

# Barriers and facilitators for colorectal cancer screening in a low-income urban community in Mexico City

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## Research

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# Abstract

Background Colorectal cancer (CRC) incidence and mortality are increasing in many middle- and lower-income countries, possibly due to a combination of changing lifestyles and improved healthcare infrastructure that facilitates diagnosis. Unfortunately, a large proportion of cases may be diagnosed at advanced stages, resulting in poor outcomes. Decreasing trends in higher income countries are likely due to improved early detection combined with best practices in CRC treatment and management. More data on implementation of better quality CRC screening programs are needed for contexts where incidence is increasing. Therefore, we sought to identify potential barriers and facilitators for future implementation of fecal immunochemical test (FIT)-based CRC screening in a public healthcare system in a middle-income country with increasing CRC incidence and mortality.

Methods. Qualitative study including semi-structured individual and focus group interviews with different stakeholders of colorectal cancer screening: 30 average-risk lay people, 13 health care personnel from a local public clinic, and 7 endoscopy unit personnel from a cancer referral hospital. All interviews were transcribed verbatim for analysis. Data was analyzed using the constant comparison method, under the theoretical perspectives of the Social Ecological Model (SEM), the PRECEDE-PROCEED Model, and the Health Belief Model.

Results. We found multiple barriers and facilitators for implementation of a FIT-based CRC screening program at different levels of the SEM. The main barriers in each of the SEM levels, were: 1) at the social context level: poverty, health literacy and lay beliefs related to gender, cancer, allopathic medicine, and religion; 2) at the health services organization level: the lack of CRC knowledge among health care personnel and the community perception of poor quality of health care; 3) at the individual level: a lack of CRC awareness and therefore lack of risk perception, together with fear of participating in screening activities and finding out about a serious disease. The main facilitators perceived by the participants were CRC screening information and the free provision of screening tests.

Conclusions. This study's findings suggest the need for a multi-level CRC screening program that includes complementary strategies aimed at reducing perceived barriers and enhancing facilitators, starting with: 1) free provision of screening tests, 2) education of primary health care personnel, and 3) promotion of non fear-based CRC screening awareness among the target population, taking into account their lay beliefs.

## Contributions To The Literature:

In low- and middle-income countries there is a gap in the integration of qualitative research findings into the design of sustainable cancer screening programs.

Designing culturally appropriate colorectal cancer screening interventions is necessary as barriers and facilitators for screening completion in other countries may not be sufficient to inform program implementation.

Our study highlights the relevance of qualitative methods to uncover context-specific barriers and facilitators as perceived by the different stakeholders as a prior step to the design of health interventions in a middle-income country.

## Background

Colorectal cancer (CRC) is preventable and curable with screening and early detection, yet it remains a leading cause of cancer mortality worldwide.(1) CRC incidence and mortality varies by country and region but is increasing in lower- and middle-income countries while decreasing trends have been observed only in some higher income countries, where rates nevertheless remain high.(2) CRC results in approximately 800,000 deaths per year globally, with most of these deaths occurring in low and middle-income countries (LMICs).(3) Most of these deaths could be avoided with implementation of screening programs, as indicated by the decreasing trends in CRC incidence and mortality in some high-income countries.(2, 4) Evidence from randomized clinical trials has formed the basis for international guidelines(5–7) recommending CRC screening for at-risk adults, and reflect different approaches to screening including stool-based tests and visual exams of the colon and rectum.(4)

Stool-based tests, including the fecal immunochemical test (FIT), guaiac-based fecal occult blood test (gFOBT), and fecal DNA tests, are highly sensitive and non-invasive. However, they lack specificity, require serial testing at short intervals, and a subset of patients must still undergo direct visualization following receipt of a positive result. Visual exams of the colon and rectum, including colonoscopy, flexible sigmoidoscopy, and computer tomographic colonography offer enhanced specificity but are more invasive and costly. In resource-constrained settings, the use of non-invasive stool tests offers the advantage of higher screening uptake and lower demand on endoscopy resources.(4)

In Mexico, as in other middle-income countries, CRC incidence and mortality are on the rise, possibly due to the combined effect of changing lifestyles and the improvement of healthcare infrastructure to facilitate diagnosis.(8) Unfortunately, a large proportion of cases are diagnosed at advanced stages, resulting in poor outcomes.(9) Even though the Mexico's National Clinical Practice Guidelines recommend annual gFOBT for average-risk individuals, efforts to formally implement CRC screening programs in Mexico are nascent.(10) As data about the implementation of fecal immunochemical test (FIT)-based CRC screening could be useful to healthcare systems in a number of contexts, including Mexico, we first sought to identify potential barriers and facilitators for the future implementation CRC screening in Mexico City.

## Methods

### Study setting and design

We undertook a qualitative study and report according to the standards for reporting qualitative research (SRQR).(11) We collected data using semi-structured individual and focus group interviews with lay

people representative of the average-risk population for CRC screening, primary care providers and endoscopy unit personnel.

