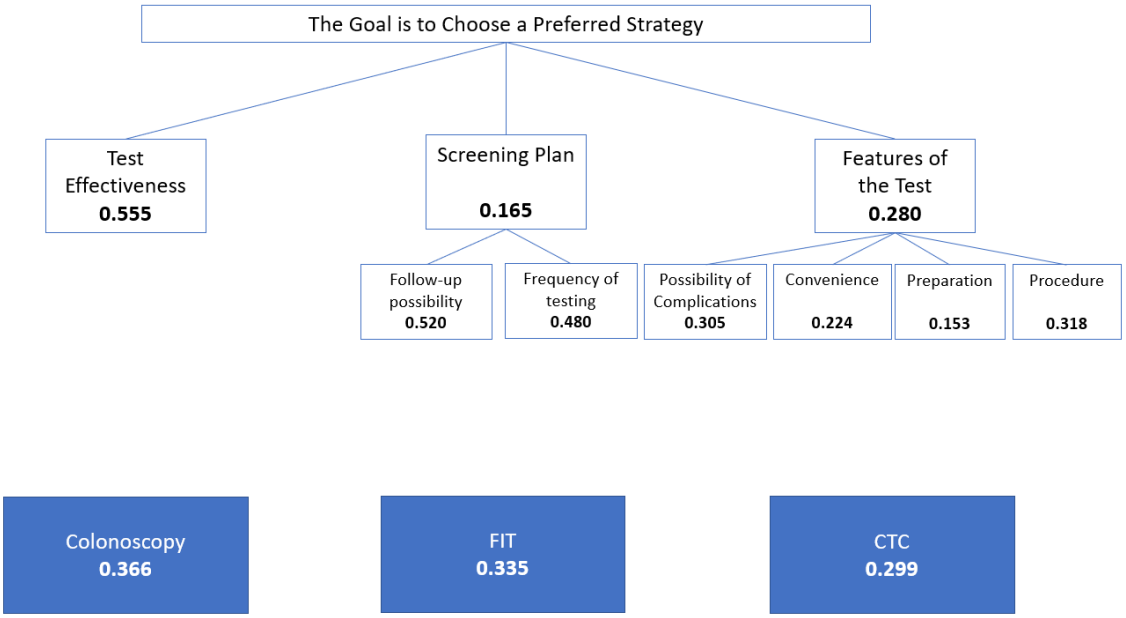


Figure 3: Group decision weighting factor results N=247

Table 3: Normalized priorities of screening strategies by criteria/sub-criteria

		Overall n=247	Under 50 n=161	Over 50 n=86
Test effectiveness	Colonoscopy	**0.417**	**0.415**	**0.421**
	FIT	0.284	0.281	0.292
	CTC	0.299	0.304	0.287
Screening Plan	Colonoscopy	**0.425**	**0.436**	**0.403**
	FIT	0.279	0.263	0.310
	CTC	0.296	0.301	0.287
Follow up	Colonoscopy	**0.456**	**0.468**	**0.432**
	FIT	0.277	0.262	0.308
	CTC	0.267	0.270	0.260
Frequency	Colonoscopy	**0.397**	**0.410**	**0.372**
	FIT	0.280	0.264	0.312
	CTC	0.323	0.326	0.316
Features of the test	Colonoscopy	0.218	0.230	0.197
	FIT	**0.481**	**0.464**	**0.513**
	CTC	0.301	0.306	0.290
Complications	Colonoscopy	0.200	0.210	0.179
	FIT	**0.520**	**0.505**	**0.554**
	CTC	0.280	0.285	0.267
Convenience	Colonoscopy	0.176	0.185	0.156
	FIT	**0.488**	**0.477**	**0.508**
	CTC	0.336	0.338	0.336
Procedure	Colonoscopy	0.266	0.279	0.241
	FIT	**0.413**	**0.393**	**0.453**
	CTC	0.321	0.328	0.306
Preparation	Colonoscopy	0.217	0.228	0.196
	FIT	**0.548**	**0.535**	**0.572**
	CTC	0.235	0.237	0.232

Chapter 5: Screening for colorectal cancer in individuals age under 50: decisional self-efficacy and desired role in decision-making

Screening for colorectal cancer in individuals age under 50: decisional self-efficacy and desired role in decision-making

T. Hyams[1,2], B. Golden[3], S. Sultan[4], E. King-Marshall[1], M. Wang[1], B. Curbow[1]

1. University of Maryland, College Park, School of Public Health, Department of Behavioral and Community Health; 2. National Cancer Institute, Division of Cancer Control and Population Sciences, Office of the Director; 3. University of Maryland, College Park, Robert H. Smith School of Business, Department of Decision, Operations, and Information Technologies; 4. University of Minnesota, Department of Medicine, Division of Gastroenterology, Hepatology, and Nutrition

Introduction: Shared decision-making (SDM) is a decision-making where a doctor and their patient collaborate on a decision about the patient's healthcare. Shared decision making is appropriate when there is uncertainty surrounding a decision or when the outcomes of each option are relatively equal. Due to increasing risk, the American Cancer Society updated their recommendations to include individuals age 45-49 for age based colorectal cancer screening. Because of the uncertainty surrounding this issue, a shared decision-making framework is appropriate for this age group. A key component of shared decision-making is that individuals are participating in the process at their desired level. In this study, we evaluate people under age 50, their desired role in decision making and their self-efficacy for making decisions about colorectal cancer screening. **Methods:** We recruited 579 participants from Amazon Mechanical Turk (MTurk) for a survey on perceptions about colorectal cancer screening. We evaluated participants desired role in general medical decision making as well as whether to get screened for colorectal cancer and with which screening test to use with a modified control preferences scale (CPS). We used the Decisional Self-Efficacy Scale (DSES) to evaluate participant's self-efficacy for making these decisions. We used multinomial logistic regression and linear regression models to evaluate age as a predictor of the CPS and DSES. **Results:** We found that being under age 50 was associated with a desire for shared or passive role (compared to active) in decisions about getting screened ($p<.000$) for colorectal cancer and with which screening strategy to use ($p=.001$). We did not find age to be associated with decisional self-efficacy. **Discussion:** If we incorporate younger people into screening programs for colorectal cancer, a shared decision-making framework is appropriate. However, we must be mindful that younger people may want to take a different role in the decision-making process than their older counterparts.

Introduction:

Shared Decision-making

Shared decision-making (SDM) is a process between a patient and clinician with the goal of making an informed and joint decision about the patient's healthcare.[17,19,151] A shared decision-making model (compared to physician driven) is beneficial because patients that are engaged in their healthcare decision-making typically have higher levels of satisfaction with their care and can have better outcomes.[152] Shared decisions are appropriate when there is a decision to be made between options with similar outcomes, when there is a high level of uncertainty between options, or when options are highly preference sensitive because the outcomes of the decision are relatively equal. [4]

Colorectal Cancer

The overall incidence and mortality of colorectal cancer (CRC) are declining in the United States.[8,72] Reductions in CRC incidence and mortality are primarily attributed to the uptake of screening according to guidelines based on age.[4] The United States Preventive Service Task Force (USPSTS), an independent policy recommending organization whose recommendations guide clinical care, has recommended that individuals at average risk of developing CRC should begin screening at age 50.[153] However, recent analysis using the Surveillance, Epidemiology, and End Results (SEER) database show that the risk of both colon and rectal cancer in the United States are increasing in individuals under age 50.[8] Due to this shift, in 2018, the American Cancer Society gave a qualified recommendation for individuals age 45-49, at average risk, to initiate screening for CRC.[3]

In light of these new recommendations, a shared decision-making framework is appropriate for colorectal cancer screening in individuals age 45-49 because any screening strategy is recommended over no screening and strategy selection (stool based or structural exam) is highly sensitive to an individual's preferences.[23] Evidence also suggests that shared decision-making in colorectal cancer screening leads to higher intention to be screened and higher satisfaction with the decision-making process.[93]

Desired Role in Decision-making and Decisional Self-Efficacy

Shared decision-making between individuals and their doctor require that the individuals are participating in the decision at their desired level.[19] An assessment of patient willingness to participate in decision-making is also a critical component of the SDM process.[19] There may be considerable variation in an individual's desired role. A 2012 systematic review of 115 studies on shared decision-making preferences in patients found that, in 63% of studies assessed, shared decision-making was the majority preference while, in 21% of studies, physician delegated decision-making was preferred by the majority of participants.[120] Desired role has been studied in the context of colorectal cancer screening.[93,94,123] However, none of these studies measured both general and situation specific role preferences nor did they sample individuals who were under the age of 50, so very little information is available regarding these individuals' preferences for participating in the colorectal cancer screening decision-making process.

If individuals desire to be involved in the decision-making process, it follows that they must also have the self-efficacy for making decisions about their healthcare. Self-efficacy is a central health behavior construct and is important for health behaviors across multiple domains such as cigarette smoking, exercise and weight control, and alcohol

use.[154] If self-efficacy and desired role are mismatched, tools can be built to increase self-efficacy for making decisions,[155] thus, empowering patients and improving satisfaction with the screening process and their subsequent adherence to a screening strategy.

Current Study:

Younger age may play a role in desired role in the decision-making process. A review on shared decision-making found that younger and more highly educated individuals tended to desire more involvement in making medical decisions.[152] However, colorectal cancer may not be on younger people's 'radar' and uncertainty and lack of clarity on guidelines and screening modalities, may influence patients to defer decisions to their doctors. No work, to our knowledge, has assessed the desired role and self-efficacy for making CRC screening decisions in individuals under the age of those that historically would be screened. In this study, we explored whether the desired role in decision-making varies for individuals under age 50 compared to those who are over age 50. We also evaluated predictors of decisional self-efficacy in our sample to evaluate targets for interventions to increase individual's confidence in making medical decisions.

Methods:

Sample:

This study was part of a larger study on perceptions about colorectal cancer in individuals under age 50. Survey data were collected using Qualtrics[126] after participants self-selected to participate from Amazon Mechanical Turk (mTurk). We took best-practice measures to ensure high quality data including requiring workers to have

completed tasks with a high approval rating and including qualitative responses to screen for 'bots' or automated responses. Inclusion criteria for this study included being age 18+, living in the United States, and never having been screened for colorectal cancer.

Measures:

Dependent Variables:

Desired role was measured using a modified Control Preferences Scale (CPS) (Table 1).[156] Participants were asked a single question about their general medical decision role preference and also 2 scenario specific role preferences for the decision *to get screened* for colorectal cancer and the decision of *which test to get*. Responses to these questions were collapsed into Patient driven (Active) (1), collaborative/shared (2), and Doctor driven (Passive) (3) roles**.**

Decisional self-efficacy was measured using the decisional self-efficacy scale (DSES).[28] The 11-item DSES measures one's confidence in their decision-making abilities in the context of general medical decision-making on 5-point Likert scales (0-4).
Items are averaged and then transformed for a final scale score range of 0-100.

Independent Variables: Demographic variables included: age (1= <50, 2= ≥50); education (1= Highschool or less, 2= some college, 3= college completion, 4=higher than college); household income (1= <30k, 2=30-59,999, 3=60-89,999, 4= >90k); gender identity (1=man, 2=woman), self-identified primary race (recoded as 1=white, 2=other); type of insurance coverage (recoded as 0=no, 1=public, 2=private, relationship status (recoded as 1=single, 2=dating or cohabitating but not married, 3=married). We also assessed general health (continuous 1=Poor, 5=excellent); health literacy[136] (continuous 4-20); subjective numeracy[137] (continuous 1-6); and having a regular medical provider

(0=no, 1=yes) as independent variables. Finally, we included independent variables related to cancer experience: having somebody close who has died of cancer (0=no, 1=yes); family, spouse, or anybody else close having been tested for CRC (recoded 0=no/don't know, 1=yes); self being diagnosed with cancer (0=no, 1=yes); worry about cancer (continuous 1=not at all, 5=extremely); perceived likelihood of getting cancer (1= very unlikely, 5= very likely); and stage of commitment to CRC testing (1=have not thought about getting tested-5=committed to getting tested).

