

Eliciting vulnerable patients' preferences regarding colorectal cancer screening: a systematic review

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Background: Patient preferences are important to consider in the decision-making process for colorectal cancer (CRC) screening. Vulnerable populations, such as racial/ethnic minorities and low-income, veteran, and rural populations, exhibit lower screening uptake. This systematic review summarizes the existing literature on vulnerable patient populations' preferences regarding CRC screening.

Methods: We searched the CINAHL, PsycINFO, PubMed, Scopus, and Web of Science databases for articles published between January 1, 1996 and December 31, 2017. We screened studies for eligibility and systematically abstracted and compared study designs and outcomes.

Results: A total of 43 articles met the inclusion criteria, out of 2,106 articles found in our search. These 43 articles were organized by the primary sub-population(s) whose preferences were reported: 27 report on preferences among racial/ethnic minorities, eight among low-income groups, six among veterans, and two among rural populations. The majority of studies (n=34) focused on preferences related to test modality. No single test modality was overwhelmingly supported by all sub-populations, although veterans seemed to prefer colonoscopy. Test attributes such as accuracy, sensitivity, cost, and convenience were also noted as important features. Furthermore, a preference for shared decision-making between vulnerable patients and providers was found.

Conclusion: The heterogeneity in study design, populations, and outcomes of the selected studies revealed a wide spectrum of CRC screening preferences within vulnerable populations. More decision aids and discrete choice experiments that focus on vulnerable populations are needed to gain a more nuanced understanding of how vulnerable populations weigh particular features of screening methods. Improved CRC screening rates may be achieved through the alignment of vulnerable populations' preferences with screening program design and provider practices. Collaborative decision-making between providers and vulnerable patients in preventive care decisions may also be important.

Keywords: colorectal cancer screening, systematic review, vulnerable populations, patient preference

Introduction

Colorectal cancer (CRC) is the third most common type of cancer and the second leading cause of cancer deaths in the US. In 2017, there were an estimated 135,430 new cases diagnosed and 50,260 CRC-specific deaths nationally.¹ Annually, CRC costs the US healthcare system approximately \$14 billion.² Screening has been shown to reduce CRC incidence and mortality by 30%–60% and has the potential to save an estimated 18,800 lives per year.^{3,4} Since early stage CRC is asymptomatic, screening is especially important for early detection and appropriate treatment.⁵ The US Preventive Services Task Force (USPSTF) has recommended screening using colonoscopy, sigmoidoscopy,

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or fecal testing, such as fecal occult blood testing (FOBT) and fecal immunochemical testing (FIT), at appropriate intervals (eg, colonoscopy every 10 years, sigmoidoscopy every 5 years, fecal testing annually), for average-risk adults aged 50–75 years.⁶ Colonoscopy and fecal testing are the most commonly used modalities in the US.⁷

The US has seen an increase in CRC screening over time, yet the 2015 national rate of 62.6% is well below the Healthy People 2020 target of 70.5% set by the US Department of Health and Human Services.^{8,9} CRC screening rates are particularly low within many vulnerable sub-populations, including racial and ethnic minorities and foreign-born, low-income, publicly insured, uninsured, veteran, disabled, lesbian, gay, bisexual, transgender, queer (LGBTQ), and rural populations.^{10–15} Lack of consideration of patient preferences is one of several factors contributing to lower screening rates.¹⁶ To improve uptake, communication between providers and patients about decision alternatives, preferences, and risk–benefit tradeoffs is important.¹⁷ Shared decision-making, in which the provider and patient work together to agree upon an optimal decision, has been increasingly recommended for screening.¹⁸ Considerations for CRC screening include test characteristics, such as accuracy, invasiveness, and comfort, and delivery characteristics, including cost, convenience, and ease of access.¹⁹ For example, some patients may prefer fecal testing, due to its non-invasive nature and low cost. Presenting choices that match individuals' preferences may increase CRC screening uptake.

Systematic reviews have previously assessed CRC screening preferences within the general population and found that while accuracy and clinical effectiveness are valued, there is not an overwhelming preference for a single modality.^{20–22} Given that vulnerable populations screen at lower rates and face greater barriers to preventive care, their CRC screening preferences may differ in important ways.^{23–27} Thus, a better understanding of preferences among vulnerable populations is needed to inform interventions and policies that aim to increase their CRC screening rates. To do this, we conducted a systematic review with the objective of capturing the preferences of vulnerable populations with respect to CRC screening. We aimed to capture all aspects of preference in the context of screening, such as modality, test attributes, and program features. To our knowledge, this is the first systematic review to address CRC screening preferences specifically among vulnerable patients.

Methods

We conducted a systematic review according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.²⁸ We adapted the Population, Intervention, Comparison, Outcome, Time (PICOT) framework, adding in both study setting and design, to identify the studies of interest in this review.²⁹ Since the PICOT framework is often used in the context of eliciting the effect of a treatment, and we were interested in reviewing a wide range of study types, some of which did not include a specific intervention, we omitted the intervention component of the framework. Table 1 outlines

Table 1 Inclusion/exclusion criteria

Criterion	Inclusion	Exclusion
Population	Vulnerable patient populations <ul style="list-style-type: none"> • Rural residents • Racial/ethnic minorities • Low-income populations • Limited English proficiency (LEP) or non-English speaking • Immigrants/foreign-born • Disabled • Lesbian, gay, bisexual, transgender, queer (LGBTQ) populations • Medicaid enrollees • Dually insured (Medicare/Medicaid) • Uninsured • Veterans 	All other non-vulnerable patient populations
Comparison	Modalities of CRC screening as well as screening program delivery features and other attributes	All other comparisons
Outcome	Patient-level CRC screening preferences related to test modalities, test features, incentives, screening program design, service delivery, source of information, communication method	All other outcomes
Time	Articles published from January 1, 1996 to December 31, 2017	Articles published outside of this time period
Setting	All developed country settings (including international studies)	Developing countries
Study design	Quantitative (including discrete choice experiments/conjoint analyses), qualitative, and mixed-methods	Literature reviews, systematic reviews

the inclusion and exclusion criteria for this review based on the adapted PICOT framework.