We selected a low-income urban community of approximately 20,000 people located in the Tlalpan district of Mexico City. We chose this community because of its high levels of marginalization, capabilities of the community-based clinic, and apparent accessibility to the Instituto Nacional de Cancerología (INCan), a national cancer referral hospital with an Endoscopy Unit in Mexico City (approximately 10 km and 40 minutes away via public transportation). The community clinic selected (Cultura Maya clinic) provides services for uninsured patients and those covered by a governmental health insurance program called Seguro Popular. It employs 11 physicians, 16 nurses, and 7 social workers and offers free primary care services, basic x-ray imaging, and routine laboratory tests; colorectal cancer screening is not currently offered as a part of routine care. At the time of this study, the clinic served an estimated 4,213 adults between the ages of 50 to 74, which is considered as the population at-risk for CRC according to U.S. guidelines.(12)

### **Study participants**

We had three groups of participants. The “community participants” group was composed of lay people residing in the vicinities of the Cultura Maya health center. The “primary healthcare participants” included health care personnel employed at the Cultura Maya clinic (i.e. social workers, nurses, and primary care physicians). Finally, the “endoscopy unit participants” were health care personnel laboring at INCan’s Endoscopy Unit (i.e. endoscopists, nurses and screening program administrative personnel).

### **Theoretical perspectives**

This study was guided overall by the broad theoretical perspective of the Social Ecological Model (SEM). (13) This model emphasizes the interaction and interdependence between factors within and across all levels of a health problem or behavior: intrapersonal or individual, interpersonal, institutional or organizational, community, and public policy levels. We also used the PRECEDE-PROCEED (Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation - Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development) model to guide the analysis of the CRC screening program planning process.(14)

Based on the premise that an educational diagnosis of the problem is essential before development and implementation of the intervention plan, the current study focused only on the PRECEDE phase. Our analysis of individual or intrapersonal factors was guided by the Health Belief Model (HBM).(15) HBM addresses an individual’s perceptions of the threat posed by a health problem (perceived susceptibility and perceived severity), the perceived benefits of avoiding the threat and factors influencing the decision to act (perceived barriers, cues to action, and self-efficacy).(16)

### **Data collection**

We used semi-structured, open-ended questions to ask participants about their perceptions of barriers and facilitators, knowledge, attitudes, and beliefs about CRC and CRC screening, and strategies for motivating behavior change among lay people and health personnel. Data were collected between September 2018 and January 2019. We conducted a total of 22 semi-structured interviews and three focus group interviews with 28 community participants, to achieve saturation with a total of 50 participants: 13/22 interviews were with primary care personnel, 7/22 with endoscopy unit participants, and 2/22 with community members..

Community participants were recruited by two social workers from the local health clinic, each covering a different geographic area, and by outreach through a local support group for the elderly. We stratified focus groups by gender in an effort to facilitate a more open discussion. We conducted two focus groups in women (20 total participants) and one in men (8 participants). The focus groups were led by two experts in qualitative research (KUS and MST), with one moderating and the other assisting with organization and on-site coding of responses. We also collected demographic data from all community participants including age, marital status, years of education, family income, and housing characteristics.

After the initial open questions regarding knowledge about CRC and CRC screening, we provided basic information on these topics to the participants in order to elicit their perceived barriers and facilitators for implementation of FIT-based screening and colonoscopy. The interviews with primary care providers and community participants took place in a private room at the community health clinic in Tlalpan, and those with endoscopy personnel at INCan's Endoscopy Unit. Individual interviews lasted between 30 and 60 minutes, and focus groups lasted between 60 and 90 minutes. Community participants received a gift card valued at 10 USD as a small token of compensation. All interviews were carried out in Spanish, audio recorded, and transcribed verbatim.

## Data analysis

All data was de-identified prior to transcription. Transcripts and field notes were organized with Atlas.ti software to aid the analysis. Data was coded by two researchers using the constant comparison method under the SEM, PRECEDE-PROCEED, and HBM theoretical perspectives.(17) The coding results were then reviewed with adjudication in the cases of differing results, reaching consensus between the two coders to establish the final codes. Data saturation was achieved with the last focus group and, therefore, no more participants were recruited. To determine saturation, we used the on-site coding to determine when no new codes appeared and each of the codes had been applied to a sufficient amount of data.

## Results

A total of 30 community members and 20 healthcare providers participated in the study. Participant characteristics are summarized in **Tables 1 and 2**. Following the PRECEDE-PROCEED model, we organized our findings into two broad categories: (1) barriers and (2) facilitators of CRC screening. Additionally, each barrier and facilitator was classified within a level of the Social Ecological Model. **Figure 1** summarizes our findings. It represents the perceived barriers and facilitators for participation in a CRC screening

program in this community at the different levels of the Social Ecological Model, where all levels interact with each other. Representative examples of participants' quotes for the most relevant codes are presented in **Tables 3 and 4**.

## **INSERT TABLES 1 AND 2 HERE**

### ***Perceived Barriers to CRC screening***

#### **Health policy barriers**

Barriers at this level were identified only by healthcare providers employed at the Endoscopy Unit at INCan, who reported numerous barriers to the expansion and sustainability of INCan's current CRC screening program. Identified barriers included: budget constraints, lack of interest from policy makers leading to insufficient promotion of CRC screening, and dissemination of inaccurate information about CRC in mass media campaigns.