Analysis:

We used descriptive statistics to evaluate the prevalence of each role preference for general medical decisions, the decision to get screened (GS), and the decision of which screening strategy to use (WS). We then calculated bivariate statistics using GS and WS as dependent variables. We then entered variables that were significant at the bivariate level ($p<.10$) into a multinomial logistic regression using the 3 nominal categories as outcomes (active, passive, shared roles). We used the active (patient driven) role as the reference category. We calculated Cronbach's alpha for the DSES. We then conducted multiple regression to determine multivariable associations with independent variables and the DSES. Because this analysis was exploratory, we used a backwards stepwise procedure with $p>.10$ as a cutoff for removal. We conducted all analysis using SPSSv25.[148]

Results:

Sample demographics:

The sample was majority women (61.5%), white/Caucasian (82.9%), used English as their primary language (99%), born in the United States (96.2%), and married (48.2%). Approximately 54.9% of the sample had completed a college degree or above and most participants were insured with either private (67.9%) or public insurance (15.5%).

Preferred Role (control preferences scale):

For general medical decisions, 57.5% of the sample preferred a patient driven (active role), 32.6% preferred a shared role, and 9.8% preferred a doctor driven (passive role). For the decision of whether to get screened 57.8% preferred a patient driven (active role), 27.7% preferred shared, and 14.5% preferred doctor driven (passive). For deciding which screening strategy to use, 53% preferred active, 25.9% preferred shared, and 21.1% preferred the passive role. Participants' general role preference was highly associated with their role preferences for both the decision to get screened (GS) for colorectal cancer ($p<.000$) and for the decision about which screening strategy (WS) they would use ($p<.000$) (Table 2). Participants switched role preference from the general decision to each of the situation specific decisions between 4.5% and 24.3% of the time.

Bivariate Statistics:

Bivariate Statistics can be found in Table 3. Briefly, we found age; gender; having a family member, spouse, or anybody else close ever tested for CRC; anybody close ever died of cancer; cancer worry; and commitment to testing were significantly associated with role preference for the decision to get screened (GS) at the $p=.05$ level. We also found that relationship status, health literacy, and perceived likelihood of cancer were

significantly associated with role preference for GS at the .10 level. For what screening strategy to use (WS), we found age, gender, health literacy, perceived likelihood of getting cancer, cancer worry, and commitment to testing were significantly associated with role preference at the .05 level. At the .10 significance level, we found decisional self-efficacy, to be associated with the role preference for WS.

Multinomial Logistic Regression:

The results of both adjusted multinomial logistic regression models can be found in Table 4. All multinomial results use the patient driven (active role) as the reference category.

Whether to get Screened

For the decision about whether to get screened, compared to the patient driven (active role) (reference category), individuals in the <50 age group (compared to ≥50) were more likely to prefer the shared role (OR=1.904, p=.003) and the passive role (OR=3.087, p<.000). For shared role preference compared to active, we also found significant associations for men (OR=.646, p=.049), higher cancer worry (OR=1.276, p=.027), and higher commitment to testing (OR=1.297, p=.002). For passive role preference compared to active, we found significant associations for not having somebody close tested for CRC (OR= 1.947, p=.018), higher cancer worry (OR=1.351, p=.029), and higher commitment to testing (OR=1.449, p=<.000).

What screening strategy to use

For the decision about what screening strategy to use, compared to the patient driven (active role) (reference category), individuals in the <50 age group (compared to ≥50) were more likely to prefer the shared role (OR=1.649, p=.022) and the passive role

(OR= 2.233, p=.001). For shared role preference compared to active, we also found significant associations for higher cancer worry (OR=1.296, p=.019) and higher commitment to testing (OR=1.261, p=.005). For passive role preference compared to active, the only other variable that remained significant in the adjusted model was commitment to testing (OR=1.301, p=.004).

Decisional Self Efficacy:

The internal reliability of the DSES scale was α= .92. Since we did not find that the DSES score was associated with desired role preference for either the decision to get screened or the decision for which screening strategy to choose, we conducted an exploratory analysis to evaluate predictors of the DSES using a backwards, stepwise, multiple linear regression. The results of the regression model can be found in Table 5. We did not find decisional efficacy was associated with age. However, we found significant associations between higher scores on the DSES and having high school or less education (p=.011); having a regular doctor (p=.012); higher subjective numeracy (p=.001); higher health literacy (p<.000); and higher general health (p<.000).

Discussion:

In our sample, we found that an active role was preferred by our participants more often than the shared or passive role for all three decisions that we evaluated. These results contrast with other studies in the literature that explored role preference in the context of colorectal cancer screening. In a sample of primarily white individuals, 45% preferred *decision-making for CRC* to be shared with the doctor, 25% desired to be the primary decision maker (after considering the doctor's opinion), 16% preferred the doctor

to make the decision, and 15% preferred to make the decision on their own.[94] In a study on a novel decision aid for shared decision-making, Schroy and colleagues (2011) found that in their primarily African American sample that patients desired role in "*decision-making"* was primarily shared (53.3%) followed by mostly patient (27.5%) and then mostly doctor (19.2%).[93] In a primarily Hispanic sample, a collaborative role for *decisions about health* was preferred by 53.3% of participants while passive was preferred by 26.4% and active by only 20.3%.[123] While other studies have evaluated desired role in this context, our study is unique because we collected a national sample over the internet as well as our inclusion of individuals under age 50.

We found that age is associated with role preference in the decision to be screened for CRC and for deciding which screening strategy to use. Contrary to findings by Frosch and Kaplan[152], who find that younger age is associated with desiring an active or shared role, in our sample people <50 would prefer a shared or passive role. These results could indicate that those under age 50 have not yet begun to consider CRC screening, increasing the likelihood for them to want to talk through and make a shared decision with their doctor or simply defer those decisions all together. Alternatively, younger individuals may not feel that they have enough information to take the patient-driven role. Regardless, clinicians should clarify the role that patient's would like to take in the decision-making process and attempt to match patient's preferred style with the care that they deliver.[157] We also found other participant characteristics were associated with desired role that will be useful for future work that explores these two decisions e.g. male participants prefer active over shared for deciding whether to get screened.

In our sample, role preference was only stable from general medical decisions to the decision to get screened and the decision of which screening strategy to use between 56.1%-84% of the time. This aligns with concerns that researchers should be careful appropriately conceptualize, represent, and thus appropriately measure the construct of interest whether it be the more stable role "style", as intended by the original scale developers, or the "situation specific" role preference.[158] In our sample, role preference for these two decisions share some associations like age, worry about cancer and commitment to testing but differ for others such as not having somebody close who has tested for CRC is only predictive for the passive role for the decision to be screened and not for which strategy to use. This raises important questions about whether researchers should evaluate role preference for each decision of interest versus more broadly.

We did not find that the decisional self-efficacy scale (DSES) was associated with role preference. This is evidence that desired role in the CRC decision-making process may not be a question of efficacy. However, several variables were associated with decisional efficacy, which point to ways that researchers and clinicians can identify targets for interventions that improve efficacy, namely those without a regular doctor, those with lower health literacy, lower numeracy, and lower self-reported general health. This association between those with the lowest education in our sample displaying the highest levels of decisional self-efficacy in the adjusted models warrants further investigation.

Limitations:

This study has several limitations that must be addressed when interpreting results. First, the cross sectional, exploratory nature of this study did not allow us to

determine whether role preference or efficacy are related to CRC screening behavior. Future work with under 50 samples should explore whether these relationships will influence clinical care. Second, our sample lacked racial and ethnic diversity. This limitation is consistent with other studies that use mTurk to collect data.[138] Evaluating these associations with more diverse samples who are disproportionately burdened by colorectal cancer will reveal whether these associations are stable. Finally, we asked a sample of the general public that had never been screened for colorectal cancer what their desired roles are in these decision-making processes. These expressed roles may not accurately reflect the role that a patient may want during an actual clinical encounter. However, we predict that these associations would be stronger in a clinical sample, rather than weaker.

Strengths:

The conclusions drawn from our study are strengthened by several factors. First, we measured role preference for general medical decisions, deciding whether to get screened, and for deciding which screening strategy to use. Using these three different measures allows us to tap into the stable and situation specific role preferences that many other studies do not differentiate between.[158] Another strength of our study is our large sample size and the robust collection of cancer experience variables that we included in our multi-variable models. Adjusting for these variables gives us confidence that the associations that we found between age and role preference are not spurious findings.

Clinical Implications/Conclusions:

If new recommendations for individuals age 45-49 are adopted by the USPSTF, this will add approximately 19 million individuals to the eligible screening pool and even more that will be approaching the age of screening.[125] Clinicians will have to decide the best way to approach the subject of screening with their patients, which should include discussions about their desired role in decision-making if using a shared decision-making framework. In order to reap the benefits of patients' engagement in the decision-making process, such as satisfaction, intention to be screened, and ultimately, adherence to the chosen screening strategy, care should be tailored to include patients at their desired level.

We have shown that younger age is associated with passive role preference for both the decision to be screen and for the decision of which screening strategy to use in our national sample. These results are not surprising because people under 50 have not been targets of long-standing public health messages that have encouraged people over 50 to initiate screening. If we are to incorporate younger people into screening programs, building appropriate tools to engage these individuals will be necessary.

The following statements are about the role you feel you and your doctor should have in making decisions about … 1. … your health 2. …about whether you should get screened for colorectal cancer. 3. … about what screening strategy for colorectal cancer you should get. Which of the following best describes what you think:	Coding
I prefer to make the decision about which treatment I will receive	Patient Driven Role (active role) (1)
I prefer to make the final decision about my treatment after seriously considering my doctor's opinion	Patient Driven Role (active role) (1)
I prefer that my doctor and I share responsibility for deciding which treatment is best for me	Collaborative/Shared Role (2)
I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion	Physician Driven Role (passive role) (3)
I prefer to leave all decisions regarding treatment to my doctor	Physician Driven Role (passive role) (3)

Table 1: Modified control preferences scale measure and responses

	Active to be screened (%)	Shared to be screened (%)	Passive to be screened (%)	Active what strategy (%)	Shared What strategy (%)	Passive what strategy (%)
Active General	84	11.4	4.5	79.3	10.2	10.5
Shared General	22.2	61.4	16.4	19.6	56.1	24.3
Passive General	22.8	10.5	66.7	10.5	17.5	71.9

Table 2: Participants role preferences for CRC decisions concordance with general role preference

	Whether to get screened (GS)				With what screening strategy to use (WS)			
Categorical Variables	**Patient Driven (Active) N (%)**	**Shared N (%)**	**Doctor Driven (Passive) N (%)**	**p-values χ^2**	**Patient Driven (Active) N (%)**	**Shared N (%)**	**Doctor Driven (Passive) N (%)**	**p-values χ^2**
Age <50	183 (51.1)	109 (30.4)	66 (18.4)	<.000[c]	170 (47.4)	100 (27.9)	89 (24.8)	.001[b]
≥50	151 (68.6)	51 (23.2)	18 (8.2)		137 (62.3)	50 (22.7)	33 (15.0)	
Education HS or Less	56 (58.9)	27 (28.4)	12 (12.6)	.441	52 (54.2)	24 (25.0)	20 (20.8)	.166
Some college	103 (62.8)	43 (26.2)	18 (11.0)		95 (57.9)	42 (25.6)	27 (16.5)	
College graduate	108 (57.1)	48 (25.4)	33 (17.5)		96 (50.8)	42 (22.2)	51 (27.0)	
Some graduate/grad school	67 (51.9)	41 (31.8)	21 (16.3)		64 (49.6)	41 (31.8)	24 (18.6)	
Income LT30k	76 (67.9)	22 (19.6)	14 (12.5)	.116	66 (58.9)	26 (23.3)	20 (17.9)	.214
30-59,999	107 (59.4)	45 (25.0)	28 (15.6)		90 (49.7)	42 (23.2)	49 (27.1)	
60-89,999	75 (55.1)	43 (31.6)	18 (13.2)		75 (55.1)	39 (28.7)	22 (16.2)	
GT90k	75 (50.3)	50 (33.6)	24 (16.1)		75 (50.3)	43 (28.9)	31 (20.8)	
Gender Woman	202 (57.1)	110 (31.1)	42 (11.9)	.013[a]	193 (54.4)	102 (28.7)	60 (16.9)	.006[b]
Man	131 (59.0)	49 (22.1)	42 (18.9)		113 (50.9)	48 (21.6)	61 (27.5)	
Race White / Caucasian	284 (59.3)	128 (26.7)	67 (14.0)	.273	261 (54.4)	119 (24.8)	100 (20.8)	.303
Not white/Caucasian	50 (50.5)	32 (32.3)	17 (17.2)		46 (46.5)	31 (31.3)	22 (22.2)	
Relationship status Single	132 (62.3)	44 (20.8)	36 (17.0)	.084	117 (55.2)	48 (22.6)	47 (22.2)	.388
Dating/cohabitating	50 (58.1)	26 (30.2)	10 (11.6)		45 (51.7)	20 (23.0)	22 (25.3)	
Married	152 (54.7)	88 (31.7)	38 (13.7)		145 (52.2)	81 (29.1)	52 (18.7)	
Insurance No	64 (68.8)	19 (20.4)	10 (10.8)	.229	57 (61.3)	21 (22.6)	15 (16.1)	.538
Public	50 (56.2)	27 (30.3)	12 (13.5)		46 (51.1)	24 (26.7)	20 (22.2)	
Private	220 (56.0)	111 (28.2)	62 (15.8)		203 (51.7)	104 (26.5)	86 (21.9)	
Anybody close ever tested for CRC Yes	226 (58.2)	115 (29.6)	47 (12.1)	.04[a]	209 (53.9)	98 (25.3)	81 (20.9)	.831
No	108 (56.8)	45 (23.7)	37 (19.5)		98 (51.3)	52 (27.2)	41 (21.5)	
Have regular doctor Yes	191 (54.7)	106 (30.4)	52 (14.9)	.149	175 (50.0)	101 (28.9)	74 (21.1)	.105
No	143 (62.4)	54 (23.6)	32 (14.0)		132 (57.6)	49 (21.4)	48 (21.0)	