We focus our review on vulnerable populations who experience widely observed health disparities and are at risk for poor quality of care and poor health outcomes due to non-clinical, discriminatory, and marginalizing factors.^{30–34} The National Academy of Medicine (formerly Institute of Medicine) and Agency for Healthcare Research and Quality have, for decades, placed elimination of health disparities at the center of healthcare quality initiatives, noting that high-quality care should not be differentially received by people because of race, ethnicity, gender identity, sexual preference, geography, or socioeconomic status.^{35–38} The US Department of Health and Human Services (HHS) Office of Minority Health describes a health disparity as “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage.”^{39,40} HHS characterizes underserved, vulnerable, and special need populations as communities that include members of minority populations or individuals who have experienced health disparities, specifically Latinos, African Americans, American Indians/Alaska Natives, refugees/migrants, individuals with Limited English Proficiency (LEP), uninsured, low-income, rural, LGBT, and disabled people, including disabled veterans, as well as pregnant women and children.^{39,40} We adopt this inclusive definition of “vulnerable and medically underserved”

populations in our review, excluding pregnant women and children, who are not age-eligible for CRC screening and therefore not relevant to this review.

Since little was known about the literature addressing vulnerable patients' CRC screening preferences, including the types of preferences assessed, we attempted to cast a wide net on this topic. We included all articles that met our review criteria with a variety of study designs (eg, observational and experimental) because our goal was to understand vulnerable patients' preferences about CRC screening generally. That is to say, we did not constrain our review to specific aspects of preferences, such as preference tradeoffs or changes in preference as a result of experimental intervention; both of these types of articles were viewed as relevant and within scope.

We searched the PubMed, CINAHL, PsycINFO, Scopus, and Web of Science databases for articles published from January 1, 1996 to December 31, 2017 (Figure 1). We selected this timeframe because the USPSTF released its first CRC screening guidelines in December 1995.⁴¹ The following search string was used to identify relevant articles: ((“colorectal” AND “cancer” OR “colon” AND “cancer”) AND (“screening” OR “detection” OR “testing” OR “test”) AND ((“preference” OR “preferences” OR “perception” OR “perceptions”) OR (“discrete” AND “choice”) OR (discrete AND choices))) AND PUBYEAR > 1995.

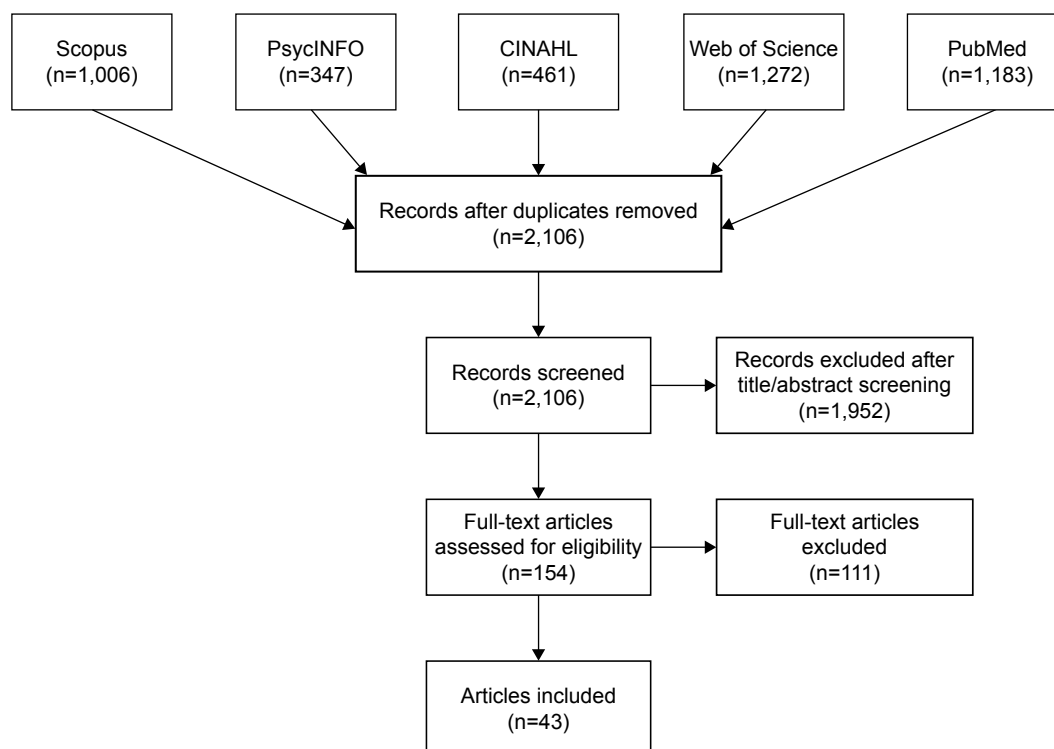


Figure 1 PRISMA Flow Diagram.

Since our goal was to capture a range of vulnerable populations, we did not list the particular populations of interest, as identified in Table 1, in this initial search string. This strategy allowed us to discern whether vulnerable populations were included in each article rather than exclude studies outright that failed to mention a specific term that we associated with “vulnerable” or “underserved.” Studies from the US and other developed country contexts that comprised subgroup analyses regarding screening preferences for one or more vulnerable populations were eligible for inclusion.

In total, 4,269 articles were initially identified and imported into F1000 Workspace (Faculty of 1000 Ltd, 2018), a reference management database. After duplicates were removed, 2,106 articles were transferred to Covidence (Veritas Health Innovation Ltd, 2018) to be screened.