#### **Social context barriers**

Poverty was the most commonly perceived barrier to uptake of CRC screening, as reported both by community participants who would be the targets of screening and the primary healthcare providers who serve this population. Participants in all groups consistently brought up concerns about costs of tests and described living conditions that prevail in the area and the daily difficulties that patients face to cover basic needs (e.g., drinking water, food, and medicines). Among elderly male participants, most complained about the difficulty finding work at their age. Among the female participants, several reported being completely dependent on government programs for food and medical care.

Belief systems about cancer, health in general, and medical treatments were identified as another social context barrier. For example, community participants spoke about the commonly shared fatalistic view of cancer as a death sentence accompanied by suffering, pain, and expensive treatments that have a negative economic impact on the family. They also spoke about a common attitude of carelessness towards one's health, reflecting the perception that many take health for granted. They shared the observation that many do not prioritize preventive health care and postpone health service utilization until symptoms are severe. Moreover, the role of gender with regard to beliefs about health was consistently mentioned by participants from all groups, with the shared impression that men are less likely to utilize healthcare services than women. Many attributed this to men being less concerned about health than women. Additionally, community participants thought that having a colonoscopy would be harder for men to accept due to the anal penetration associated with the procedure, with possible sexual associations. One more barrier related to gender beliefs that could potentially affect the uptake of colonoscopy by women in Mexico is *machismo* or a sense of masculine pride that includes control over the female partner. Some participants described the possibility that some men may forbid their wives from seeking medical care, particularly if the doctor is a male and the consultation could require a woman to show intimate parts of her body.

Numerous participants in all groups perceived the lack of knowledge about CRC and CRC screening among community and primary healthcare participants as a relevant barrier. In particular, community participants lacked even basic knowledge about CRC and saw lack of knowledge as a barrier to participation in screening. Few community participants had heard of colonoscopy and knowledge of the procedure was limited. None of our community participants had heard about FIT as an option for CRC screening. The primary health care personnel possessed little knowledge about CRC and options for screening.

Finally, there were characteristics of the community that primary healthcare providers perceived as barriers for a successful implementation of a CRC screening program. The health workers perceived the population they serve as poorly educated. They described it was challenging for them to understand instructions for participation in diagnostic tests, for management of chronic conditions (e.g., diabetes), and therefore for adhering to treatment and follow-up. Also, the primary healthcare providers perceived the community as accustomed to participating in health programs in response to incentives (e.g. food parcels), which is a common practice with the delivery of social programs in Mexico. The primary care participants also described street violence as a barrier to provide outreach in certain neighborhoods. They also commented on the community's cultural diversity, with migrants from different ethnic origins, which in their view further complicates the primary care personnel's usual outreach activities. Finally, primary care providers reported that it is common for a significant proportion of community turnover due to migration from and to other states in Mexico or even change of residence within the city, and this could pose challenges to successful follow-up of individuals with positive FIT results.

### **Health service organization barriers**

Community participants perceived the following potential barriers to participation in CRC screening: (1) previous experiences of patient abuse or mistreatment in healthcare; (2) poor quality of health services; and (3) challenges in doctor-patient communication. Several participants, including primary care physicians, shared negative personal experiences as patients in public health services that have subsequently prevented them from seeking care. These included perceived poor quality of care as well as stories of patient abuse where participants felt they were discriminated against due to their low-income status or appearance. Finally, community participants complained about not getting satisfactory explanations from healthcare providers about their health conditions, details for the rationale of medical recommendations related to screening and treatment, and wording that is easy to understand. Also, they said they wished doctors were more empathetic towards their life experiences.

At the primary care clinic level, the most prominent barriers perceived by our two groups of health care personnel participants (primary care and endoscopy unit) were: (1) lack of CRC knowledge among the primary care providers; (2) work overload in the primary care clinic; (3) insufficient infrastructure, personnel, and supplies; and (4) resistance to or lack of interest among primary care personnel in participating in new programs. The second barrier listed appeared to be a central issue: a majority of healthcare providers identified work overload as a significant problem, articulating that it would be very

difficult to recommend screening during patient visits due to numerous competing medical priorities and short consultation times during patient visits. They also complained about having too much administrative workload, which reduces time for direct patient contact. Additionally, healthcare personnel referred to the daily challenges of doing their job in the midst of insufficient infrastructure, lack of supplies, and inadequate staff. Also, they perceived the lack of interest among staff and their resistance towards participation in new programs as an expression of fear regarding impact on an already heavy workload.

Finally, community participants described as potential barriers (apparently based on previous experiences), the long waiting times for referrals to other hospitals, complicated administrative procedures, and long distances for transportation to the health services. Although INCan is located only 10 km away from the community, distance was perceived by the community population as a barrier specific to getting a colonoscopy at the Endoscopy Unit of INCan, as public transportation is limited and can take much longer than private transportation.

### **Interpersonal barriers**

At the interpersonal level, one of the endoscopists mentioned that negative colonoscopy experiences among peers might influence the uptake of this procedure. Among our community participants, nobody knew anyone who had a colonoscopy; however, one female participant narrated to the rest of the group a horrible experience with the sedation of her son during an endoscopic procedure and expressed her fear of submitting herself to something similar.