Anybody close ever died of cancer Yes	183 (55.0)	106 (31.8)	44 (13.2)	.031[a]	172 (51.7)	95 (28.5)	66 (19.8)	.230
No	151 (61.6)	54 (22.0)	40 (16.3)		135 (54.9)	55 (22.4)	56 (22.8)	
Ever been diagnosed with cancer Yes	26 (53.1)	14 (28.6)	9 (18.4)	.688	26 (53.1)	12 (24.5)	11 (22.4)	.956
No	307 (58.1)	146 (27.7)	75 (14.2)		280 (52.9)	138 (26.1)	111 (21.0)	
Continuous Variables	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**p-value ANOVA**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**p-value ANOVA**
Decisional self-efficacy	81.59 (16.07)	79.39 (16.84)	79.29 (14.32)	.262	82.00 (16.19)	79.42 (16.20)	78.75 (15.35)	.097
General Heath	3.36 (.96)	3.43 (.87)	3.45 (.94)	.594	3.40 (.96)	3.40 (.86)	3.35 (.96)	.881
Health Literacy	17.98 (2.44)	17.8 (2.35)	17.27 (2.83)	.062	18.13 (2.25)	17.58 (2.58)	17.41 (2.83)	.009[b]
Numeracy	4.66 (.94)	4.54 (.95)	4.64 (.99)	.443	4.67 (.94)	4.54 (.99)	4.63 (.92)	.420
Likelihood of cancer	3.13 (.95)	3.32 (.90)	3.13 (.93)	.080	3.08 (.97)	3.28 (.90)	3.32 (.84)	.021[a]
Worry about cancer	2.46 (1.08)	2.88 (1.14)	2.86 (1.08)	<.000[c]	2.43 (1.08)	2.87 (1.13)	2.84 (1.08)	<.000[c]
Commitment to testing	2.47 (1.28)	2.90 (1.37)	2.92 (1.37)	<.000[c]	2.47 (1.31)	2.85 (1.31)	2.84 (1.37)	.003[b]

Table 3: Bivariate statistics a= significant at .05, b= significant at .01, c= significant at <.001

		Whether to get screened						With what screening strategy to use					
		Shared role			Doctor driven (passive)			Shared role			Doctor driven (passive)		
Categorical Variables	Coding	Exp (B)	95% CI	p value	Exp (B)	95% CI	p value	Exp (B)	95% CI	p value	Exp (B)	95% CI	p value
Age	<50 vs ≥50	1.904	1.248-2.906	.003[b]	3.087	1.710-5.573	<.000[c]	1.649	1.077-2.527	.022[a]	2.233	1.361-3.662	.001[b]
Gender	Man vs woman	.646	.419-.998	.049[a]	1.184	.703-1.996	.526	.730	.470-1.136	.163	1.562	.982-2.483	.060
Relationship status	Single vs married	.671	.427-1.054	.083	1.387	.795-2.420	.249	.826	.526-1.296	.405	1.328	.806-2.189	.266
	Dating/cohabitating vs married	.890	.495-1.597	.695	.897	.388-2.073	.799	.778	.416-1.455	.432	1.238	.633-2.418	.533
Anybody close ever tested for CRC	No vs yes	1.083	.684-1.716	.733	1.947	1.118-3.388	.018[a]	1.386	.878-2.187	.161	1.274	.768-2.113	.347
Anybody close ever died of cancer	No vs yes	.804	.518-1.250	.333	1.086	.626-1.882	.770	.900	.575-1.409	.644	1.382	.848-2.252	.194
Continuous Variables													
Decisional self-efficacy	Cont.	.989	.975-1.003	.121	.999	.981-1.017	.874	.995	.981-1.010	.523	.990	.974-1.006	.201
Health Literacy	Cont.	1.036	.939-1.144	.480	.954	.852-1.068	.416	.952	.865-1.048	.318	.977	.879-1.085	.660
Likelihood of cancer	Cont.	.957	.736-1.245	.745	.808	.585-1.116	.196	.996	.766-1.295	.975	1.186	.883-1.591	.257
Worry about cancer	Cont.	1.276	1.029-1.584	.027[a]	1.351	1.032-1.767	.029[a]	1.296	1.043-1.611	.019[a]	1.268	.996-1.614	.054
Commitment to testing	Cont.	1.297	1.104-1.523	.002[b]	1.449	1.183-1.775	<.000[c]	1.261	1.071-1.484	.005[b]	1.301	1.085-1.560	.004[b]

Table 4: Multinomial logistic regression using patient driven (active role) as the reference category a= significant at .05, b= significant at .01, c= significant at <.001

		DSES		
Variable	coding	B	95% CI	p value
Categorical variables				
Age	≥50	NS	NS	NS
Education	More than college (ref)			
	College grad	-1.051	-4.111-2.009	.500
	Some college	2.308	-.896-5.512	.158
	HS or less	4.890	1.125-8.655	.011
Have regular doctor	Yes vs no	3.062	.668-5.456	.012
Continuous variables				
Health Literacy	Cont.	2.915	2.439-3.392	<.000
Subjective Numeracy	Cont.	2.216	.994-3.487	.001
General health	Cont.	2.597	1.352-3.843	<.000

Table 5: Results of the Backwards Stepwise Linear Regression predicting Decisional Self Efficacy Scale (DSES) score

Nonsignificant variables: Race, anybody close tested for CRC, gender, cancer worry, perceived likelihood of cancer, ever been diagnosed with cancer, anybody close ever died of cancer, income, relationship status, insurance status, commitment to testing

Chapter 6: Integrated Discussion

Considering the recent guidelines from the American Cancer Society,[3] and the rising risk for CRC in people under 50[8], this project is both timely and appropriate. Several studies in the literature have included individuals under 50 and others have evaluated age differences in their analysis, but this is the first study, to our knowledge, designed to explicitly evaluate the differences between people over 50 and under 50. In all 3 manuscripts that were written as part of this dissertation, I found differences by age when evaluating shared decision-making constructs. In the following sections I will summarize the main findings of the 3 manuscripts, evaluate the strengths and weaknesses of this project, and explore the policy and clinical implications of these results.

6.1 Synopsis of studies and findings

6.1a

RQ1: Are people under age 50 able to correctly identify risk factors of CRC? (Paper 1)

Central to the shared decision-making framework is that an individual (the patient) is knowledgeable about the disease about which they are making decisions. Additionally, shared decision-making is often thought of as a process. An evaluation of the patient's current knowledge is an important step in this process that builds rapport between a patient and doctor team and allows the doctor to fill in the necessary knowledge gaps for a patient to make informed decisions.[21]

For paper 1, I created 2 indices to assess participants' knowledge of colorectal cancer risk factors and symptoms. Of these, the knowledge of risk factors is more proximal to shared decision-making for CRC screening, while knowledge of symptoms is

more closely related to diagnostic evaluation of symptomatic individuals. However, both constructs are valuable to assess in this context because the gaps in knowledge could inform future education programs for people under 50. I evaluated the scores for individual items, tested whether knowledge of these two domains differed between the two age groups (<50 and ≥50), and tested the moderating role of age in composite knowledge scores.

I found that participants' knowledge of both risk factors and symptoms were high, ranging from 44.2%-88.9% correctly identifying individual risk factors and 59.8%-85.5% correctly identifying individual symptoms. For risk factors, participants generally scored the lowest for behavioral risk factors like alcohol use (52.8%) and tobacco use (47%). For symptoms, participants scored the lowest for symptoms that were related to cancer more generally such as persistent anemia (59.8%) and unexplained weight loss (68.9%), rather than symptoms specific to gastrointestinal cancers. **I found that knowledge scores for symptoms and risk factors did not vary in these two age groups.** However, I did find evidence for age moderating the relationships in multivariable models. Of note, predictors of risk factor knowledge in the <50 age group were subjective numeracy, knowing somebody close to them who tested for CRC, and commitment to testing whereas in the ≥50 age group knowledge of symptoms was predicted by public insurance and previous cancer diagnosis. The <50 age group also revealed predictors for symptom knowledge including female gender, knowing somebody close tested for CRC, and higher perceived likelihood of getting cancer. In the ≥50 group, only knowing somebody who has died of cancer remained predictive of symptom knowledge.

The results from paper 1 show that, while knowledge of risk factors is generally high, there is room for improvement in behavioral risk factors and general symptoms of cancer compared to symptoms associated specifically with CRC. Results also provide evidence that age might be an important factor when targeting interventions to improve knowledge. While I did not find differences in knowledge by age, this paper is the first, to my knowledge, to explicitly test the moderating role of age on these knowledge constructs. As risk continues to rise in people under age 50, an understanding of individuals' knowledge will be essential to evaluate a starting point for shared decision-making. The constructs that we have found associated in the <50 group may be considered as targets for further research.

6.1b

RQ2 What screening strategy do individuals under 50 prefer and on what are these preferences based? (Paper 2)

Another critical component of shared decision-making is that preferences are elicited. In paper 2, I used a technique from decision and operations research called the Analytic Hierarchy Process. This technique is a multicriteria decision analysis technique that breaks down a complex decision into a hierarchical structure, allowing somebody to focus on one small decision at a time. The AHP has been used widely for healthcare decision-making and, to my knowledge, three other times in the colorectal cancer literature.[117,118,143,145] However, we add to the colorectal cancer literature in several novel ways (described in Chapter 4).

I found that colonoscopy was the preferred strategy in our overall sample. This finding adds to a large but inconclusive body of literature that explores test preferences across various populations.[112] The variability in this literature is likely related to the sample studied and how researchers present the details of each screening strategy. A strength of this study is that I plan to publish details of descriptions used for each screening strategy so that other researchers can evaluate or use them in their own work. I also paid careful attention to the length, reading level, parallel structure and equality of characteristics described for each strategy (Appendix B). I found that the 'test effectiveness' was the most important criteria for participants in our sample when deciding which screening strategy they would choose. This finding aligns with the other studies that have used AHP to explore colorectal cancer screening although each author has operationalized this construct differently (i.e., preventing cancer[116], test accuracy[117], and sensitivity/specificity[118]). I also found that the 'screening plan,' including the follow-up and frequency' were not as important for participants' decision-making process.

The primary contribution to the literature is that I tested the AHP derived preferences by age groups (<50 and ≥50). This is the first study, to my knowledge, that was designed with this framing and intent in mind. I found that people under age 50 were more likely to prefer colonoscopy, while people over age 50 were more likely to prefer the FIT option. The differences that I found were statistically significant (p=.002). I also found that individuals' AHP derived preferences matched their stated preference, after going through the activity, about 60% of the time.