Using Covidence, two reviewers (SL and MO) independently screened the titles and abstracts of the articles for patient-level studies focused on CRC screening. The reviewers began with a small pool of 20 articles to ensure consistency and to refine the inclusion/exclusion criteria. These reviewers resolved any discrepancies in their ratings and, when a consensus could not be reached, a third reviewer (SW) assessed the article and made the final decision. These same procedures were then used to review the titles and abstracts of the remaining articles. In this initial phase, we excluded articles that were not related to CRC screening, such as studies about other health conditions, CRC studies regarding treatment, survivorship, or genetics, and non-patient-level CRC studies (eg, provider-only interventions). This strategy provided the opportunity to review the full-text of CRC screening studies to consider if a sub-population analysis was included and if a preference-related outcome was measured, even if the larger objective of the article was not specific to these areas. During the title/abstract screening process, 1,952 articles were removed, leaving 154 full-text articles to be reviewed.

During the full-text review, the reviewers assessed whether each article should be included or excluded according to the criteria outlined in Table 1 and categorized the excluded articles by reason for exclusion. Discrepancies regarding whether the article should be included or excluded, as well as the reason for exclusion, were resolved by the two reviewers (SL and MO) with the third reviewer (SW) making the final decision about any remaining discrepancies. Of the 154 full-text articles, 111 were excluded, most commonly because they did not provide a subgroup analysis for a vulnerable population ($n=70$). The other primary reasons for exclusion were outcomes outside the scope of this

analysis, such as the reporting of screening behaviors without addressing patient preferences ($n=20$), the wrong study design including systematic and literature reviews ($n=16$), duplicate studies ($n=3$), non-English publications ($n=1$), and publication dates outside the study window ($n=1$).

The two reviewers abstracted the data from the included articles into a literature matrix using Microsoft Excel 2010 (Microsoft Corporation, Redmond, WA). The literature matrix included more than 20 structured fields such as title, study design, US or international study, sub-population studied, total sample size and the sample size of the vulnerable patients, baseline population characteristics (eg, age, sex, race), outcome measure, and findings. For the studies in which an intervention was implemented, we also reported the type of intervention, mode of delivery, and who conducted the intervention. Given the number of metrics and heterogeneity across studies, in this paper we report the primary type of vulnerable population included in each article, study objective, study design, sample sizes of the total and vulnerable populations, outcome measured, and findings to provide an understanding of the breadth of research currently available on vulnerable patients' preferences.

Results

A total of 43 articles that addressed patient preferences regarding CRC screening among vulnerable groups are included in this systematic review. The selected articles are organized by the types of vulnerable population(s) whose preferences are reported. Of these studies, 27 reported preferences among racial/ethnic minorities, eight among low-income groups, six among veterans, and two among rural populations. Notably, many studies elicited preferences from more than one underserved population, since these categories are not necessarily mutually exclusive. For example, studies often included racial or ethnic minorities as well as low-income individuals. In this analysis, studies were categorized based on the vulnerable population prioritized during sampling and analysis.

Grouping by outcomes or study design, rather than sub-population of interest, was considered, but we ultimately decided that categorizing by sub-population would better assist public health practitioners and researchers in designing interventions for these specific sub-groups. However, within each section, we organized the study results by outcome. Of the 43 studies, 34 measured preference in terms of modality, displaying a marked tendency to focus on modality rather than other aspects of preference within research; 23 measured preference in terms of test attributes. The other types of

preferences assessed were source of information (n=2), type of decision-making (n=2), program delivery (n=2), expert recommendation (n=1), willingness to pay (WTP; n=1), and provider characteristics (n=1).

Racial/ethnic minorities (n=27)

Twenty-seven articles reported CRC screening preferences for a single or multiple racial/ethnic minority groups (Table 2).^{42–68} Out of these studies, nine were conducted among African Americans,^{42,44,48,49,54,57–59,61} five among Hispanics/Latinos,^{47,53,55,62,68} eight among both African Americans and Hispanics/Latinos,^{43,45,50,51,63–66} four among non-whites,^{46,56,60,67} and one among Korean Americans.⁵² Race was self-reported in nearly all of these articles, except for a study in which recruitment was conducted at a community-based organization serving Korean Americans,⁵² a study that used health insurance claims data with enrollment database-reported race/ethnicity,⁵⁹ and a study that did not clearly specify how race/ethnicity was obtained.⁶³ In terms of outcomes, 22 studies reported preferences in terms of test modality and/or specific test attributes.^{42–46,48–51,53,56–67} Of the remaining five articles, two examined preferences regarding shared decision-making,^{54,55} two investigated preferred sources of information,^{47,52} and one considered preference for the sex and ethnicity of endoscopists.⁶⁸

Screening modality

There was a significant variation in the preferred screening modality within the studies primarily focused on minority racial and ethnic groups. Five papers reported colonoscopy as the preferred test, six studies reported fecal testing as the preferred screening method, four studies found mixed or inconclusive results, and five studies found that race/ethnicity was not associated with preferred modality. Of those who reported colonoscopy as the preferred test, four focused on African Americans only,^{48,57,58,61} and one included both African Americans and Hispanics.⁴⁵ Of the six studies that reported fecal testing as the preferred screening method, two studies reported a preference for home-based fecal tests over colonoscopy among multiracial/multiethnic groups,^{43,67} one study reported a preference specifically for FOBT among minority racial groups,⁴⁶ one study reported a preference specifically for FIT among African Americans,⁴⁹ and two studies, one among African Americans⁴² and one among a non-white study population⁶⁰ identified stool-based DNA testing as the preferred option. Finally, of the five studies that found that race/ethnicity was not associated with preferred test modalities, four found colonoscopy as the preferred

screening test in the general population;^{44,50,56,59} the remaining study found that FOBT was preferred over colonoscopy in the general population.⁶⁶