### **Individual barriers**

One of the most evident barriers was lack of awareness about CRC among community participants. A majority of participants openly acknowledged not knowing anything about CRC and were unable to identify the location of the colon. Once information on CRC, FIT-based screening, and colonoscopy was provided, the most commonly reported barrier was fear. Participants discussed the fear of finding out they have a serious disease like cancer. Three additional kinds of fear came up in relation with colonoscopy: (a) fear of pain; (b) fear of not knowing what to expect during the procedure; and (c) fear of embarrassment regarding the actual colonoscopy procedure, particularly among the male participants.

Community participants also reported lack of time for utilizing health services due to personal obligations and daily life activities. Male participants mentioned fear of losing their jobs, and female caretakers consistently put their families' needs before their own. Respondents explained that community members have too many competing responsibilities, and preventive health care is not a priority.

According to participants, preferences for traditional rather than allopathic medicine, particularly among people who migrated from rural areas to Mexico City, were identified as a potential barrier to participation in CRC screening. Reluctance to use health services due to distrust of healthcare providers was

consistently reported. Other barriers that were mentioned were lack of self-care, low self-esteem, procrastination, disinterest in health, and low perceived risk of CRC.

## **INSERT TABLE 3 HERE**

### ***Perceived facilitators for participation in CRC screening***

#### **Health policy facilitators**

Only health workers at the Endoscopy Unit identified facilitators at this level of the Social Ecological Model. In their opinion, mass media campaigns about the relevance and recommendations of CRC screening have potential to increase awareness in the target population.

#### **Social context facilitators**

Health workers at the primary care clinic perceive that the population they serve has been highly engaged in other health programs offered in the past. They perceive that this openness of the community to participate in health programs could facilitate uptake of CRC screening.

#### **Health service organization facilitators**

The main perceived facilitator for screening participation by all participants was that FIT kits and colonoscopy be offered at no cost. Another key facilitator identified by both healthcare personnel and community participants was promotion of CRC screening at community clinics. They hypothesized that people would participate in CRC screening if the primary care physicians were mandated to give information and request a CRC screening test from all their patients >50 years. Other relevant facilitators for FIT uptake were: (1) availability of the FIT kits at the local clinic; (2) possibility of reception of completed FIT samples at the local clinic; (3) good doctor-patient relationships with satisfactory communication skills among doctors; and (4) a history of positive experiences with health service utilization. For uptake of colonoscopy, the opportunity to have the procedure done by a physician of the same gender was seen as a facilitator.

Primary care personnel commented on the need for appropriate work environments. A majority reported that motivating the primary care personnel to participate in the CRC screening program would be a facilitator to successful implementation of the program. Finally, in order to improve their CRC screening knowledge and communication skills, primary care personnel suggested the use of short informative videos. They commented on the importance of observing others to learn medical procedures, which could also be applied to learning to communicate more effectively regarding the relevance of CRC screening.

#### **Interpersonal facilitators.**

Some community participants reported that knowing someone affected by cancer, particularly a family member or a close friend, would be a motivation to participate in cancer screening. Social support was also considered an important facilitator. Many reported that it would be easier for them to participate in

screening if a family member or friend encouraged them to do so or shared with them a personal positive experience.

### **Individual facilitators**

Almost all participants expressed that access to information on CRC and the benefits of screening is an important facilitator. The community participants were very interested in receiving more information about CRC screening and prevention. The information they received in the focus groups made them feel at risk (and this risk perception was accompanied by the knowledge that the cancer could be detected early and treated), and several mentioned this perception as a motivation to participate in CRC screening. Other potential facilitators were that the participants perceived sample collection for the FIT test and return of the kit to the health center as simple procedures. Knowing that the test could be done at the privacy of their homes was seen as an advantage. Finally, having personal experiences with serious illnesses came up as a facilitator. Some participants reflected upon their own negative health experiences and said that they were willing to participate in any screening activity that would prevent them from additional suffering due to health issues.

**INSERT TABLE 4 HERE**

## **Discussion**

We identified multiple barriers and facilitators to successful implementation of a FIT-based CRC screening program in a low-income urban community in Mexico City. The main barriers at the social context level were poverty, health literacy, and community health and gender-related beliefs. At the health services organization level the lack of knowledge of CRC among health care personnel and common perception of poor quality of health care services provided at public facilities were identified as major barriers. We identified lack of awareness about CRC risk and fear of serious disease as the preeminent barriers at the individual level. The major perceived facilitators for a CRC screening program were health education on CRC screening and access to screening tests at no cost to the patient.