A shared decision-making framework is most appropriate when the decision to be made is preference dependent, meaning the outcomes are either uncertain or in relative

equipoise based on risks and benefits. Colorectal cancer screening for individuals age 45-49 represents these criteria and the results of this study will be valuable as a springboard for future work in this area. Results pointing to the association between younger age and preference for colonoscopy must be replicated. At the time of writing this dissertation (October 2020) this manuscript is under review with the journal *BMC Health Services Research.*

6.1c

RQ3: When making CRC screening decisions, what level of control (role preference) do people under 50 prefer and do they feel confident in their ability to make decisions?(Paper 3)

The final component of shared decision-making that I explored in this dissertation project is role preference or desired role. The shared decision-making framework stipulates that an individual should be participating in the decision-making process at a level at which they are comfortable and willing. An evaluation of a patient's willingness to participate in decision-making is critical so that providers can match their care with patient preferences[157], whether those preferences are for shared decision-making, patient driven (active) or doctor driven (passive). Patients who are engaged in decision-making can have better outcomes and higher satisfaction with the decision-making process.[25]

Desired role in the decision-making process is widely studied in the medical decision-making literature and in the context of colorectal cancer screening and evidence suggests that there is considerable variation in desired role by topic and sample. However, desired role in colorectal cancer screening has not been studied before in

individuals under age 50. In this study, I measured desired role in 3 ways: for general medical decisions, for deciding whether to get screened for CRC, and for which screening strategy to use. This study is also novel because I was able to measure the differences between the stable, general role preference and the situation specific role preferences.

I found that the active role was preferred by participants most often for general medical decisions, deciding whether to get screened, and deciding which screening strategy to use. Participants' role preference was stable from general medical decisions to the situation specific decisions 56.1%-84% of the time. In the multivariable, multinomial logistic regression models that I performed, I found that age was significantly associated with the decision for whether to get screened and which screening strategy to use. For both decisions, people under age 50 generally preferred a shared or passive role compared to an active role. This is contrary to findings in the literature that show that younger people generally prefer an active role in decision-making compared to their older counterparts.[25] The preference for shared or passive role in younger people may be related to colorectal cancer not being on their 'radar' or not feeling that they have enough information to take an active role in making these decisions.

Role preference may be important to consider if we incorporate people under age 50 into colorectal cancer screening programs. Consistent public health messaging has ingrained the idea that screening should begin at age 50 so people younger than this may not have had the opportunity to process the need to make decisions about screening for themselves. Physicians will have to evaluate the best ways to match care with a patient's desired role when working with individuals who are under age 50. This may require

researchers to develop and test tools that can be embedded into health systems that prime patients to think about these decisions and thus prepare them to take a more active role in their healthcare. Engaging these patients in the decision-making process can improve satisfaction with care and thus subsequent adherence to their chosen screening strategy.

6.2 Common Elements Across Papers

Age

In all 3 manuscripts, I found age (<50) to be an important factor when evaluating the constructs of interest. In paper 1, age moderated the association between independent variables and knowledge of symptoms and risk factors; in paper 2, I found that age was associated with preferences for screening strategy; and in paper 3, age was associated with desired role in deciding whether to get screened and deciding which screening strategy to use. These findings are consistent with the primary motivation for conducting this project: to evaluate whether people under age 50 think differently about screening for CRC than people over age 50.

There are several explanations for the differences that I found. First, colorectal cancer may not be on younger people's 'radar.[103] Consistent public health messaging has focused on establishing and normalizing age appropriate, guideline-based screening for colorectal cancer. This messaging has focused on initiating screening starting at age 50. In this sense, younger people may see colorectal cancer as a disease of older age and, in many ways, this is a correct way of thinking. As age increases, the risk of developing CRC increases. However, age 50 is not a point in time where risk begins to dramatically increase, rather it is chosen as a time where the benefits versus burdens begin to shift in favor of population-based screening. In fact, when data are analyzed by year, many of the

cancers that are found at age 50 when people begin screening are likely already clinically significant well before age 50.[124] Evidence from paper 1 points to another explanation: that people under age 50 process information about colorectal cancer differently than their older counterparts. We found that knowledge index scores for both symptoms and risk factors were not statistically different in both age groups, but the predictors of these scores varied by age. If this is the case, then incorporating younger people into screening programs may not be as simple as increasing their awareness of the importance of screening and putting the disease on their 'radar'. It may involve identifying and targeting the moderating and mediating factors that differ in younger groups.

Colorectal cancer represents the third highest mortality of cancer sites for both sexes.[1] As an important cancer control priority, CRC has a large body of evidence exploring different facets of the disease and associated processes. As noted throughout this work, individuals under the age of 50 have not been traditionally included in research that evaluates colorectal cancer screening. Long standing guidelines have shaped research and the age samples that investigators have studied. Recent population-based analysis point to the steady rise in risk for CRC in individuals as young as 20. In fact, the risk is increasing the fastest for people in the youngest age brackets.[8] These findings may push researchers to fill the gaps in knowledge for people younger than 50. In this project I evaluated perceptions that may be important for screening but there are numerous research questions yet to be unraveled in younger age groups across the cancer continuum related to concepts like etiology, diagnosis, survivorship, perceptions about CRC and disparities, among many others, along with the unique mediating and moderating factors that influence all of these.

Cancer Experience

In this study, I collected variables such as whether the participant had ever been diagnosed with cancer, whether anybody close to the participant has died of cancer, if they knew anybody close to them who had ever been screened for CRC, commitment to testing for CRC, perceived likelihood of having cancer and how worried the participant was about cancer. These variables were associated with several of the key dependent variables that we evaluated in papers 1 and 3. In papers 1 and 3, the cancer experience variables were more highly associated with knowledge and role preference than most of the demographic variables that I measured. In breast cancer work, researchers have found that experience with cancer, such as death of a family member, predicts beliefs about screening more than family history alone.[159] These results point to important contextual features that future work should assess when exploring perceptions about colorectal cancer screening in this age group.

Heath Literacy

Health literacy and subjective numeracy are concepts that appear throughout cancer control research. In colorectal cancer, literacy and numeracy are related to a variety of concepts including knowledge[160], attitudes,[161] barriers to screening[160], and perceptions of risk information[161]. These concepts also appear as themes throughout this project. In paper 1, higher numeracy was significantly associated with higher knowledge of risk factors and this relationship was moderated by age with the relationship remaining significant only in those under 50. In paper 2, lower health literacy was significantly associated with exclusion from the AHP exercise due to inconsistency and with the preference for CTC (the 'middle option'). In paper 3, both literacy and numeracy were

associated with lower? decisional self-efficacy. Future work should evaluate both literacy and numeracy longitudinally in the context of shared decision-making to assess whether they facilitate or hinder patients' decision-making processes.

6.3 Study Limitations

There are several limitations to note when interpreting the results of this dissertation. These are identified in each individual paper and will be summarized here in the context of the overall project.

Sample racial/ethnic diversity

A primary limitation of this dissertation is the racial and ethnic diversity of the sample that responded to the survey. Our sample was primarily female (61.8%), white (82.9%), insured by private insurance (67.9%), English speaking (99%), high health literacy (mean 17.8/20), high subjective numeracy (4.6/6), and married (48%). These demographic features are typical of MTurk samples[138] and reflect the individuals that are taking research tasks through the MTurk platform. However, these demographic features are not reflective of an average community sample nor of those that are at highest risk of dying from colorectal cancer, namely those who are male and black.[162]

More recent work on young-onset colorectal cancer indicates that, among those under 50 diagnosed with CRC, Asians (10%), blacks (12%), and Pacific Islanders (45%) have higher odds of developing advanced stage disease. [163] Additionally, in the young onset age group (<50), those that are married have 11% lower odds of developing advanced CRC.[163] Our sample was also not collected using clinical samples, however, I anticipate that the relationships that I found would be stronger in individuals that were

actively thinking and processing the colorectal cancer screening experience. This dissertation is a first step in evaluating the associations between age and perceptions of CRC and CRC screening. Because I have detected signals across several domains, future work should use targeted sampling to evaluate whether these associations remain stable for those at highest risk and for samples that are representative of an average community sample.

Survey collection:

This study is limited by its use of cross sectional, self-guided, online survey procedures. This limitation was noted across several aspects of the project. The cross-sectional nature of the study did not allow us to explore beyond associations and it is difficult to determine the temporality of the associations that I did find. I consider the purpose of this project was not to prove causality, rather, I aimed to reveal associations that have not been studied before in people under age 50 to identify areas for more targeted evaluations. Future work should evaluate whether these associations correspond to colorectal cancer screening behavior.

To collect the needed information to answer our research questions, I had to ensure that the survey was an appropriate length to keep participants engaged and to reduce respondent burden. This limitation was compounded by the impersonal nature of the MTurk platform that removes researcher-participant interaction. This meant that I had to exclude areas of interest in the survey to be sure that I was receiving high quality data for the primary research questions. Of note, if I were able to engage research participants in person, I would have liked to evaluate the unprompted assessments of colorectal cancer symptom and risk factor knowledge. An in-person evaluation would have also

allowed us to administer the original card-sorting control preferences scale.[156] Finally, had I done an in-person assessment, I could have ran a guided session or used an interactive activity such as DefinitivePro[149] for the AHP assessment. This may have reduced the number of participants that I had to exclude due to inconsistency. Our online study excluded a lower proportion than Hummel, et al, who used a web-based survey for their AHP assessment. I excluded a larger proportion than Xu (2015), who used mail-in surveys with participants who had been previously engaged, and Dolan (2013), who used guided, in-person interviews.[118]

6.4 Study Strengths

The limitations that I have identified are balanced by several strengths. I have identified these strengths in each manuscript and will summarize in the following section in the context of the overall project.

Sample Size

I was able to recruit 579 individuals into this study using targeted convenience sampling through the MTurk platform at a relatively low cost compared to other survey research platforms. The large sample that I was able to recruit provided several advantages. First, this study was powered to detect the small effect sizes that we often see in psychological studies of behavioral constructs and processes. Second, the large sample size allowed me to include many variables in my multivariable models. Because I aimed to explore novel associations between variables, rather than build predictive models, controlling for many variables adds strengths to the associative conclusions that I made in each manuscript. Finally, I had power to study age subgroups. In both paper 1 and paper 2, I split the sample into the two age subgroups and analyzed them separately. Without a

large sample size, the point-estimates in the multivariable models would have been unreliable.

Sample Characteristics

Despite the limitations mentioned above, using the MTurk platform allowed me to collect a large, national sample of participants who had never been screened for colorectal cancer before. Our sample represents individuals who may have not thought much about colorectal cancer and certainly those who do not have experience with the screening process. This is a strength of the study and we predict in more experienced samples, that the associations that we found would be stronger because they are actively processing their screening experience. The sample was diverse on several other characteristics besides race and ethnicity. We were able to recruit individuals from a range of income categories and individuals were spread relatively evenly among categorical income brackets with 19.3% of the sample making a household income of less than $30,000 and 25.7% making more than $90,000. Participants also represented a wide range of educational attainment levels, 16.6% had a high school education or less and 22.3% had some graduate school or a graduate degree. Finally, we were able to recruit enough individuals who were uninsured (16.1%, n=93) and on public insurance (15.5%, n=90) to analyze these individuals as separate categorical groups. These demographics features are typical of average MTurk samples and similar scrutiny should be used when comparing any online convenience sample to a representative community sample.[164]

Robust collection of cancer experience variables

As previously mentioned, this study is strengthened by the robust collection of cancer experience variables. Cancer experience variables are often left out of analysis in favor of demographic predictors. Including these variables in the multivariable models adds strength to the conclusions that I have drawn. We found associations that were highly significant across all three manuscripts, even when controlling for both demographic and cancer experience variables. This gives me confidence that the associations that I found are not spurious findings.

6.5 Policy Implications

Guideline Implications

The Affordable Care Act mandates that insurance coverage, and thus, clinical care is guided by the recommendations of the United States Preventive Services Task Force,[88] rather than the recommendations made by the American Cancer Society. At the time of defending this dissertation (October 2020) the USPSTF has released their draft research plan to update their 2016 guidelines.[165] It is unclear whether the updated recommendation will address colorectal cancer screening in individuals age 45-49 as the American Cancer Society guidelines did in 2018. Should the USTSPF also recommend screening in this age group, clinical practice and research will dramatically shift to accommodate these guidelines.

The American Cancer Society guidelines for individuals age 45-49 are designated as ‘qualified’ recommendations. This is because research in this age group is lacking considerably to be able to accurately quantify the benefits and burdens associated with

screening in individuals under age 50. This dissertation provides evidence to begin exploring the details of screening in this population that has not been evaluated elsewhere in the literature. As evidence builds, the certainty around this recommendation will increase and give organizations that recommend policies more confidence in making recommendations to guide clinical care.