Test attributes

Nine articles reported attributes that racial and ethnic minority patients value in particular CRC screening tests or programs.^{42,45,51,53,57,61,63,65,66} Test accuracy was commonly reported as an important attribute, regardless of the preferred test or particular group.^{42,45,51,57,61,63} For example, although Hawley et al found differences in the preferred modality between African Americans, Hispanics, and whites, accuracy was rated as the most important attribute across all groups.⁵¹ Accuracy was also an influential factor among African Americans who preferred sDNA,⁴² as well as African Americans who preferred colonoscopy.⁶¹ Palmer et al reported that accuracy and thoroughness were the most positive attributes of colonoscopy, while test ease and non-invasiveness were viewed as the best attributes of FOBT for African Americans.⁵⁷ Similarly, Chablani et al found that the most preferred attribute of colonoscopy is test accuracy, whereas the top attribute of Cologuard is the lack of preparation needed, in a sample of African Americans and Hispanics.⁴⁵ Among African Americans, Hispanics/Latinos, and whites who prefer FOBT, convenience was identified as the most important attribute.⁶⁶ A discrete choice experiment conducted among Latinos determined that patients in the study were more concerned about the costs of screening and any required follow-up care than the type of modality used or the amount of time required for travel.⁵²

This review also highlighted some differences in perceptions regarding test attributes between racial and ethnic groups. Although African Americans and Hispanics/Latinos both ranked accuracy and comprehensiveness of the test as two of the most important features, African Americans were also concerned about discomfort and potential complications, while Hispanics/Latinos focused on the extent of scientific evidence available.⁶³ African Americans were more likely to be embarrassed by stool-based DNA testing than whites,⁴² and less likely to associate low cost with SEPT9 blood testing, and to consider the frequency of each test as important to decision-making, compared to whites and Hispanics/Latinos.^{51,63}

Source of information

Two articles addressed minority patients' preferences for their source of information regarding CRC screening.^{47,52} Jo et al conducted interviews among Korean Americans and

Table 2 Characteristics of studies with racial/ethnic minorities

Study	Objective	Vulnerable population	Study design	Total sample size	Size of vulnerable population	Outcome measured	Findings
Abola et al (2015) ⁴²	To assess patients' perceptions of the sDNA test and if perceptions vary by race	African Americans	Survey	423	127	Screening test modality preference (colonoscopy or sDNA); test attribute preferences	Both African Americans and whites preferred sDNA. More African Americans than whites preferred a colonoscopy. African Americans perceived sDNA to be more accurate but were more embarrassed by it
Brenner et al (2016) ⁴³	To test the effect of a CRC screening decision aid on screening-related communication and decision-making within primary care	Hispanics/Latinos & African Americans	RCT	262	204 ^a	Screening test modality preference (colonoscopy or FOBT/FIT)	Preference for FOBT/FIT over colonoscopy among both the intervention (67.1% vs 26.0%) and control (45.8% vs 22.2%) groups, with the intervention arm more likely to state a preference than the control arm (93.1% vs 68.0%)
Calderwood et al (2011) ⁴⁴	To assess patient preferences for CRC screening modalities using a decision aid within primary care	African Americans	Survey	100	73	Screening test modality preference (colonoscopy, FOBT, sDNA, or CTC)	Race was not associated with test preference. Among the total study population, 59% preferred colonoscopy, 17% preferred FOBT, 14% preferred sDNA, and 10% preferred CTC
Chabiani et al (2017) ⁴⁵	To assess patient preferences for CRC screening modality, identify the test attributes that influence preferences, assess the strength of preferences, and determine if preference varies by patient characteristics	Hispanics/Latinos & African Americans	Survey	90	90	Screening test modality preference (colonoscopy, FIT, CTC, or Cologuard)	Colonoscopy (64.4%) and Cologuard (31.1%) preferred over CTC (2.2%) and FIT (2.2%). The most common reason for preference for colonoscopy was its accuracy for detecting CRC, while the lack of preparation needed was the most common reason for Cologuard preference
Debourcy et al (2008) ⁴⁶	To determine CRC test preference after reviewing a written presentation of CRC screening modalities and potential differences by participant characteristics	Non-white	Survey	323	154	Screening test modality preference (colonoscopy or FOBT)	Minority race/ethnicity was associated with a preference for FOBT over colonoscopy. In multivariate analysis, the preference for FOBT over colonoscopy was greater among Latinos than non-Latino whites
Ellison et al (2011) ⁴⁷	To identify preferred sources of information about CRC screening	Hispanic/Latinos	Survey	395	395	Preference for source of information	Top four preferred sources of information: doctor/provider (99%), health brochures (84%), television (80%), and someone who speaks the same language (80%)
Greiner et al (2005) ⁴⁸	To explore CRC screening knowledge, attitudes, barriers, and preferences in order to develop culturally appropriate interventions	African Americans	Focus groups	55	55	Screening test modality preference (colonoscopy, sigmoidoscopy, or FOBT)	Following an educational lecture, 33% of the participants preferred colonoscopy and 26% preferred FOBT. The rest would follow their doctors' recommendation