Previous studies have reported similar barriers to the ones observed in the current study. At the social context level health beliefs and attitudes, like fatalism(18–20), sexism, and stigma related to the digital rectal exam(21) have been reported in several studies. At the level of the health system/ health services level the following barriers have been previously reported: negative experiences with healthcare services or poor perception of the quality of healthcare provided by personnel(22, 23), insufficient explanations by doctors about the evidence to support use of the screening studies(24), lack of confidence in the health system(25–27), difficulties with appointments, referrals, long waiting times and failures in reminders(28, 29), and access problems due to health insurance and test costs(23). At the interpersonal level, lack of social support has also been reported as a barrier to CRC screening participation(30). Finally, at the individual level, previously reported barriers include lack of knowledge about detection and disease(22, 31–34), underestimation of CRC risk(35, 36), procrastination(37), fear of a cancer diagnosis (21, 28, 34, 37–39), fear of discomfort or pain during colonoscopy(34, 40, 41), and shame about getting a

colonoscopy(34, 40, 41). Our study participants perceived as hypothetical facilitators the removal of financial barriers and implementation of educational interventions for patients and providers. Both of these have also been found to be among the most successful facilitators of CRC screening in other countries where screening programs have been piloted or are already in place. (26, 42, 43)

Contrary to research findings from countries such as Spain(44), the Netherlands(45), the United Kingdom(46) and the United States(43), our study subjects did not report taboos or unpleasantness of handling stool samples as a significant barrier to patient participation. Awareness of CRC screening was highly deficient among our participants at baseline, but once they were given information on CRC, the benefits of screening and the details regarding the screening tests, interest in participating in the collection of stool samples for the FIT was high, and no concerns regarding the actual procedural aspects were expressed.

CRC screening recommendations and screening programs are highly variable around the world, in part due to variations in CRC incidence, economic resources, and healthcare infrastructure.(4) In general, organized population-level CRC screening programs only exist in high-income countries (HIC), mainly in Western Europe, Japan, Australia and several provinces of Canada.(4) However, efforts to establish organized CRC screening programs are emerging in a few countries in Latin America which are impacted by disproportionately high rates of CRC, including Argentina, Brazil, Chile, and Uruguay.(4) Feasibility and cost-effectiveness studies are critical to guiding decisions by policymakers regarding the appropriateness of investment in organized CRC screening programs, as well as to determine the most cost-effective CRC screening modality for a particular setting. Qualitative research studies conducted prior to program design and implementation, engaging stakeholders at multiple levels of the social ecological model, and aimed at identifying local barriers and facilitators, can provide valuable information to increase the likelihood of successful program adoption, implementation, and sustainability.

Our findings highlight the need for culturally appropriate CRC screening interventions that address perceived barriers and facilitators for successful implementation. First, it is relevant to consider the characteristics of the target population. Individuals and populations afflicted by poverty are likely to prioritize fulfillment of basic needs over preventive services.(47, 48) Once participants in our study received information regarding CRC screening, most expressed a willingness to participate in CRC screening, although test costs were perceived as a very important barrier. Therefore, access to tests free of charge needs to be guaranteed if people living in limited-resource settings are to be targeted by screening programs. In the Mexican context, diagnostic colonoscopies are not currently covered by the national health insurance plan that was in place when this study was carried out, Seguro Popular, and efforts are ongoing to address the critical need for downstream capacity and coverage for the diagnostic colonoscopies that are necessitated by a positive FIT result.

Second, the knowledge gaps about CRC risk among members of the primary healthcare team, including physicians, emerged as a very important barrier to target prior to implementation of a CRC screening program. Primary care personnel need to be educated about the relevance of CRC: the epidemiologic

burden, the role of screening for prevention and early detection and the specific feasible screening recommendations, as well as cultural competence and communication skills relating to promotion of screening.(49) Finally, increasing awareness of CRC among the lay population will be critical to create familiarity with the recommendation for screening.(50) Addressing these barriers thoughtfully and sequentially will be necessary to ensure that access to screening and diagnostic tests are well-established before promoting awareness among the at-risk population, in order to avoid escalation of a health need that the health system is not prepared to meet.

Some limitations of this study need to be acknowledged. First, study participants were instructed by focus group facilitators to speak on behalf of cultural views that would be representative of their communities, though participants were not restricted in the actual discussions and may also have provided personal views. However, we believe this information is valuable as well, as personal views are often a reflection of shared cultural values. Also, we recognize that there is important demographic and socioeconomic heterogeneity within Mexico City that may not be reflected in our sample. The neighborhoods sampled were among the poorest in Mexico City, but results may not be entirely generalizable to communities with higher income levels. However, to address this issue, we purposefully sampled individuals of different gender and age from different neighborhoods surrounding the clinic. We also included a multidisciplinary sample of healthcare personnel who would be directly involved in implementation of a community-based CRC screening program. This purposefully sought gender, age and multidisciplinary heterogeneity of our 50 participants allowed us to achieve data saturation. Because poverty remains highly prevalent in Mexico City, the types of barriers and facilitators perceived by our informants are likely to be representative of a large proportion of neighborhoods across Mexico City.

## Conclusions

We identified three main barriers to CRC screening in a low-income, urban community in Mexico City: 1) a need for free provision of FIT tests and diagnostic colonoscopies; 2) training for primary health care personnel; and 3) promotion of CRC screening awareness among the target population. As we consider steps necessary for the implementation of a successful CRC screening program among marginalized communities in Mexico City, we aim to create an intervention that is implemented through a well-coordinated multidisciplinary team that includes all these complementary elements. Our future research activities will aim to address each of these three barriers in a stepwise fashion through a multi-level approach that engages policy makers, stakeholders within multiple healthcare settings, and community leaders and members.