Costs

In paper 2, I found that people under 50 preferred colonoscopy as a screening strategy more often than people over the age of 50. This was due to their relative assignment of 'features of the test' compared to 'test effectiveness'. While colonoscopy is generally considered the gold standard of colorectal cancer screening, it is also the costliest to perform and becomes more costly when you factor in age-based risk. Although all patients should be able to receive preference aligned care, there is no denying the costs associated with providing them with the most expensive option, especially if limited funds must be diverted from those at the highest risk. These findings align with the concerns of critics of expanding the screening age.[13] In their 2019 paper, Ladabaum and colleagues showed that beginning colonoscopy screening starting at age 45 is, indeed, cost effective.[85] However, the resources used for additional colonoscopies in this age group could be used more efficiently by either: (1) providing colonoscopy every 10 years to unscreened individuals 55 years old; (2) providing colonoscopy screening every year to currently unscreened individuals 65 years old; or (3) increasing follow-up colonoscopy after abnormal FIT from 60%-90% in the current cohort of people who participate in yearly FIT screening. [85] Future work may need to explore the best way to reconcile preferences of younger individuals with the costs associated with their

preferred screening strategy should the age-preference associations that we found hold across studies.

6.6 Clinical Implications

These results also have clinical implications to consider. From the results of this study and prior work in this area we are developing an understanding that individuals under 50 may perceive colorectal cancer screening differently than their older counterparts. In this study, we explored the moderating role of age on knowledge, differences in screening strategy preferences, and different desired roles. Younger individuals also experience more social and practical problems in attaining colonoscopy[91], low knowledge of available screening tests[24], and financial strain in seeking colonoscopy[92].The reasons for these differences have not yet been fully explored in the literature but this knowledge should be incorporated into clinical care when working with patients under age 50. Clinicians may need to use time and resources to evaluate knowledge more thoroughly and assess preferences and desired role. They also may need to modify clinical care to encourage shared decision making. Public health professionals need to incorporate messaging about young-onset colorectal cancer and encourage younger people to be vigilant about risk factors, symptoms, and screening for the disease. Researchers should develop resources for individuals who encounter social and practical problems and fill in the gaps in research for the clinical implications of younger age on CRC screening programs.

There is also an opportunity to build interactive tools that encourage the shared decision-making process that can be embedded into a clinic's or health system's procedures. Activities such as the AHP exercise in Paper 2 can be evaluated as a tool to

encourage preference formulation that is key to the SDM process. An AHP activity could also be incorporated into larger tools that also address knowledge gaps or link patients to the resources that address their specific needs. Prior work has developed and tested tools that encourage shared decision making with some success in improving knowledge and intention to get screened but no tools to my knowledge have been specifically created to address the needs of younger individuals. Successful tools in this age group must addressed the unique challenges, knowledge gaps, and preferences of people under 50 while paying special attention to some of the issues we have encountered in this study like literacy and numeracy.

6.7 Conclusions

In this dissertation, I have evaluated 3 key components of the shared decision-making framework in the context of colorectal cancer screening in individuals under the age generally considered for age appropriate, guideline-based screening. The primary focus of this work was to determine whether people under age 50 think differently about colorectal cancer and its associated screening processes than people over age 50. I found in all 3 manuscripts that age was an important factor to consider. I found that age was a moderator to knowledge about risk factors and symptoms, was associated with preferences for screening tests, and was related to role preference in the decision-making process for deciding whether to get screened and deciding which screening test to choose.

Screening for CRC in individuals under age 50 is a controversial topic in the research literature. At the time of defending this dissertation project, these practices have not currently been incorporated into regular clinical care. In this sense, this project is exploratory and preemptive in nature. However, we have already seen shifts in practice in

the months following these guideline recommendations.[139] These findings will act as a foundation for future work if it becomes necessary to incorporate younger people into colorectal cancer screening programs.

Appendix A: Data Collection Instrument

Start of Block: Demographics

Q1
This is the beginning of your mTurk Task.

After you have completed this task, you will be provided with your survey code.

Page Break

Q2 **We are going to start by asking you a few questions about yourself.**

Q3 On your last birthday, how old did you turn?

	18 26 34 42 50 59 67 75 83 91 99
Age ()	

Q4 Are you Hispanic or Latino/a?

- ○ No, not Hispanic or Latino/a (1)
- ○ Yes, Hispanic or Latino/a (2)

Q5 What country were you born in?

- ○ United States (1)
- ○ Other (what country?) (2) _____

Q6 Is English your primary spoken language?

- ○ Yes (1)
- ○ No (please specify your primary spoken language) (0)

_____

Page Break

Q7 What sex were you assigned at birth, on your original birth certificate?

- ○ Male (1)
- ○ Female (2)
- ○ Intersex (3)

Q8
Which one of these terms do you identify with most?

- ○ Man (1)
- ○ Woman (2)
- ○ Transgender man (3)
- ○ Transgender woman (4)
- ○ Other (please describe) (5)

_____

Q9
Sexual orientation is often used to describe who you are emotionally, romantically,

or sexually attracted to. What one **best** describes your current sexual orientation?

- ○ Heterosexual/straight (1)
- ○ Asexual (2)
- ○ Bisexual (3)
- ○ Lesbian/Gay (4)
- ○ A sexual orientation not listed above (please specify) (9)

_____

Page Break

Q10 What zip code do you currently live in?

_____

Q11 What is the highest level of education you've **completed**?

- ○ 1st grade (1)
- ○ 2nd grade (2)
- ○ 3rd grade (3)
- ○ 4th grade (4)
- ○ 5th grade (5)
- ○ 6th grade (6)
- ○ 7th grade (7)
- ○ 8th grade (8)
- ○ 9th grade (9)
- ○ 10th grade (10)
- ○ 11th grade (11)
- ○ 12th grade/GED (12)
- ○ College freshman (13)
- ○ College Sophomore/Associate's degree (14)
- ○ College Junior (15)
- ○ College completion (16)
- ○ Some graduate school but no degree received (17)
- ○ Master's degree (18)

○ Some professional school (such as law or medical school) but no degree received (19)

○ Doctorate or professional degree (20)

Q12 Have you completed a technical or trade school program (such as beautician, cosmetology, mechanic, business, appliance repair, computer, etc.)?

○ No (0)

○ Yes (1)

Page Break

Q13 Think about the **family members in your household who live with you right now**. About how much income did you and your family members make in the last year before

taxes? (Include child support, cash payments and assistance from the government—for example, SNAP, TANF, SSI, or unemployment compensation)

- ○ Less than $10,000 (1)
- ○ $10,000 - $19,999 (2)
- ○ $20,000 - $29,999 (3)
- ○ $30,000 - $39,999 (4)
- ○ $40,000 - $49,999 (5)
- ○ $50,000 - $59,999 (6)
- ○ $60,000 - $69,999 (7)
- ○ $70,000 - $79,999 (8)
- ○ $80,000 - $89,999 (9)
- ○ $90,000 - $99,999 (10)
- ○ More than $100,000 (11)

Q14 How many people are supported on this income?

- ○ 1 (just me) (1)
- ○ 2 (2)
- ○ 3 (3)
- ○ 4 (4)
- ○ 5 (5)
- ○ 6+ (6)

Q15 How many children under the age of 18 live in your household?

_____

Page Break

Q16 Would you say that you make enough money to buy the things that you need? why?

_____
_____
_____
_____
_____

Page Break

Q17 Are you currently covered by any of the following types of health insurance or health coverage plans?

	Yes (1)	No (4)
Insurance through a current or former employer or union (1)	○	○
Insurance purchased directly from an insurance company (2)	○	○
Medicare, for people 65 and older or people with certain disabilities (3)	○	○
Medicaid (or MediCal in California), medical assistance, or any kind of government-assistance plan for those with low incomes or a disability (4)	○	○
TRICARE or other military health care (5)	○	○
VA (including those who have ever used or enrolled for VA health care) (6)	○	○
Indian Health Service (7)	○	○
Any other type of health insurance or coverage plan (please specify) (8)	○	○

Q18 Describe your current relationship status. [Select the one best answer]

- ○ Single but dating (1)
- ○ Single and not dating (2)
- ○ In a committed relationship but unmarried (3)
- ○ Legally married / domestic partnership (4)
- ○ Living with a permanent partner but unmarried (5)
- ○ In a committed relationship with multiple partners (if so, how many) (6) _____
- ○ Divorced (7)
- ○ Widowed (8)
- ○ Other (9) _____

Q19
In general, would you say your health is...

- ○ Excellent (1)
- ○ Very good (2)
- ○ Good (3)
- ○ Fair (4)
- ○ Poor (5)

Page Break

Q20 Overall, how confident are you about your ability to take good care of your health?

- ○ Completely confident (1)
- ○ Very confident (2)
- ○ Somewhat confident (3)
- ○ A little confident (4)
- ○ Not confident at all (5)

Q21 Overall, how confident are you that you could get advice or information about health or medical topics if you needed it?

- ○ Completely confident (1)
- ○ Very confident (2)
- ○ Somewhat confident (3)
- ○ A little confident (4)
- ○ Not confident at all (5)

End of Block: Demographics

Start of Block: Numeracy and Literacy

Q22 How confident are you filling out medical forms by yourself?

- Extremely (1)
- Quite a bit (2)
- Somewhat (3)
- A little bit (4)
- Not at all (5)

Q23 How often do you have someone help you read medical materials?

- Always (1)
- Often (2)
- Occasionally (3)
- Sometimes (4)
- Never (5)

Q24 How often do you have problems learning about your medical condition because of difficulty understanding written information?

- Always (1)
- Often (2)
- Occasionally (3)
- Sometimes (4)
- Never (5)

Q25 How often do you feel you don’t understand what the doctor tells you?

- Always (1)
- Often (2)
- Occasionally (3)
- Sometimes (4)
- Never (5)

Page Break

Q26 How good are you at working with fractions?

- 1 Not at all good (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Extremely good (6)

Q27 How good are you at working with percentages?

- 1 Not at all good (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Extremely good (6)

Q28 How good are you at calculating a 15% tip?

- 1 Not at all good (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Extremely good (6)

Q29 How good are you at figuring out how much a shirt will cost if it is 25% off?

- 1 Not at all good (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Extremely good (6)

Page Break

Q30 When reading the newspaper, how helpful do you find tables and graphs that are parts of a story?

- 1 Not at all helpful (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Extremely helpful (6)

Q31 When people tell you the chance of something happening, do you prefer that they use words (eg. "it rarely happens") or numbers (eg. "there's a 1% chance")?

- 1 Always prefer words (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Always prefer numbers (6)

Q32 When you hear a weather forecast, do you prefer predictions using percentages (e.g., “there will be a 20% chance of rain today”) or predictions using only words (e.g., “there is a small chance of rain today”)?

- 1 Always prefer percentages (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Always prefer words (6)

Q33 How often do you find numerical information to be useful?

- 1 Never (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Very often (6)

End of Block: Numeracy and Literacy

Start of Block: Relationship with provider

Q34 Not including psychiatrists and other mental health professionals, is there a particular doctor, nurse, or other health professional that you see most often?

- No (0)
- Yes (1)

Display This Question:
If Not including psychiatrists and other mental health professionals, is there a particular doctor,... = Yes

Q35 What kind of medical provider is this (the one you go to most frequently)?

- ○ Primary, family, or general care (1)
- ○ OBGYN (2)
- ○ Oncologist (3)
- ○ Gastroenterologist (4)
- ○ Dermatologist (5)
- ○ Other (please describe) (6)

_____

Display This Question:
If Not including psychiatrists and other mental health professionals, is there a particular doctor,... = Yes

Q36
How would you describe your relationship with this provider?

- ○ Excellent (1)
- ○ Very good (2)
- ○ Good (3)
- ○ Fair (4)
- ○ Poor (5)
- ○ Very poor (6)

Page Break

Q37
In the past 12 months, not counting times you went to an emergency room, how many times did you go to a doctor, nurse, or other health professional to get care for yourself?

- None (1)
- 1 time (2)
- 2 times (3)
- 3 times (4)
- 4 times (5)
- 5-9 times (6)
- 10 or more times (7)

Q38 Overall, how would you rate the quality of health care you received in the past 12 months?

- Excellent (1)
- Very good (2)
- Good (3)
- Fair (4)
- Poor (5)

Q39
Some people avoid visiting their doctor even when they suspect they should. Would you say this is true for you or not true for you?