Harden et al (2011) ⁴⁹	To explore knowledge, beliefs, and attitudes about CRC screening, particularly FIT, in order to design an FIT screening intervention	African Americans	Focus groups	28	28	Screening test modality preference (colonoscopy, FIT, or FOBT)	FIT was preferred over colonoscopy and FOBT. Compared to FOBT, FIT was preferred because it requires no food restrictions
Hawley et al (2012) ⁵⁰	To examine associations between psychosocial variables and CRC test preference, and to assess the concordance between the type of test preferred and completed	Hispanics/Latinos & African Americans	Randomized experiment	1,224	796	Screening test modality preference (colonoscopy, FOBT, sigmoidoscopy, or barium enema)	Race was not associated with test preference. Among the total study population, 41.1% preferred colonoscopy, 34.7% preferred FOBT, 12.7% preferred sigmoidoscopy, 5.7% preferred barium enema, and 5.8% did not report a preference
Hawley et al (2008) ⁵¹	To describe variation in CRC screening preferences within primary care	Hispanics/Latinos & African Americans	Conjoint analysis	212	138	Screening test modality preference (colonoscopy, FOBT, sigmoidoscopy, barium enema, FIT, or virtual colonoscopy); test attribute preferences	Hispanics were more likely to prefer FOBT and barium enema, whereas African Americans were more likely to prefer sigmoidoscopy and virtual colonoscopy, as compared to whites. All racial/ethnic groups rated accuracy as the most important CRC testing attribute. More African Americans rated the frequency of the test as important compared to other groups
Jo et al (2008) ⁵²	To understand predictors, facilitators, barriers, and intervention preferences regarding CRC screening in order to inform future interventions	Korean Americans	Interviews	151	151	Preference for source of information	An educational seminar (42%) was the most preferred source of information, followed by the Korean media (30%) and print materials (20%)
Martens et al (2016) ⁵³	To understand screening program characteristics and preferences and to assess CRC screening barriers and facilitators	Hispanics/Latinos	DCE	38	38	Preference for screening program design/delivery, including screening modality options, travel time, money paid for screening, and the portion of the cost of follow-up care paid out of pocket	Being given a choice between two or three CRC screening tests was preferred over either colonoscopy or the stool test alone. Costs of the screening test and follow-up care were more important than having testing modality options or travel time
Messina et al (2005) ⁵⁴	To assess consistency between patient preferences for participation in screening decisions and their usual decision-making practices and potential differences by participant characteristics	African Americans	Survey	2,119	122	Decision-making preferences	Being African American vs white was associated with a greater likelihood of a preference for shared decision-making with the provider vs making all decisions independently
Molokwu et al (2017) ⁵⁵	To describe general decision-making preferences	Hispanics/Latinos	Survey	780	780	Decision-making preferences	A collaborative decision-making role (53.3%), compared to a passive (26.4%) or active role (20.3%), was preferred by the majority of the study population

(Continued)

Table 2 (Continued)

Study	Objective	Vulnerable population	Study design	Total sample size	Size of vulnerable population	Outcome measured	Findings
Myers et al (2008) ⁵⁶	To determine the impact of tailored navigation on CRC screening within primary care	Non-white	Survey	154	29	Screening test modality preference (colonoscopy or FOBT)	Race was not associated with test preference. Among the total study population, colonoscopy was preferred over FOBT
Palmer et al (2010) ⁵⁷	To understand the influence of test attributes on CRC screening modality preferences	African Americans	Interviews	60	60	Screening test modality preference (colonoscopy, sigmoidoscopy, FOBT, or barium enema); test attribute preferences	Colonoscopy (57%) preferred over FOBT (43%), with no participants preferring barium enema or sigmoidoscopy. The preferred attributes of colonoscopy included its thoroughness and accuracy, whereas the preferred attributes of FOBT included the ease of the test and its non-invasiveness
Ruffin et al (2009) ⁵⁸	To assess the most and least preferred CRC screening tests by participant characteristics in order to develop a web-based decision-making tool	African Americans	Survey + focus groups	93	51	Screening test modality preference (colonoscopy, sigmoidoscopy, FOBT, or DCBE)	More whites than African Americans preferred FOBT, whereas more African Americans than whites preferred colonoscopy. Among African Americans, the most preferred test was colonoscopy, and the least preferred was DCBE
Schroy et al (2011) ⁵⁹	To assess the effectiveness of a decision aid on shared decision-making within primary care	African Americans	RCT	666	418	Screening test modality preference (colonoscopy, sigmoidoscopy, FOBT, sigmoidoscopy + FOBT, DCBE, or no preference)	Race was not associated with test preference for colonoscopy vs FOBT. Among the total study population, colonoscopy was preferred (59%), followed by FOBT (26%)
Schroy and Heeren (2005) ⁶⁰	To compare patient perceptions of CRC screening tests and elicit preferences	Non-white	Survey	3,359	358	Screening test modality preference (colonoscopy, FOBT, or sDNA)	sDNA preferred (42.5%) over FOBT (30.5%) or colonoscopy (27.0%) among the non-white population
Schroy et al (2007) ⁶¹	To assess patient preferences given media attention about colonoscopy and the introduction of sDNA testing	African Americans	Survey	263	92	Screening test modality preference (colonoscopy, FOBT + sigmoidoscopy, DCBE, or sDNA); test attribute preferences	African Americans were more likely to prefer colonoscopy and value test accuracy
Sheikh et al (2004) ⁶²	To identify patient attitudes and beliefs about screening tests and assess the potential impact of public education and targeted interventions	Hispanics/Latinos	Survey	193	38	Screening test modality preference (colonoscopy, sigmoidoscopy, or FOBT)	Hispanics were more likely to prefer no screening and to prefer sigmoidoscopy over colonoscopy, compared to non-Hispanics
Shokar et al (2010) ⁶³	To describe patient test preferences and to identify test attributes that influence their decision-making	Hispanics/Latinos & African Americans	Cognitive ranking tests	168	108	Test attribute preferences for colonoscopy, sigmoidoscopy, FOBT, or barium enema	African Americans ranked accuracy, amount of colon examined, discomfort,