## Abbreviations

CRC

Colorectal cancer

FIT

Fecal immunochemical test

gFOBT

Guaiac-based fecal occult blood test

HBM

Health belief model

HIC

High income countries

INCan

Instituto Nacional de Cancerología (Mexican National Cancer Institute)

LMIC

Low and middle-income countries

PRECEDE-PROCEED Model

Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation - Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development Model

SEM

Social Ecological Model

## Declarations

**Ethics approval and consent to participate.** The study received approval from the institutional review board at INCan and was considered exempt at UCSF (19-27349). Written informed consent was obtained from all participants prior to recruitment.

**Consent for publication.** Informed consent was also obtained for publication of participants' responses. No personal data is included.

**Availability of data and materials.** Data available on request from the authors.

**Competing interests:** None

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**Authors' contributions.** KU and ML conceived the study. KU, MS, and ML designed the study. KU and MS collected and analyzed the data, and drafted the manuscript. All authors contributed in data interpretation and manuscript preparation.

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## Tables

Table 1. Characteristics of community participants (n=30)

	Num.	%
<b>Age (Mean, range)</b>	64.33 (49-80)	
<b>Sex</b>		
Female	22	70.0
Male	9	54.9
<b>Marital status</b>		
In a cohabiting relationship	20	66.7
Not in a cohabiting relationship	10	33.3
<b>Illiterate</b>		
Yes	21	70.0
No	9	30.0
<b>Education</b>		
None	5	16.6
6 years or less	17	56.7
7 to 9 years	6	20.0
10 years or more	2	6.7
<b>Monthly family income</b>		
<1 minimum wage salary*	18	60.1
2-3 minimum wage salaries	8	26.6
>3 minimum wage salaries	1	3.3
No response	3	10.0

\*One minimum wage salary in 2018 in Mexico City was equivalent to \$139.2 USD per month.

Table 2. Characteristics of health care personnel (n=20)

	Num.
<b>Sex</b>	
Female	13
Male	7
<b>Health care facility</b>	
Primary care clinic	13
Endoscopy Unit	7
<b>Job</b>	
Primary care physician	4
Primary care nurse	4
Primary care social worker	5
Endoscopist	5
Chief nurse at endoscopy unit	1
Coordinator at endoscopy unit	1

Table 3. Participant quotes of perceived barriers to colorectal cancer screening

Code	Informant	Quote
<i>Health policy level</i>		
Budget constraints	Endoscopy medical personnel	We are historically used to investing in resources for treatment of advanced colon cancer, palliative care, chemotherapy, radiotherapy, studies for staging and follow-up, but we have not invested in prevention and diagnostics. We need to guarantee the funding of programs like this, and find out how much they can actually expand otherwise the effort will be useless. Its funding needs to be guaranteed by <i>Seguro Popular</i> or something of the sort for the (screening) program to keep running.
Lack of interest of decision makers	Endoscopy medical personnel	This kind of programs could fail due to the lack of support of decision makers. I see that many authorities are not interested in colorectal cancer, they don't think for a minute about the possibility of having a prevention program. Some authorities in our hospital are aware of the relevance of this, but not all...
Insufficient promotion of CRC screening	Endoscopy medical personnel	The main challenge is that more people need to get into the program. We need a lot of promotion, a lot of promotion, a lot of promotion, we need to increase the number of participants, yes!
<i>Social context level</i>		
Poverty	Male lay participant	I owed the payment of two months of my water service. So I saved money, about \$1000 (USD 50) but still I could not pay it. Somebody told me I could get a discount with my elderly person card, but it turned out that it only works for transportation. I had to pay \$ 2026... I told him I have nothing more, so I just paid what I could and I still owe \$ 1026.
	Primary care personnel: doctor	The people are humble, they are very noble people... but when you talk to them about their children's nutrition, and insist that they need to feed their malnourished children, they cannot stand it, they ask you: what can I feed them if I only have an egg for each day?
Beliefs: Gender	Male lay participant	Men my age and older, it is very difficult that they will agree (to having a colonoscopy), because they are going to say that they are being raped. They will say: at this age they are going to rape me with the finger? No, you are crazy, I tell you the truth.
	Female lay participant	We are far from many things, because first we start under the assumption that us women are destined to be nothing more than a housewife, and if you have a controlling and jealous husband, forget it, how do you think you are going to go get this tests done?
Beliefs: Cancer	Female lay participant	I was told by a doctor that sometimes women can get colorectal cancer because when you are in labor you push a lot, and pushing so hard brings problems in the colon.
Health literacy	Primary care personnel: doctor	The patients have low levels of school education, people with maximum 3 years of primary school, so we face many complications because they do not understand how to take the treatment or how to take samples for lab tests
Conditional participation in health programs	Primary care personnel: doctor	Above all, I have seen it happen a lot in the pap smear tests. It is very common that the results are not picked up, despite the fact that they are visited at their homes, that they receive phone calls... it is a lack of interest because they have already received the money and everything they can get and that's it.
Insecurity (violence)	Primary health care: social worker	I feel, well not feel, I have perceived that many people, maybe approximately sixty percent, has had or has a relative in jail, and I don't think that is without reason. In the area there has been violence... any act or infraction committed by their relatives or themselves is because there has been violence.
Cultural diversity	Primary health	In this particular area there are very different cultures, I see it within the same group of people. One lady behaves differently from the other and suddenly there are many cultural shocks, right? Because there is one that

care: says: "this is how things are done", and there is another one that says: "no, how can you think that?"... I think this makes it difficult to form community groups in this health center... this is a particular situation that I see in this area.