- ○ Not true (0)
- ○ True (1)

End of Block: Relationship with provider

Start of Block: RQ3: Control Preferences

Q40 Which of the following best describes what you think **when making decisions <u>about your health</u>**:

- ○ I prefer to make the decision about which treatment I will receive (1)
- ○ I prefer to make the final decision about my treatment after seriously considering my doctor's opinion (2)
- ○ I prefer that my doctor and I share responsibility for deciding which treatment is best for me (3)
- ○ I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion (4)
- ○ I prefer to leave all decisions regarding treatment to my doctor (5)

Page Break

Q41 Which of the following best describes what you think **when making decisions <u>about whether you should get screened for colorectal cancer</u>**:

- ○ I prefer to make the decision about whether I should get screened (1)
- ○ I prefer to make the final decision whether I should get screened after seriously considering my doctor's opinion (2)
- ○ I prefer that my doctor and I share responsibility for deciding whether I should get screened (3)
- ○ I prefer that my doctor makes the final decision about whether I should get screened, but seriously considers my opinion (4)
- ○ I prefer to leave all decisions regarding whether I should get screened to my doctor (5)

Page Break

Q42 Which of the following best describes what you think **when making decisions <u>about what screening test for colorectal cancer you should get</u>**:

○ I prefer to make the decision about what screening test I should get (1)

○ I prefer to make the final decision about what screening test I should get after seriously considering my doctor's opinion (2)

○ I prefer that my doctor and I share responsibility for deciding what screening test I should get (3)

○ I prefer that my doctor makes the final decision about what screening test I should get, but seriously considers my opinion (4)

○ I prefer to leave all decisions regarding what screening test I should get to my doctor (5)

End of Block: RQ3: Control Preferences

Start of Block: DSES before

Q43
Below are listed some things involved in making an informed **<u>medical</u>** choice between several options. Please show how confident you feel in doing these things by answering the following questions: On a scale of 1 to 5, with 1 being not confident at all and 5 being very confident. I feel confident that I can:

	Not at all confident (1) (0)	(2) (1)	(3) (2)	(4) (3)	Very confident (5) (4)
Get the facts about the options available to me (1)	○	○	○	○	○
Get the facts about the benefits of each option (2)	○	○	○	○	○
Get the facts about the risks and side effects of each option (3)	○	○	○	○	○
Get the best available care (4)	○	○	○	○	○
Understand the information enough to be able to make a choice (5)	○	○	○	○	○
Ask questions without feeling dumb (6)	○	○	○	○	○
Express my concerns about each option (7)	○	○	○	○	○
Ask for advice (8)	○	○	○	○	○
Figure out the option that best suits me (9)	○	○	○	○	○
Get my test results as quickly as possible (10)	○	○	○	○	○
Handle unwanted pressure from others in making my choice (11)	○	○	○	○	○
Let the clinic team know what's best for me (12)	○	○	○	○	○
Delay my decision if I feel I need more time (13)	○	○	○	○	○

End of Block: DSES before

Start of Block: RQ1: Knowledge of Risk Factors

Q44 Which of the following would increase the risk for somebody to get colon or rectal cancer?

	Yes (1)	No (2)	I don't know (3)
Increased age (1)	○	○	○
Obesity or Higher body mass index (BMI) (2)	○	○	○
Exposure to the sun without sunscreen (3)	○	○	○
A diet high in red or processed meats (4)	○	○	○
Diabetes (5)	○	○	○
Inflammatory bowel disease such as Irritable bowel disorder (IBD) (6)	○	○	○
Alcohol consumption (7)	○	○	○
Exposure to violent video games (8)	○	○	○
Smoking cigarettes or other tobacco products (9)	○	○	○
A family member with colon or rectal cancer (10)	○	○	○

End of Block: RQ1: Knowledge of Risk Factors

Start of Block: Knowledge of Symptoms

Q45 Which of the following are likely symptoms of colon or rectal cancer?

	Yes (1)	No (2)	I don't know (3)
Blood when you wipe after using the bathroom (blood in your stool) (1)	○	○	○
Persistent abdominal pain (2)	○	○	○
Persistent anemia (paleness, weakness, fatigue) (3)	○	○	○
Persistent indigestion or heart burn (4)	○	○	○
Unexplained weight loss (5)	○	○	○
Frequent urges to urinate (6)	○	○	○
Persistent changes in bowel habits (narrowing of stool, diarrhea, or constipation) (7)	○	○	○
Frequent headaches (8)	○	○	○

End of Block: Knowledge of Symptoms

Start of Block: AHP INTRODUCTION

Q48 The following questions refer to **<u>the procedure</u>**

Q50
When considering the **procedure**:

On a scale from 1 - 9, how well does colonoscopy fit your preferences?

	Does not fit (1)	(2)	Slightly fits (3)	(4)	Strongly fits (5)	(6)	Very strongly fits(7)	(8)	Extremely fits (9)
1 (1)	○	○	○	○	○	○	○	○	○

Q52
When considering the **procedure:**

On a scale from 1 - 9, how well does the fecal immunochemical test (FIT) fit your preferences?

Q54
When considering the **procedure:**

On a scale from 1 - 9, how well does the computed tomography colonography (CTC) fit your preferences?

Q55 The following questions refer to **preparation**

Q57
When considering the **preparation**:

On a scale from 1 - 9, how well does colonoscopy fit your preferences?

Q59
When considering the **preparation:**

On a scale from 1 - 9, how well does the computed tomography colonography (CTC) fit your preferences?

Q61
When considering the **preparation:**

On a scale from 1 - 9, how well does the fecal immunochemical test (FIT) fit your preferences?

Page Break

Q62 The following questions refer to **convenience**

Q64
When considering the **convenience**:

On a scale from 1 - 9, how well does colonoscopy fit your preferences?

Q66
When considering the **convenience:**

On a scale from 1 - 9, how well does the fecal immunochemical test (FIT) fit your preferences?

Q68
When considering the **convenience:**

On a scale from 1 - 9, how well does the computed tomography colonography (CTC) fit your preferences?

Page Break

Q69 The following questions refer to **the possibility for complications**

Q71
When considering the **possibility for complications**:

On a scale from 1 - 9, how well does colonoscopy fit your preferences?

Q73
When considering the **possibility for complications:**

On a scale from 1 - 9, how well does the fecal immunochemical test (FIT) fit your preferences?

Q75
When considering the **possibility for complications:**

On a scale from 1 - 9, how well does the computed tomography colonography (CTC) fit your preferences?

Page Break

Q76 The following questions refer to **the frequency of testing**

Q78
When considering the **frequency of testing:**

On a scale from 1 - 9, how well does colonoscopy fit your preferences?

Q80
When considering the **frequency of testing:**

On a scale from 1 - 9, how well does the fecal immunochemical test (FIT) fit your preferences?

Q82
When considering the **frequency of testing:**

On a scale from 1 - 9, how well does the computed tomography colonography (CTC) fit your preferences?

Page Break

Q83 The following questions refer to **the follow up possibility**

Q85
When considering the **follow up possibility:**

On a scale from 1 - 9, how well does colonoscopy fit your preferences?

Q87
When considering the **follow up possibility:**

On a scale from 1 - 9, how well does the fecal immunochemical test (FIT) fit your preferences?

Q89
When considering the **follow up possibility:**

On a scale from 1 - 9, how well does the computed tomography colonography (CTC) fit your preferences?

Page Break

Q90 The following questions refer to **effectiveness**

Q92
When considering the **test effectiveness:**

On a scale from 1 - 9, how well does colonoscopy fit your preferences?

Q94
When considering the **test effectiveness:**

On a scale from 1 - 9, how well does the fecal immunochemical test (FIT) fit your preferences?

Q96
When considering the **test effectiveness**

On a scale from 1 - 9, how well does the computed tomography colonography (CTC) fit your preferences?

End of Block: RQ2: AHP preferred test for criteria

Start of Block: RQ2: AHP when considering the screening plan

Q97
Please read carefully. For the following question:

Frequency of testing refers to how often you must get the test when your results come back normal

Possibility for follow-up refers to the follow-up for an abnormal test

Q98
When considering the **screening plan**:

Which is more important for your decision: **the possibility for follow-up** or **the frequency of testing**?

- ○ Possibility for follow-up (1)
- ○ Frequency of testing (2)
- ○ They are equally important (3)

Skip To: End of Block If When considering the screening plan: Which is more important for your decision: the possibility... = They are equally important

Q99 On a scale from 1 - 9, how much more important?

End of Block: RQ2: AHP when considering the screening plan

Start of Block: RQ2: AHP when considering features of the test

Q100
When considering the **features of the test** :

Which is more important for your decision, **the possibility of complications** or **the**

convenience of the test?

- ○ Possibility of complications (1)
- ○ Convenience of the test (2)
- ○ They are equally important (3)

Skip To: Q102 If When considering the features of the test : Which is more important for your decision, the poss... = They are equally important

Q101 On a scale from 1 - 9, how much more important?

Page Break

Q102
When considering the **features of the test** :

Which is more important for your decision, **the possibility of complications** or **the procedure**?

- ○ Possibility of complications (1)
- ○ The procedure (2)
- ○ They are equally important (3)

Skip To: Q104 If When considering the features of the test : Which is more important for your decision, the poss... = They are equally important

Q103 On a scale from 1 - 9, how much more important?

Page Break

Q104
When considering the **features of the test** :

Which is more important for your decision, **the possibility of complications** or **the preparation**?

- ○ Possibility of complications (1)
- ○ The preparation (2)
- ○ They are equally important (3)

Skip To: Q106 If When considering the features of the test : Which is more important for your decision, the poss... = They are equally important

Q105 On a scale from 1 - 9, how much more important?

Page Break

Q106
When considering the **features of the test** :

Which is more important for your decision, **the convenience of the test** or **the procedure**?

- ○ The convenience of the test (1)
- ○ The procedure (2)
- ○ They are equally important (3)

Skip To: Q108 If When considering the features of the test : Which is more important for your decision, the conv... = They are equally important

Q107 On a scale from 1 - 9, how much more important?

Page Break

Q108
When considering the **features of the test** :

Which is more important for your decision, **the convenience of the test** or **the preparation**?

- ○ The convenience of the test (1)
- ○ The preparation (2)
- ○ They are equally important (3)

Skip To: Q110 If When considering the features of the test : Which is more important for your decision, the conv... = They are equally important

Q109 On a scale from 1 - 9, how much more important?

Page Break

Q110
When considering the **features of the test** :

Which is more important for your decision, **the procedure** or **the preparation**?

- ○ The procedure (1)
- ○ The preparation (2)
- ○ They are equally important (3)

Skip To: End of Block If When considering the features of the test : Which is more important for your decision, the proc... = They are equally important

Q111 On a scale from 1 - 9, how much more important?

End of Block: RQ2: AHP when considering features of the test

Start of Block: RQ2: AHP when choosing a preferred test

Q112
We are now going to ask you a few questions about the most important things for you to make a decision about choosing your preferred test.

Page Break

Q113
Please read carefully. For the following questions you will rate the following on which is most important for your decision to choose a preferred test:

Test effectiveness refers to the tests effectiveness **Features of the test** refers to the procedure, the preparation, the convenience of the test, and the possibility for complications **Screening plan** refers to frequency of testing, and the follow up possibility

Page Break

Q114
When choosing a preferred test:
Test effectiveness refers to the tests effectiveness
Screening plan refers to frequency of testing, and the follow up possibility

Which is more important for your decision, **test effectiveness** or **the screening plan**?

- ○ Test effectiveness (1)
- ○ The screening plan (2)
- ○ They are equally important (3)

Skip To: Q116 If When choosing a preferred test: Test effectiveness refers to the tests effectiveness Screening pl... = They are equally important

Q115 On a scale from 1 - 9, how much more important?

Page Break

Q116
When choosing a preferred test:

Screening plan refers to frequency of testing, and the follow up possibility **Features of the test** refers to the procedure, the preparation, the convenience of the test, and the possibility for complications

Which is more important for your decision, **the screening plan** or **the features of the test**?

- ○ The screening plan (1)
- ○ Features of the test (2)
- ○ They are equally important (3)

Skip To: Q118 If When choosing a preferred test: Screening plan refers to frequency of testing, and the follow u... = They are equally important

Q117 On a scale from 1 - 9, how much more important?

Page Break

Q118
When choosing a preferred test:

Features of the test refers to the procedure, the preparation, the convenience of the test, and the possibility for complications

Test effectiveness refers to the tests effectiveness

Which is more important for your decision, **the features of the test** or **test effectiveness**?