								and complications as most important. Hispanics considered accuracy, scientific evidence available, and amount of colon examined to be the most important attributes
Shokar et al (2005) ⁶⁴	To assess knowledge, attitudes, and beliefs about cancer, CRC, and CRC screening test preferences	Hispanics/ Latinos & African Americans	Interviews	30	20	Screening test modality preference (colonoscopy, sigmoidoscopy, FOBT, barium enema, any modality, no test, or up to doctor)	The most preferred test was FOBT (n=4) for African Americans and colonoscopy (n=5) for whites, but there was no clear preference for Hispanics, who selected colonoscopy (n=3), FOBT (n=2), or had no preference (n=2)	
Taber et al (2014) ⁶⁵	To examine attitudes about the SEPT9 blood test	Hispanics/ Latinos & African Americans	Survey	100	62	Screening test modality preference (colonoscopy, sigmoidoscopy, FOBT, or SEPT9 blood test)	Among unscreened individuals, Hispanics were less likely to prefer SEPT9 blood testing than whites, but more likely to prefer SEPT9 than African Americans. Unscreened African Americans were least likely to identify low cost as a positive SEPT9 attribute. Unscreened African Americans were more likely to prefer colonoscopy than unscreened Hispanics and even more likely than unscreened whites	
Wolf et al (2006) ⁶⁶	To understand patient preferences for CRC screening and how these preferences translate into test performance	Hispanic/ Latinos & African Americans	Survey	216	164	Screening test modality preference (colonoscopy, FOBT, or no preference); test attribute preferences	Race was not associated with test preference. FOBT preferred over colonoscopy by the majority of the study population, including blacks, Hispanics, and whites. Among those who preferred FOBT, the main reason was convenience	
Wolf et al (2016) ⁶⁷	To examine the role of patient test preference and CRC screening uptake	Non-white	Survey	453	330	Screening test modality preference (colonoscopy or home stool test)	Home stool test preferred over colonoscopy more often among whites (69%) compared to non-whites (52%)	
Zapatier et al (2011) ⁶⁸	To evaluate sex and ethnicity preferences for endoscopists	Hispanics/Latinos	Survey	438	195	Sex and ethnicity preference for endoscopist providers	Hispanic women were more likely to prefer sex of endoscopist to be female. Hispanics were more likely to prefer ethnicity of endoscopist to be Hispanic	

Note: *The size (absolute number) of the vulnerable population is estimated based on percentages available in the study.

Abbreviations: CT C, computed tomographic colonography; DCBE, double-contrast barium enema; DCE, discrete choice experiment; FIT, fecal immunochemical testing; FOBT, fecal occult blood test; RCT, randomized controlled trial; sDNA, stool DNA testing.

determined that study participants had the strongest desire to learn from an educational session, followed by the Korean media and print materials.⁵² In surveys with Hispanic/Latino patients, Ellison et al found that the preferred sources of information included providers, health brochures, television, and someone who speaks the same language.⁴⁷ Therefore, there is evidence to suggest that ethnic minority patients look to cultural sources for resources related to preventive care.

Decision-making process

The two articles that studied decision-making preferences indicated the importance of shared decision-making for CRC screening among African Americans⁵⁴ and Hispanics/Latinos.⁵⁵ For example, Molokwu et al found that over half of the Hispanic/Latino participants preferred a collaborative role, rather than a passive or active role, in the decision-making process.⁵⁵ Similarly, Messina et al determined that African Americans, as compared to whites, would rather engage in shared decision-making than make CRC screening decisions independently.⁵⁴

Provider demographics

Zapatier et al found that Hispanics overall exhibited a preference for the sex and ethnicity of endoscopist.⁶⁸ In particular, Hispanic women prefer to have a female endoscopist and Hispanics regardless of sex prefer to have an endoscopist who is also Hispanic.⁶⁸

Low-income populations (n=8)

Eight articles reported CRC screening preferences among low-income populations (Table 3).^{69–76} Six of these studies were conducted in an international setting,^{69,70,72–75} and two were conducted domestically.^{71,76} Four studies reported monthly incomes,^{69,72,74,75} two studies reported annual incomes,^{70,76} one study used social grade as a proxy for socioeconomic status,⁷³ and one study only included participants with an annual household income <150% of the federal poverty level (FPL).⁷¹ Since the studies were conducted in different settings, most did not use a standardized threshold for defining low income, such as a percentage of the FPL. With the exception of Quick et al,⁷¹ we instead included studies that provided a subgroup analysis by income or social grade and focused on the results for the lowest income or social grade category.

Six of the eight studies focused on preference of FIT over colonoscopy,^{69,71,72,74–76} while the other two studies focused on WTP⁷⁰ and preference for an expert recommendation.⁷³ In the WTP study, Frew et al found that low-income patients had lower WTP values for CRC screening and higher-income

patients had higher WTP values.⁷⁰ Quick et al pointed to a possible relationship between lower income and colonoscopy preference.⁷¹ Yet, Wong et al showed that low-income participants were more likely to shift preference from colonoscopy to FIT after an educational session,⁷⁵ and two other studies found higher income to be associated with colonoscopy preference.^{69,76} In contrast, Saengow et al and Wong et al did not find any association between income and preference,^{72,74} and Waller et al did not find an association between lower social grade and preference for expert recommendation.⁷³

Veterans (n=6)

Six studies sampled patients exclusively from the US Veterans Health Administration, and all focused on modality preferences (Table 4).^{77–82} Four of these studies indicated that colonoscopy was the preferred modality among veterans.^{77–79,81} Rajapaksa et al found that the preference for computed tomographic colonography (CTC) vs colonoscopy was not significantly different.⁸² This study also found that racial/ethnic minorities among the veteran population were less likely to prefer CTC over colonoscopy.⁸² Moawad et al is the only study that suggested that colonoscopy is not the preferred modality among veterans; rather, in this study, veterans preferred CTC.⁸⁰

Rural (n=2)

Two studies focused primarily on US rural populations' preferences for CRC screening (Table 5).^{83,84} Pham et al studied a rural population that consisted of predominantly Hispanics, but a subgroup analysis to see whether preference varied by race was not conducted.⁸³ This study assessed delivery attributes of different fecal test options and found that participants prefer tests that use probes and vials, require a single stool sample, and provide clear, visual instructions.⁸³

Pignone et al sampled from a rural setting and included a large percentage of uninsured and low-income individuals.⁸⁴ This study assessed preferences for four screening program delivery attributes (testing options available, travel time, money received for completing screening, and out-of-pocket follow-up care costs). Pignone et al showed that screening costs and follow-up costs are more important factors in rural patients' preferences than travel time and specific test modality and that participants value having the option of fecal testing, rather than only being offered colonoscopy.⁸⁴

Discussion

This review provides insight into the current literature regarding the CRC screening preferences of vulnerable populations. This information can be used to strengthen targeted