Floating population Primary health care: social worker While the patients are from this health center, as long as they do not change residence there is no problem for the follow-up ... but it is common that they move, change their address. So you go looking for them and they are gone and you don't know where they moved to... we have to deliver results and they are no longer there.

*Organizational level (health services)*

Tests costs Male lay participant If the cost of the tests is covered by popular insurance or if the cost is low, it is most likely to be done, if it is not covered or if the cost is very high, it is difficult for a patient to perform it.

Experiences of abuse in health services Male lay participant It is true that security guards are sometimes very bad, completely inhuman, right? They say: you are not from around here, you need to show me your health service identity card, if not then look elsewhere... If it is already a hardship to get to one hospital, then imagine having to move from one place to another.

Experiences of abuse in health services Primary health care: social worker If they would explain to the patient what they are going to do with him, the patient would be relaxed, he would know that there is not going to be a bigger problem, right? But no, they go "let's see, get on here, take your clothes off, hold on and shut up!"

Poor quality of health services Primary care personnel: doctor As health personnel we have to keep updating, then they send us to a course for anything and it is to reduce the attention time and the quality of attention

Doctor-patient communication problems Male lay participant I did not understand. I got confused. He sent me to pathology, and he sent me to do some chest studies, and some study of my entire skeleton. I did not understand what they were for. I thought that with those same papers I had to come back to the hospital in my next visit. It was not like that... now I pay more attention to what this is and that... They give you so many different papers.

Lack of CRC knowledge Primary care personnel: doctor I think we would need more information, we would need more in the sense that maybe, well in my case, I do not know anything about the disease and about the test, I do not know about which one is the best. I think the specialist that has to do the study would be the proctologist, but I do not have more information, nothing more. I would say that in my service we require more information.

Work overload Primary care personnel: doctor It's only a nurse, a doctor, a social worker and a lot of people, so obviously you cannot cope with the attention for all the patients. You have to organize your times, because there are so many activities. If a procedure gets a bit complicated or takes you a little extra time, you will not be able to perform two or three pap smears. I would like to be able to organize my activities, but there is so much to be done by one person, and also there is so much administrative work.

Lack of supplies Primary care personnel: doctor In primary care clinics we are tied of hands, because sometimes we do not even have medicines, so to do specific studies is very difficult.

Insufficient infrastructure Primary health care: social worker We are very tight as you can see, there are no spaces, obviously the planning of this unit was a result, as in many cases, to an emergent situation, and there is no planning for the future, they do not have that kind of vision, that the population is going to keep growing.

Lack of personnel Primary care I was in a health center and they moved the nurse suddenly, the nurse had to do another nursing activity and she was called from one day to the next, suddenly. So, if you have programmed activities with a nurse, you cannot perform them as planned because suddenly they have sent him/her to another site.

	personnel: doctor	
Lack of interest	Primary health care: social worker	I am sincere, if someone is not interested, for example: there will be a partner who will propose you a new program and if that person is not interested so how I am going to work in that project? more if it's his/her job, I'm going to support you but if you're not enthusiastic, how I'm going to get excited if you do not
Distant medical appointments	Male lay participant	And then, you have the appointments after a month. Now, for example, there are no appointments until March, April of the next year, there are no appointments, since June, July, since October there are no appointments for this year.
Long waiting time	Male lay participant	It takes a whole day at the health center to get an appointment, all day one goes to be there
Administrative procedures	Primary care personnel: doctor	Lately I don't go to my social security clinic anymore because there is too many people, they cannot treat us all. One arrives, takes a turn, and they send you to do the single line to wait to see a doctor, but not your family doctor. If you have studies you do not see your doctor, you have to see another one, it's such a big mess! So, what is the point of going there?
<i>Interpersonal level</i>		
Peers' fear of colonoscopy	Primary health care doctor	Well, it's fear, right? Fear of the procedure (colonoscopy). More if a neighbor or relative tells them that colonoscopy is very painful. I think that would be a barrier.
<i>Individual level</i>		
Fear of colonoscopy	Female lay participant	But that study is dangerous, right? You can die there or something? ... because they put a tube all the way up to here... I'm afraid I could die.
Fear of finding out about a serious disease	Female lay participant	I believe that when people already have certain symptoms and they need to have the study done, they have fear to be told they have a disease. That is what happened to my son-in-law. He was afraid to be told that he had cancer... that they will find something bad in him.
Embarrassment of having a colonoscopy	Female lay participant	I would be embarrassed that a doctor sees me, that a doctor introduces a camera, through my rectum.
Lack of time for use of health services	Male lay participant	Those comments are very frequent among my friends ... "They fired me from work, I went to the doctor, and it turns out that they fired me and right now I am unemployed." So I think: I have a job and I will take care of it. So that's what worries me, you do the study or not, but how are you going to detect your illness in your body? For example, now I have about four or five years since I found a job, which was hard to find.
Procrastination	Female lay participant	I have invited people to many programs and they tell me, oh yes, lets see, some day, once I decide I'll go, let me check when I have time.
Disinterest towards health	Primary health care: social worker	I also believe, sorry to be very rough, but I think that some patients have no strengths. You call them for follow-up and referral and: "I haven't been able to go, I am not interested, the hospital is too far away". I tell them, it's your health, I mean cancer is a priority, but people do not go, even if they have dysplasia or BIRADs 4, they don't go. They make up a thousand excuses.
Preference for traditional medicine	Primary health care: social worker	Many times there are people who have already arrived here from the countryside and they are not used to the use of medicines, they want to return to natural treatments, naturists, herbs, teas. There are people who are diabetic and say "I am going with a naturalist doctor and the doctor tells me that he will cure me ... they swear that they are going to be cured of diabetes and when they come back with us they come in very uncontrolled states and it is very difficult.