- ○ Features of the test (1)
- ○ Test effectiveness (2)
- ○ They are equally important (3)

Skip To: End of Block If When choosing a preferred test: Features of the test refers to the procedure, the preparation, th... = They are equally important

Q119 On a scale from 1 - 9, how much more important?

End of Block: RQ2: AHP when choosing a preferred test

Start of Block: Test choice actual

Q120 After completing this exercise, which test for colorectal cancer would you choose?

- ○ CTC (1)
- ○ FIT (2)
- ○ Colonoscopy (3)
- ○ I would not choose any of these tests (4)

Display This Question:
If After completing this exercise, which test for colorectal cancer would you choose? = CTC
Or After completing this exercise, which test for colorectal cancer would you choose? = FIT
Or After completing this exercise, which test for colorectal cancer would you choose? = Colonoscopy

Q121 Why would you choose this test?

_____
_____
_____
_____
_____

Display This Question:
If After completing this exercise, which test for colorectal cancer would you choose? = I would not choose any of these tests

Q122 Why would you not choose any of these tests?

_____

End of Block: Test choice actual

Start of Block: RQ3: Control preferences After

Q123 Which of the following best describes what you think **when making decisions <u>about your health</u>**:

- ○ I prefer to make the decision about which treatment I will receive (1)
- ○ I prefer to make the final decision about my treatment after seriously considering my doctor's opinion (2)
- ○ I prefer that my doctor and I share responsibility for deciding which treatment is best for me (3)
- ○ I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion (4)
- ○ I prefer to leave all decisions regarding treatment to my doctor (5)

Page Break

Q124 Which of the following best describes what you think when **making decisions <u>about whether you should get screened for colorectal cancer</u>**:

- ○ I prefer to make the decision about whether I should get screened (1)
- ○ I prefer to make the final decision whether I should get screened after seriously considering my doctor's opinion (2)
- ○ I prefer that my doctor and I share responsibility for deciding whether I should get screened (3)
- ○ I prefer that my doctor makes the final decision about whether I should get screened, but seriously considers my opinion (4)
- ○ I prefer to leave all decisions regarding whether I should get screened to my doctor (5)

Page Break

Q125 Which of the following best describes what you think when **making decisions <u>about what screening test for colorectal cancer you should get</u>**:

- ○ I prefer to make the decision about what screening test I should get (1)
- ○ I prefer to make the final decision about what screening test I should get after seriously considering my doctor's opinion (2)
- ○ I prefer that my doctor and I share responsibility for deciding what screening test I should get (3)
- ○ I prefer that my doctor makes the final decision about what screening test I should get, but seriously considers my opinion (4)
- ○ I prefer to leave all decisions regarding what screening test I should get to my doctor (5)

End of Block: RQ3: Control preferences After

Q126 Below are listed some things involved in making an informed **<u>medical</u>** choice between several options. Please show how confident you feel in doing these things by answering the following questions:	Not at all confident (1) (1)	(2) (2)	(3) (3)	(4) (4)	Very confident (5) (5)
Get the facts about the options available to me (1)	○	○	○	○	○
Get the facts about the benefits of each option (2)	○	○	○	○	○
Get the facts about the risks and side effects of each option (3)	○	○	○	○	○
Get the best available care (4)	○	○	○	○	○
Understand the information enough to be able to make a choice (5)	○	○	○	○	○
Ask questions without feeling dumb (6)	○	○	○	○	○
Express my concerns about each option (7)	○	○	○	○	○
Ask for advice (8)	○	○	○	○	○
Figure out the option that best suits me (9)	○	○	○	○	○
Get my test results as quickly as possible (10)	○	○	○	○	○
Handle unwanted pressure from others in making my choice (11)	○	○	○	○	○
Let the clinic team know what's best for me (12)	○	○	○	○	○

Delay my decision if I feel I need more time (13)	○	○	○	○	○

End of Block: DSES after new

Start of Block: Family experience with cancer

Q127
In general, would you say your health is...

- ○ Excellent (1)
- ○ Very good (2)
- ○ Good (6)
- ○ Fair (7)
- ○ Poor (8)

Q128
How important is it that **you are screened for any of the types of cancer** listed below in your lifetime?

Please be sure to indicate the importance for each type of cancer by moving the slider to the right

Extremely unimportant Extremely important

0 10 20 30 40 50 60 70 80 90 100

Skin cancer ()	
Lung cancer ()	
Colon or rectal cancer ()	
Human-Papilloma (HPV) Related (anal, penile, cervical or head and neck) ()	
Breast cancer ()	
Any type of cancer ()	

Page Break

Q129 How much do you agree or disagree with each of the following statements?

	Strongly agree (1)	Somewhat agree (2)	Somewhat disagree (3)	Strongly disagree (4)
It seems like everything causes cancer (1)	○	○	○	○
There's not much you can do to lower your chances of getting cancer (2)	○	○	○	○
There are so many different recommendations about preventing cancer, it's hard to know which ones to follow (3)	○	○	○	○

Page Break

Q130
How likely are you to get cancer in your lifetime?

- ○ Very unlikely (1)
- ○ Unlikely (7)
- ○ Neither unlikely nor likely (8)
- ○ Likely (9)
- ○ Very likely (10)

Q131 In your own words, what makes somebody likely or unlikely to get cancer?

_____
_____
_____
_____
_____

Page Break

Q132
How worried are you about getting cancer?

- ○ Not at all (1)
- ○ Slightly (2)
- ○ Somewhat (3)
- ○ Moderately (4)
- ○ Extremely (5)

Q133 What makes you more or less worried about getting cancer?

_____
_____
_____
_____
_____

Page Break

Q134 In your own words, what does cancer mean to you?

_____
_____
_____
_____
_____

Q135 Have you ever been diagnosed as having cancer?

- ○ No (1)
- ○ Yes (what type) (2) _____

Q136 Have any of your family members ever been diagnosed as having cancer?

- ○ No (1)
- ○ Yes (what type) (2) _____
- ○ Not sure (3)

Q137 Has anybody **close to you** ever died of cancer?

- ○ No (0)
- ○ Yes (1)

Skip To: Q140 If Has anybody close to you ever died of cancer? = No

Q138 Who close to you has died of cancer?

_____

Q139 What type of cancer did they die from?

_____

Page Break

Q140
In your family or culture, are there any beliefs or values that influence how you think about cancer?

- ○ No (1)
- ○ Yes (2)

Display This Question:
If In your family or culture, are there any beliefs or values that influence how you think about can... = Yes

Q141 Please describe the family or cultural beliefs or values that influence how you think about cancer

_____
_____
_____
_____
_____

Page Break

Q142 Has your **partner or spouse** ever gotten tested for colon or rectal cancer?

- No (0)
- Yes (1)
- I don't know (2)

Q143 Has your **parent or guardian** ever gotten tested for colon or rectal cancer?

- No (0)
- Yes (1)
- I don't know (2)

Q144 Has anybody **else close to you** ever gotten tested for colon or rectal cancer?

- No (0)
- Yes (1)
- I don't know (2)

Display This Question:
If Has anybody else close to you ever gotten tested for colon or rectal cancer? = Yes
Or Has your parent or guardian ever gotten tested for colon or rectal cancer? = Yes
Or Has your partner or spouse ever gotten tested for colon or rectal cancer? = Yes

Q145 Who do you know that has gotten tested for colon or rectal cancer?

_____
_____
_____
_____

Display This Question:
If Has anybody else close to you ever gotten tested for colon or rectal cancer? = Yes
Or Has your parent or guardian ever gotten tested for colon or rectal cancer? = Yes
Or Has your partner or spouse ever gotten tested for colon or rectal cancer? = Yes

Q146 What test(s) did they get?

- ☐ Colonoscopy (1)
- ☐ Sigmoidoscopy (2)
- ☐ Fecal blood test (3)
- ☐ Fecal DNA test (4)
- ☐ Computed tomography colonography (CTC) (5)
- ☐ Double contrast barium enema (6)
- ☐ ⊗I don't know (7)
- ☐ ⊗None of these (8)

Q147 Which statement is **closest** to where you are now in your plans to get a screening test for colon or rectal cancer?

- ○ I have not thought about getting tested (1)
- ○ I think I need to consider getting tested (2)
- ○ I think I should get tested but I'm not quite ready (3)
- ○ I think I will probably get tested (4)
- ○ I am committed to getting tested (5)

Page Break

Q148 In your own words, has cancer impacted your life in any other way?

_____
_____
_____
_____
_____

Page Break

Q149 At what age should people begin to get screened for colon or rectal cancer?

_____

Page Break

Q150 On your last birthday, how old did you turn?

18 26 34 42 50 59 67 75 83 91 99

Age ()

Q151 Please enter your mTurk worker ID

_____

End of Block: Family experience with cancer

Appendix B: Descriptions of CRC and tests for AHP exercise

1. **Information about colorectal cancer and screening for colorectal cancer**

"Here is some information about colorectal cancer that we would like you to read:

- Colorectal cancer occurs when cell overgrowth occurs in the parts of the large intestine known as the colon or rectum.
- Development of colorectal cancer begins as a noncancerous growth or precancerous lesion, called polyps.
- Polyps are found in up to 30 to 40% of people by age 60 but only ~10% of polyps progress to cancer.
- However, over 95% of colorectal cancers begin as polyps.
- Polyps can develop into cancer over a period of 10 to 20 years.
- This is why screening for colorectal cancer is important
- **We are now going to have you read about 3 options for colorectal cancer screening and answer questions about your preferences**"

2. **Descriptions of screening strategies**

A. Test effectiveness:

Colonoscopy…	
Effectiveness	As a screening plan can reduce mortality by up to 85% over your lifetime
Prevention	Can detect polyps before they turn into cancer
Removal	Can remove polyps or cancer during the procedure
False-positive	Very unlikely to have an abnormal test if you do not have polyps or cancer

Fecal immunochemical test (FIT)…	
Effectiveness	As a screening plan can reduce mortality by up to 78% over your lifetime
Prevention	Can detect polyps before they turn into cancer if they are bleeding
Removal	Cannot remove polyps or cancer as part of the procedure
False-positive	Possible to have an abnormal test even if you do not have polyps or cancer

Computed tomography colonography (CTC)…	
Effectiveness	As a screening plan can reduce mortality by up to 80% over your lifetime
Prevention	Can detect polyps before they turn into cancer
Removal	Cannot remove polyps or cancer as part of the procedure
False-positive	Possible to have an abnormal test even if you do not have polyps or cancer

*Note: Mortality reduction estimates are derived from the CISnet modeling studies (participants not provided this reference)

Knudsen AB, Zauber AG, Rutter CM, et al. Estimation of benefits, burden, and harms of colorectal cancer screening strategies: modeling study for the US Preventive Services Task Force. JAMA. 2016;315:2595-2609.

