

# Barriers to participation in colorectal cancer screening: A systematic review and synthesis of qualitative studies

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## BACKGROUND

Colorectal cancer (CRC) screening through Fecal Occult Blood Testing (FOBT), flexible sigmoidoscopy, and colonoscopy are effective in reducing mortality from the disease. Many developed countries adopted organized CRC screening programs, yet participation is moderate, and there is evidence of lower participation among men, low socioeconomic status individuals and ethnic populations.

A better understanding of the causes of the overall low participation and inequities in participation needs to be identified and addressed.

The objectives of this review are:

- To synthesize factors that influence individuals' decisions to participate in CRC screening, and to explore how those factors vary by sex, ethnicity and socio-economic status.
- To generate a framework to better understand the perceived benefits and barriers that affect individuals' decision-making to participate in CRC screening.

## METHODS

### Synthesis methodology

We used Meta-study methodology to conduct our review.

Meta-study is a two-staged analysis.

Stage 1: meta-data analysis.

Stage 2: meta-synthesis, which extends beyond analysis to identify "truths" about the phenomenon under study, by considering how the primary researchers interpreted the data (i.e., Meta-data), the design and quality of studies (Meta-method), and the theoretical frameworks or perspectives used in these research reports (Meta-theory).

### Eligibility criteria

This review used the following PICOS criteria:

- Population: Adults aged 50 years or over referred for colorectal cancer (CRC) screening.
- Intervention: studies investigating perceptions of CRC screening as well as those investigating CRC as a disease
- Context: perceptions by sex, ethnicity, SES, and other factors influencing CRC screening behavior
- Outcomes: Perceptions related to CRC as a disease, causes of CRC, benefits and barriers to CRC screening, and any other contextual factors that motivate or influence people's decision to participate in CRC screening
- Study design: Qualitative studies and mixed-methods studies with a qualitative component.

### Information sources

We searched MEDLINE, EMBASE, CINAHL, PsycINFO, the grey literature, and the reference lists of included articles from inception to July 2013. A draft search strategy for MEDLINE is available on demand.

### Data collection process

Two reviewers independently screened titles and abstracts in duplicate; a similar procedure was used for full-text screening. Data was abstracted by one reviewer and audited by a second. Discrepancies were reviewed and resolved by discussion amongst the team.

## RESULTS

Of 9196 records identified by our search, 7860 potentially relevant titles and abstracts were identified. Of these, 505 articles were assessed in full text and 86 articles contributed to the analysis.

Figure 1. Flow chart showing study identification, duplicates, number of included and excluded studies, and reasons for exclusion

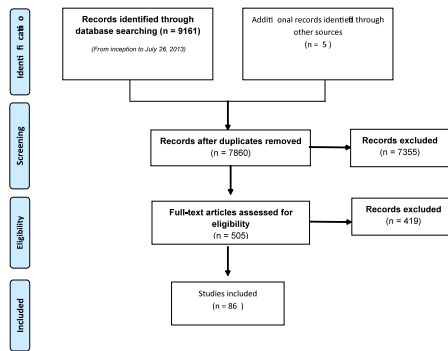


Table 1: Knowledge barriers to CRC screening participation by theme, exemplary quote, sex, ethnicity, and socio-economic status

Theme	Exemplary quote	Sex		Ethnicity					SES		
		F	M	A	W	H	C	O	L	H	
<b>Knowledge</b>											
Lack of information	"I have never heard of colorectal cancer screening. I was never recommended to do it and nobody has ever told me it's available"	+	+	+	+	+	+	+	+	+	+
Mixing-up medical terms used for screening	"men get PSA for the colorectal thing; why don't women?"	+	+	+	+	+	+	+	+	+	+
CRC screening is not as visible as other cancers	"I couldn't tell you what could cause colon cancer because they don't talk much about this subject. Talk about other types of cancer is more common."	+		+	+	+				+	

F=Women; M=Men; A=African American; W=White; H=Hispanic; C: Chinese; O=Other; SES= socio-economic status; L=Low SES; H=High-SES

Table 2: Physician encounter and test characteristic barriers to CRC screening participation by theme, exemplary quote, sex, ethnicity, and socio-economic status

Theme	Exemplary quote	Sex		Ethnicity					SES	
		F	M	A	W	H	C	O	L	H
Taking time off to visit the doctor	"A lot of folks around here have had to take a whole day off of work to get their colonoscopies. I think that is difficult for some people to do...to take a whole day off of work."							+		+
No symptom	"Nothing wrong with me. Why should I do that?"	+	+	+	+	+	+	+	+	+
Lack of physician recommendation	"My doctor never said anything to me about it. If he wanted me to have it, wouldn't he say something?"		+		+	+	+	+	+	+
FOBT	"I received the kit, I had a look at it and I decided no, I didn't want to do it. I thought it was pretty disgusting really so I decided not to do it"	+	+	+	+	+	+	+	+	+
Colonoscopy	"prep is awful"	+	+	+	+	+	+	+	+	+

Table 3: Perception barriers to CRC screening participation by theme, exemplary quote, sex, ethnicity, and socio-economic status

Theme	Exemplary quote	Sex		Ethnicity					SES	
		F	M	A	W	H	C	O	L	H
<b>Perception</b>										
Avoidance	"why go looking for trouble?" "Ignorance is a bliss"	+	+	+		+			+	+
Fear of being diagnosed	"The fear of knowing. That sounds crazy, but that's reality. It's the fear of not wanting to know that I have cancer."	+	+	+	+	+			+	+
Men's disease	"It occurs more with men and that's why it's a good idea for them definitely to have colonoscopies."		+		+		+			+
Masculinity	"Machismo is what impedes men from getting cancer tests. They don't like to go to the doctor. You can see how the man acts: 'No, I'm healthy and I don't have to go to any doctor.'"			+	+		+			+

Table 4: Cultural barriers to colorectal cancer screening participation by theme, exemplary quote, and ethnicity.

Theme	Exemplary quote	Ethnicity				
		A	W	H	C	O
<b>Cultural</b>						
Touching parts of the body is not part of the culture	"not my cultural way" "Latinos do not like to touch (ex: their loved one's priv parts."			+	+	+
Natural Remedies to prevent CRC	"The best way is to take huai hua if one has a problem in intestine stomach... This medicine can take care of heat inside the intestine and stomach"				+	+
Humiliating	"It's a humiliation" "older people will feel violated by this humiliation"		+	+	+	+
Living healthy	"I take care of myself a different way: I exercise and eat well."	+	+	+	+	+

^: Pakistani, Bangladeshi, African, Haitian

## DISCUSSION

Our next step is to generate a framework to better understand the benefits and barriers that affect decision making to participate in CRC screening among different sectors of the population. Policy makers will be able to use the framework as a frame educational materials. Physicians may use it as in patient-centered communication. Using the anticipatory framework, researchers may also design novel interventions to address those inequities, which may lead to improved quality in practice and advancement in evidence-based decision-making. Furthermore, synthesis of available qualitative evidence of barriers to participation in CRC screening currently does not exist. Therefore, our findings may trigger other systematic reviews of gaps in information that we may identify.

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