Table 3 Characteristics of studies with low-income populations

Study	Objective	Study design	Total sample size	Sample size of vulnerable population	Outcome measure	Findings
Cho et al (2017) ⁶⁹	To investigate patient preferences for CRC screening modality for the National Cancer Screening Program	Survey	396	216	Screening test modality preference (colonoscopy or FIT)	Higher income was associated with preference for colonoscopy over FIT
Frew et al (2001) ⁷⁰	To examine the willingness to pay for two types of CRC screening	Survey	2,767	549 ^a	Willingness to pay	Lower income was associated with lower willingness to pay for CRC screening
Quick et al (2013) ⁷¹	To examine the effect test-specific barriers have on CRC screening completion, reasons for non-completion, and patterns when participants are allowed to switch modalities	Survey	418	418	Screening test modality preference (colonoscopy or FIT)	Low-income population preferred colonoscopy (60%) over FIT (40%) at baseline
Saengow et al (2015) ⁷²	To estimate CRC screening test preferences and acceptance and the reasons for decisions about whether to screen	Interviews	437	167	Screening test modality preference (colonoscopy or FIT)	Lower income was not associated with screening modality preference
Waller et al (2012) ⁷³	To assess public preferences for a CRC screening recommendation within the United Kingdom's National Health Service Colorectal (Bowel) Cancer Screening Programme	Survey	1,964	701	Preference for expert recommendation (a strong recommendation for FOBT, a recommendation plus advice to make an individual choice, or no recommendation but advice to make an individual decision)	Lower social grade was not associated with recommendation preference
Wong et al (2010) ⁷⁴	To evaluate CRC screening test preferences	Survey	3,430	1,006	Screening test modality preference (colonoscopy or FIT)	Monthly income was not associated with modality preference
Wong et al (2012) ⁷⁵	To examine factors influencing CRC screening test choice and assess the impact of an educational session on this decision	Survey	7,845	5,026	Screening test modality preference (colonoscopy or FIT)	Lower income was associated with greater likelihood of changing preference from colonoscopy to FIT after an educational intervention
Xu et al (2015) ⁷⁶	To assess patient preferences for CRC screening tests	Survey	667	204	Screening test modality preference (colonoscopy or FIT)	Higher household income was associated with greater likelihood of preference for colonoscopy

Note: ^aThe size (absolute number) of the vulnerable population is estimated based on percentages available in the study.

Abbreviations: CRC, colorectal cancer screening; FIT, fecal immunochemical testing.

interventions and policies seeking to address their relatively low screening rates. We found that there is not a single preferred CRC screening test across the identified vulnerable populations. Instead, these studies highlighted opportunities to better engage diverse patients in their preventive care decisions. These opportunities include facilitating a collaborative

decision-making process regarding the type of modality used and eliciting individual patients' preferences about particular tests, for example, through a decision aid approach. The results demonstrate that efforts to promote CRC screening should address the wide range of testing modality options, since there is much variation in individual preferences.

Table 4 Characteristics of studies with veteran populations

Study	Objective	Study design	Total sample size	Sample size of vulnerable population	Outcome measure	Findings
Akerkar et al (2001) ⁷⁷	To assess and compare patients' experiences with virtual colonoscopy and conventional colonoscopy	Survey	295	295	Screening test modality preference (conventional colonoscopy or virtual colonoscopy); time tradeoff	Conventional colonoscopy preferred over virtual colonoscopy. Patients were willing to wait an average of 4.9 weeks to undergo conventional colonoscopy relative to virtual colonoscopy from the time of discharge
Friedemann-Sánchez et al (2007) ⁷⁸	To explore CRC screening barriers, attitudes and preferences by gender	Focus groups	70	70	Screening test modality preference (colonoscopy, sigmoidoscopy, FOBT, or DCBE)	Colonoscopy preferred over other screening modalities and perceived as the "complete" screening examination
Imaeda et al (2010) ⁷⁹	To elicit patient values about CRC screening test attributes and the influence on test preferences	Maximum difference scaling survey	92	75	Screening test modality preference (colonoscopy, sigmoidoscopy, FOBT, CTC, or colon capsule endoscopy); test attribute preferences	Colonoscopy (62%) preferred over other screening modalities. Test sensitivity, risk of a perforation, and potential need for a follow-up test were identified as the most important attributes
Moawad et al (2010) ⁸⁰	To assess patient preferences for screening modality	Survey	250	250	Screening test modality preference (colonoscopy or CTC)	CTC preferred over colonoscopy by 95% of the study population that completed both colonoscopy and CTC (n=54)
Powell et al (2009) ⁸¹	To assess CRC screening modality preferences among US veterans	Survey	2,068	2,068	Screening test modality preference (colonoscopy, sigmoidoscopy, FOBT, DCBE, or no screening)	Colonoscopy (37%) and FOBT (29%) preferred over other screening modalities
Rajapaksa et al (2007) ⁸²	To assess potential differences in patient experiences with and preferences for CRC screening modality	Survey	272	272	Screening test modality preference (optical colonoscopy or CTC)	No significant difference in preference for CTC vs optical colonoscopy in the total study population. Racial and ethnic minorities within the study population were less likely to prefer CRC over optical colonoscopy relative to the white participants

Abbreviations: CTC, computed tomographic colonography; DCBE, double-contrast barium enema; FOBT, fecal occult blood test.

A relatively large number of studies addressed CRC screening preferences among vulnerable patient populations (n=43); of these, seven studies were conducted in non-US developed countries. Most studies investigated the preferences of racial and ethnic minority groups, with few studies that focused on rural populations or immigrants. This is concerning, since the US comprises large swaths of rural areas and a growing immigrant population, making rural and immigrant groups important populations to consider.^{85,86} Many studies, especially those that focused on Hispanic/Latinos, may have captured immigrant populations, but did not always record immigrant status. Likewise, while some studies included participants who were vulnerable in terms

of insurance status (eg, Medicaid enrollees, the uninsured), these studies focused on preferences among a different population, such as racial or ethnic minorities or low-income populations. Notably, there have yet to be studies assessing preferences in two vulnerable populations identified in our inclusion criteria: individuals with disabilities and members of the LGBTQ community.