B. Screening plan:

i. Follow up possibility:

Colonoscopy…	
Follow up procedure	No additional follow up procedures are required
Polyps	If polyps are found, they are removed and examined for cancer
Cancer	If cancer is suspected you will be referred to a specialist

Fecal immunochemical test (FIT)…	
Follow up procedure	If the test is not normal and blood is detected in your stool, you must get a follow up colonoscopy

Polyps	This test cannot confirm polyps, only a colonoscopy can confirm polyps
Cancer	This test cannot confirm cancer, only a colonoscopy can confirm cancer

Computed tomography colonography (CTC)…	
Follow up procedure	If your test is not normal, you must get a colonoscopy
Polyps	This test cannot confirm polyps, only a colonoscopy can confirm polyps
Cancer	This test cannot confirm cancer, only a colonoscopy can confirm cancer

ii. Frequency of testing:

Colonoscopy…	
Normal result	You should be tested again in **10 years**

Fecal immunochemical test (FIT)…	
Normal result	You should be tested again in **1 year**

Computed tomography colonography (CTC)…	
Normal result	You should be tested again in **5 years**

C. Features of the test:

i. Possibility for complications:

Colonoscopy…	
Minor risks	Abdominal discomfort, cramps, bloating or gas, and minor bleeding
Serious complications	Rare and include: major bleeding (requiring hospitalization or transfusion), adverse reaction to sedation, and perforation (tearing a hole) in your colon
Increased risk	Risk goes up when more polyps are removed and as you get older

Fecal immunochemical test (FIT)…	
Minor risks	Uneasiness or anxiety from handling stool
Serious complications	Has no serious complications
Increased risk	None

Computed tomography colonography (CTC)…	
Minor risks	Cramps, bloating or gas
Serious complications	Extremely rare and include: potential development of radiation related cancer
Increased risk	Risk goes up the more times you have the test

ii. Convenience:

Colonoscopy…	
Where	Must be done at a doctors office
Driver	You must have somebody to drive you home
Work	You must take a day off of work

Fecal immunochemical test (FIT)…	
Where	Is done at home
Driver	Does not require somebody to drive you home
Work	Does not require you to take a day off work

Computed tomography colonography (CTC)…	
Where	Must be done at a doctors office
Driver	Does not require somebody to drive you home
Work	Does not require you to take a day off work

iii. Preparation:

Colonoscopy…	
Diet	No food or liquids starting the day before your test
Laxative	Drink a total of 64oz of laxative medication starting the day before your test to clean out your colon
Bowel cleanliness	Laxatives will make you use the restroom until your bowels are clear

Fecal immunochemical test (FIT)…	
Diet	There are no dietary restrictions
Laxative	There is no laxative medication
Bowel cleanliness	You do not need clear bowels

Computed tomography colonography (CTC)…	
Diet	No food or liquids starting the day before your test
Laxative	Drink a total of 64oz of laxative medication starting the day before your test to clean out your colon
Bowel cleanliness	Laxatives will make you use the restroom until your bowels are clear

iv. Procedure:

Colonoscopy…	
Method	Performed by a doctor who inserts a scope is into your anus to view the entire colon
Sedation	Sedation is given to reduce or eliminate discomfort
Time for procedure	20-30 minutes for the procedure
Recovery	A recovery period (approximately 30-60 minutes) is necessary because of the sedation you receive
Purpose	Allows a doctor to visualize the lining of the whole colon to look for polyps or cancer

Fecal immunochemical test (FIT)…	
Method	Requires you to use a mini brush to collect stool into a tube at home that you mail in for testing
Sedation	No sedation
Time for procedure	5 minutes
Recovery	No recovery
Purpose	Detects microscopic blood in your stool which may be from polyps or cancer

Computed tomography colonography (CTC)…	
Method	Performed by a doctor and requires that you to lay in a CT scanner after drinking a contrast liquid and having air pumped into your anus using a small tube
Sedation	No sedation
Time for procedure	10-20 minutes
Recovery	No recovery
Purpose	Allows a doctor to use a CT scanner to make pictures of your whole colon and detect any polyps or cancer

Appendix C: IRB Documents

INITIAL APPLICATION PART 2

1. Abstract:

Recent work using the Surveillance, Epidemiology, and End Results (SEER) database indicates that the rates for colon and rectal cancer are increasing at an alarming rate in individuals under the age of 50. Because of this, The American Cancer Society gave a qualified recommendation for average risk adults to initiate colorectal cancer (CRC) screening at age 45. While a large body of literature on CRC screening exists, very few studies have focused on individuals under the age of 50 due to the previous, relative consensus on guidelines. In this dissertation I will explore research questions related to shared decision-making for colorectal cancer for people at average risk between the ages of 45 and 49 by recruiting 600 people age 45 to 55 using the Amazon MTurk system. MTurk is a crowdsourcing system that has been shown to be effective for collecting large amounts of reliable and valid research data.

I will answer the following research questions:
RQ1: Are people ages 45 to 49 able to correctly identify risk factors of CRC?
RQ2: What tests do individuals ages 45 to 49 prefer and what are these preferences based on?
RQ3: When making CRC screening decisions, what level of control (role preference) do people ages 45 to 49 prefer and do they feel confident in their ability to make decisions?

2. Subject Selection:

a. Recruitment: For this study, we plan to enroll adults age 45-55. Participants will be recruited through the Amazon Mechanical Turk (MTurk) system, a global workforce of people who complete tasks for compensation. Previous research using the MTurk population indicates that they provide reliable and valid data for survey research.

This study will screen for individuals living in the United States, mTurk worker qualifications, and age 45-55 using the mTurk system.

We will also screen to ensure that participants have never been screened for CRC. Additionally, the Qualtrics quota function will be used to ensure that age categories are even (45-49 and 50-55) and we will oversample for black/African American participants to ensure that we have power to detect differences in the highest risk race group.

Workers will self-select into this study by selecting (clicking) on the task containing the survey. After completing screening questions, eligible participants will proceed with the rest of the survey. Ineligible participants will be asked to

return the task per the task instructions that are provided in this IRB package (recruitment page and instructions). Once the quota for each category is filled, subsequent participants will be ineligible (not eligible message).

b. Eligibility Criteria: Eligibility criteria for the study include: age 45-55, living in the United States, able to adequately read and answer question in English, over 500 approved mTurk tasks, >95% mTurk task approval rating and never been screened for colon or rectal cancer.

The literature shows that setting eligibility criteria around mTurk worker features lead to higher quality data. That is why workers must have 500 completed and approved tasks with a >95% approval rating. We are requiring that participants have never been screened for colon or rectal cancer because many of the attitudes towards screening that we are measuring will be influenced by prior experience with the screening tests.

c. Rationale: The mTurk literature shows that placing restrictions around the minimum number of tasks and task approval rating lead to higher quality research data. All mTurk workers must be at least 18 years old and our survey will be conducted in English.

Participants must have never been screened for colon or rectal cancer because our primary research questions are around perceptions of screening exams that would be different in a sample that has already been screened.

d. Enrollment Numbers: The total enrollment for this study is 600 people in the final sample and 30 people for a pilot test.

e. Rationale for Enrollment Numbers: For RQ 1 and RQ3, in order to detect a small effect size (.2) using a linear regression, with .05 alpha, .2 beta and 8 predictors, I would need approximately 84 individuals in my sample. In order to detect a small effect size using logistic regression (OR=1.7), with .05 alpha, and .2 beta, I would need 184 individuals in my sample. However, because I am using a fixed sample of 600 individuals, I performed a sensitivity analysis using similar parameters to calculate the effect sizes that I could detect based on the sample size of 600. For logistic regression, I could detect an odds ratio of 1.33. For linear regression, I could detect an effect size of .02, which makes this study highly sensitive to small effect sizes.

3. Procedures:

Pilot Test:
We will conduct a pilot test with 30 mTurk workers to ensure that our survey measures are working as intended and that participants are able to complete measures with adequate accuracy and validity. The pilot test will be conducted

exactly the same as the full survey launch. Data from the pilot test will not be analyzed with the final sample.

Full Survey Launch:
Participants will select our task (HIT) from a list of available tasks on the MTurk platform (recruitment page and instructions). Participants will accept the task for the survey, read the consent document and give informed consent with a click. Participants who choose not to give consent will be thanked for their time. Participants that do give consent will then complete screening questions related to previous screening for CRC, race, sex, and age group (Thyams_CRC_screening_dissertation-1 IRB).

If eligible, participants will continue to complete the full survey (Thyams_CRC_screening_dissertation-1 IRB) Ineligible participants will be thanked for their time and asked to return the task as described in the instructions for accepting the task (recruitment page and instructions).

The survey will cover demographics, history and experience with cancer, preferences for screening tests, and knowledge/desired role in decision-making about screening for colon and rectal cancer. At the end of the survey, participants will be provided with a random code that they will use to paste into a text-box in the MTurk platform. (end of survey message) This code will be utilized to verify that the participant has completed the survey by matching the code with the one provided by Qualtrics. Participants who provide matching codes will be compensated for their work. Workers will be compensated approximately $4.00 for completion of the survey (15-20 minutes) at a living wage of approximately $15.00/hour. Final payment will be determined after an initial pilot test of 30 individuals where we will assess how long participants take to complete the task, on average.

4. Risks:

This survey will ask questions about sensitive topics including past history with cancer, perceptions about cancer screening, and decisions around screening for cancer. Participants may feel uncomfortable or embarrassed answering these questions. However, participants will be informed, and voluntariness of questions will be reiterated so participants can be sure that they may skip questions that they do not wish to answer. Additionally, they can choose to discontinue the survey at any time they wish if they feel uncomfortable or for any other reason.

5. Benefits:

We do not anticipate any direct benefits from study participation. Results from the analysis of these data will help inform potential changes to colorectal cancer screening programs that incorporate individuals between 45-49. If differences are found in knowledge and preferences in these age groups, screening programs can be tailored to address these unique needs in the younger age group.

6. Confidentiality:

This study will not collect any Personally identifiable information such as names or address. We will collect zip code data but there will be no way to link these data to individuals. Qualtrics survey data will be password protected and requires the UMD multi-factor identification to log in. Data will be stored in the Qualtrics data base until downloaded by the investigators onto a password protected device. Only the investigators of this study that have been approved by the IRB will have access to raw data.

Payment will be provided through a randomized confirmation code at the end of the survey. When participants enter this code into the MTurk system, the provided code and entered code will be compared. If the information matches, participants will be provided compensation for their work. MTurk allows you to set the amount of time it will take for workers to be paid automatically (without code comparison). We will set this time to 7 days to give our research staff enough time to compare worker codes and approve payment.

The MTurk system provides each individual worker with a unique identification code (Worker ID). In theory, this ID could be linked to a worker's public Amazon account which may contain personal information. To safeguard against this, the investigators will only use the worker ID to accurately provide payment to workers after survey completion. Once the worker is paid, the confirmation code will be deleted from the data set. The MTurk system allows you to contact workers after they complete your task through the system through email. We will not be contacting workers after they submit responses.

To ensure that people are only allowed to take the survey one time, a script will be embedded into the MTurk survey builder from (https://uniqueturker.myleott.com/.). This script will block individuals who attempt to take the survey multiple times.

7. Consent Process:

Since there is no more than minimal risk (section 4) involved, we will utilize a modification of informed consent for this study. Participants will click to consent in lieu of a written signature. The informed consent text can be found within the survey attached to this IRB package (Thyams_CRC_screening_dissertation-1 IRB). This document can be found as supplemental material in this IRB package. This document will appear in the main survey, before participants answer any questions.

This survey asks about sensitive questions. However, participants will be given several notifications that all questions are voluntary and that they may stop at any time. Participants will read a document about the risks and benefits of the study

and will click to give consent instead of signing a consent document.

A consent modification is appropriate given the following rationale:

1. There is no more than minimal risk to participants. They may feel uncomfortable answering questions, but they will be encouraged to skip any questions that they do not feel comfortable answering.

2. A click consent will also not adversely affect the rights and welfare of the research participants. This is because any information linking their data to their Amazon profile will be deleted once they have been provided payment.

3. A click consent, rather than a signed consent document is appropriate given the online nature of this work, and the efficient work-environment that the MTurk users are working in. Obtaining a signature for consent would be inefficient and impractical for these workers.

4. There is no deception used in this study. We have no need to withhold, or give false or misleading information to participants in order to complete this study.

8. Conflict of Interest:

No conflicts of interest to report

9. HIPAA Compliance:

This research is HIPAA compliant because it will not collect any personally identifiable health information

10. Research Outside of the United States:

Not applicable

11. Research Involving Prisoners:

Not applicable

12. SUPPORTING DOCUMENTS

Your Initial Application must include a **completed Initial Application Part 1 (On-Line Document),** the information required in items 1-11 above, and all relevant supporting documents including: consent forms, letters sent to recruit participants, questionnaires completed by participants, and any other material that will be presented, viewed or read to human subject participants.

The consent forms in your approved IRBNet PACKAGE must be used. When creating or editing your consent form, please provide the most

recent IRBNet package number at the bottom, right corner of the consent form. This ensures you are using the most "up-to-date" version of the form.

To find your IRBNet package number, go to the MY PROJECTS tab and click on the title of your project. In the PROJECT OVERVIEW page, your IRBNet package number will be listed at the top, next to your project title.

UNIVERSITY OF MARYLAND
INSTITUTIONAL REVIEW BOARD

1204 Marie Mount Hall
College Park, MD 20742-5125
TEL 301.405.4212
FAX 301.314.1475
irb@umd.edu
www.umresearch.umd.edu/IRB

DATE:	December 2, 2019
TO:	Travis Hyams, MPH
FROM:	University of Maryland College Park (UMCP) IRB
PROJECT TITLE:	[1519566-1] Colorectal Cancer Screening in Individuals ages 45 to 49
REFERENCE #:	
SUBMISSION TYPE:	New Project
ACTION:	DETERMINATION OF EXEMPT STATUS
DECISION DATE:	December 2, 2019
REVIEW CATEGORY:	Exemption category # 2

Thank you for your submission of New Project materials for this project. The University of Maryland College Park (UMCP) IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact the IRB Office at 301-405-4212 or irb@umd.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

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