In terms of outcomes, most studies across vulnerable groups focused on preferences for test modality, most commonly contrasting colonoscopy and fecal testing. The high density of studies concentrating on modality points to the dearth of studies that measured test attribute, program features, how providers should approach CRC screening

Table 5 Characteristics of studies with rural populations

Study	Objective	Study design	Total sample size	Sample size of vulnerable population	Outcome measure	Findings
Pham et al (2017) ⁸³	To assess patient preferences for FIT characteristics in order to inform regional FIT selection	Survey + focus groups	18	18	FIT-specific screening test program delivery preferences	FITs that required only one sample, collected samples using a probe and vial, and included descriptive, visual instructions were preferred
Pignone et al (2014) ⁸⁴	To determine how vulnerable individuals value different aspects of CRC screening programs	DCE	150	150	Preference for screening program design/delivery, including screening modality options, travel time, money paid for screening, and the portion of the cost of follow-up care paid out of pocket	Coverage of follow-up costs identified as more important than modality options and travel time

Abbreviations: DCE, discrete choice experiment; FIT, fecal immunochemical testing.

discussions, and other aspects of preference. There was relatively strong agreement regarding a preference for colonoscopy among veterans; however, results about test modality preferences were mixed among all other sub-populations. More focus on directly eliciting preferences for specific test attributes may help to clarify our understanding of which modality or screening program design would be ideal for specific sub-populations. Studies that investigated test attributes tended to find that accuracy, sensitivity, costs, frequency of test, convenience, and comfort were important. Accuracy and sensitivity were often associated with colonoscopy, while convenience was often associated with fecal testing. Regardless of the preferred modality, accuracy was the single most common attribute identified across sub-populations. In systematic reviews that focused on the general population, accuracy was also identified as an important attribute and no specific modality was dominantly preferred.^{20–22}

The studies that measured preference for decision-making pointed to shared decision-making between patients and providers, highlighting a willingness by vulnerable patients to engage in productive and collaborative efforts to receive screening. This is paramount since consideration of patient preferences in terms of testing attributes can be combined with provider expertise to reach an optimal screening strategy. This review provides support for the use of decision aids among vulnerable sub-populations as a method of educating patients about their options and allowing patients to clarify their preferences regarding test features and screening modalities.^{43,87–89}

This study includes several strengths. This is the first systematic review, to our knowledge, to address CRC screening preferences among vulnerable populations, compiling studies from more than a 20-year timeframe. We also

highlighted the relatively large number of studies focused on modality preferences and the limited research available on other important features of the decision-making process.

However, there were also a number of limitations. In order to gauge the scope of articles addressing vulnerable patients' CRC screening preferences, we included a broad range of study designs, focus populations and outcome measurement, so the studies are not all directly comparable. For example, given that a large proportion of the studies primarily addressing low-income patients were international, cultural contexts may have influenced the results, making it difficult to generalize to US sub-populations. There may also be additional populations that could be considered vulnerable in this context, such as patients who are illiterate or have low educational levels, not included in this review. In addition, the intersectionality of identities among the vulnerable populations made it difficult to elicit a specific preference for a singular categorization. As a result, we caution against making sweeping generalizations about the preferences of these sub-groups, due to the variety of factors that influence preferences for CRC screening in specific sub-populations. Instead, this review elicited trends and themes from the literature and can be used as a guide for planning and implementing CRC screening interventions that are well-aligned with patients' stated preferences, underlying barriers and facilitators to screening, and realities of local settings and contexts.⁹⁰

This systematic review highlights several opportunities for future research to ensure CRC screening programs better align with the preferences of vulnerable patients and ultimately to improve their CRC screening rates. First, more standardized methods to capture preferences, such as discrete choice experiments and conjoint analyses, may be

needed to clarify tradeoffs, especially since a single modality preference was not found. Although many discrete choice experiments focused on CRC screening were conducted among the general population, few have focused on specific vulnerable sub-groups. Second, since multiple modalities are generally acceptable, it will be important to determine how frequently providers are offering multiple test options. Third, future research should consider the best approach to presenting screening test options to vulnerable patients in order to create a balance between providing patients with options that are consistent with their values and offer them flexibility but not providing an overwhelming number of options and features to consider. This is especially critical given that patients reported interest in a shared decision-making process, but it remains unclear how providers should initiate these discussions. Fourth, preference studies should be conducted among those groups for whom preferences have not yet been assessed, such as disabled individuals and LGBTQ individuals. Finally, assessment activities are needed to inform intervention design and create alignment between testing preferences and screening interventions.

Conclusion

Our systematic review of CRC screening preferences in vulnerable populations revealed substantial heterogeneity in outcomes measured, study design, and populations studied and demonstrated a wide spectrum of CRC screening preferences across different vulnerable populations. This review echoes the results of previous systematic reviews conducted on CRC screening preferences among the general population in that there is no specific test modality that is overwhelmingly supported by vulnerable populations; rather, having a choice between modalities may be preferred, especially in the context of shared decision-making, which vulnerable patients seem to value. All studies measuring patients' preferences for decision-making included in this review pointed to an engaged and shared decision-making between the patient and provider. In addition, screening test attributes such as accuracy, sensitivity, cost, and convenience are important features to consider. More studies that measure the various aspects of preference beyond test modalities alone are needed in the current literature.

To increase CRC screening overall, special attention must be paid to vulnerable populations that struggle with a lower screening uptake due to differential preferences and other reasons that may diverge from the general population (eg, ability to access and pay for follow-up care). The diverse findings reported in this review point to the increased value of decision aids to elicit individually how vulnerable patients weigh

certain attributes against each other when making a screening decision. Improvements in CRC screening rates may be achieved through the alignment of vulnerable sub-populations' preferences with screening program delivery and provider practices, through decision aids or other approaches that seek to clarify and enhance patients' screening decisions.

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