Distrust in public medical services	Male lay participant	What do people go to IMSS for? What do people go to see the doctor for? If they don't not give an adequate answer to your illness, so, what for? It's better this way, I prefer to look for a doctor close-by, even if I have to pay, it is better quality and it doesn't take all day long to get an appointment.
Reluctance to use health services	Male lay participant	Because one as a man has a little pain and we think that it will disappear, and we continue working, but you do not know if that is advancing, it is progressing and when it is until it is well advanced that you regret it.
Low perceived risk of CRC	Male lay participant	Well, one as a man does not know, because the ladies get breast cancer. I've heard only women with cancer, not men.
Non-acceptance of biopsy	Endoscopy medical personnel	There were 8 patients who still did not come to schedule their colonoscopy study, so I started to communicate with them and one of them, told me that she already knew about the program, but she did not want it because of the biopsy.
Lack of self-care	Primary health care: social worker	Thirty percent do not return for their results, they do not do it for indifference, not self-care, not being responsible for their own health
Low self-esteem	Female lay participant	For all that we carry as women, like stress, illnesses are for us, so if we as women do not love ourselves then we 'll die tomorrow.

**Table 4. Participant quotes of perceived facilitators to colorectal cancer screening**

Code	Informant	Quote
<i>Health policy level</i>		
Appropriate communication campaigns	Endoscopy unit medical personnel	I think that if you educate people, and the program is promoted through radio, television, newspapers, if the information is appropriate and concrete, talking about a general population, this could help get more people to accept the procedure.
<i>Social context level</i>		
Participative population	Primary health care personnel: social worker	I believe that this population is participative, if you ask for their support, and offer a service, they organize themselves and they participate.
<i>Organizational level (health services)</i>		
Preference for same-sex doctors	Female lay participant	Oh, when they tell you about the Pap smear, no!! How? And if the doctor is a man doctor, worse, you say no, no, no!. The doctor has to be female.
Doctor communication skills	Primary health care personnel: doctor	Well, there are certain skills a doctor should have: empathy, the power of communication so that there is no barrier with the patient, the skill to talk with the patient and to be persuasive.
Good experiences of health service use	Female lay participant	I have been very lucky because I have always been treated very well in social security, there my daughters were born, my husband has had several surgeries, in fact, I have run with luck that my family doctor identified myself
Good working environment	Primary health care personnel: nurse	I have felt very good here, the work environment is very good, all my colleagues focus on their work and everyone is in charge of doing their part, the atmosphere is very good
Quick referral to diagnosis and treatment	Male lay participant	Because if they give you a direct pass with the results of the positive FIT from the health center to the hospital, then is possible they do attend us quick
Delivery of FIT in health center	Female lay participant	It would be wonderful if the FIT could be given out here in the health center.
Gratuity of screening tests	Female lay participant	How wonderful if the test were free. I think all the people would get it done. There would be no exceptions.
CRC screening promotion at clinics	Primary health care personnel: nurse	The promotion could be made in the health center, there could be an exclusive module for this, so that patients are given exclusive attention.
Good doctor-patient relationship	Female lay participant	I have been very lucky with the attention I have received at IMSS. I delivered my daughters there and my husband has had several surgeries, and they treated us very well, in fact, I have been lucky. My family

doctor knows who I am, even though they treat many patients and usually they don't know the patients' names, my doctor recognizes me and we have a good doctor-patient relationship.

Motivated health care personnel Primary health care personnel: doctor Having that kind of patients motivates us to keep working, reading, studying and everything, because many things or diseases that we, or I personally did not think were so common, but actually are, I think it is important to go back and study them, that motivates me.

*Interpersonal level*

Social Support Female lay participant And the family sometimes encourage you, family support is important to encourage you

Experiences of people with cancer Male lay participant

I have a testimony from a friend who died 1 year ago. He was feeling ill, they say the body gives warnings, but sometimes that is not so, we don't give it importance. With my friend, I don't know how long it was that he fell ill, but when he went to get the medical studies done they found he had stomach cancer.

*Individual level*

CRC information Male lay participant Well, I think this is very important, just like right now with the attention we are getting from you. I think that people would be motivated if they here this information and say it is important that we have that care and get the test to see what I have, right?

Interest towards health Primary health care personnel: social worker I believe that the interest in their health is very important, the interest in their health would be a patients strength

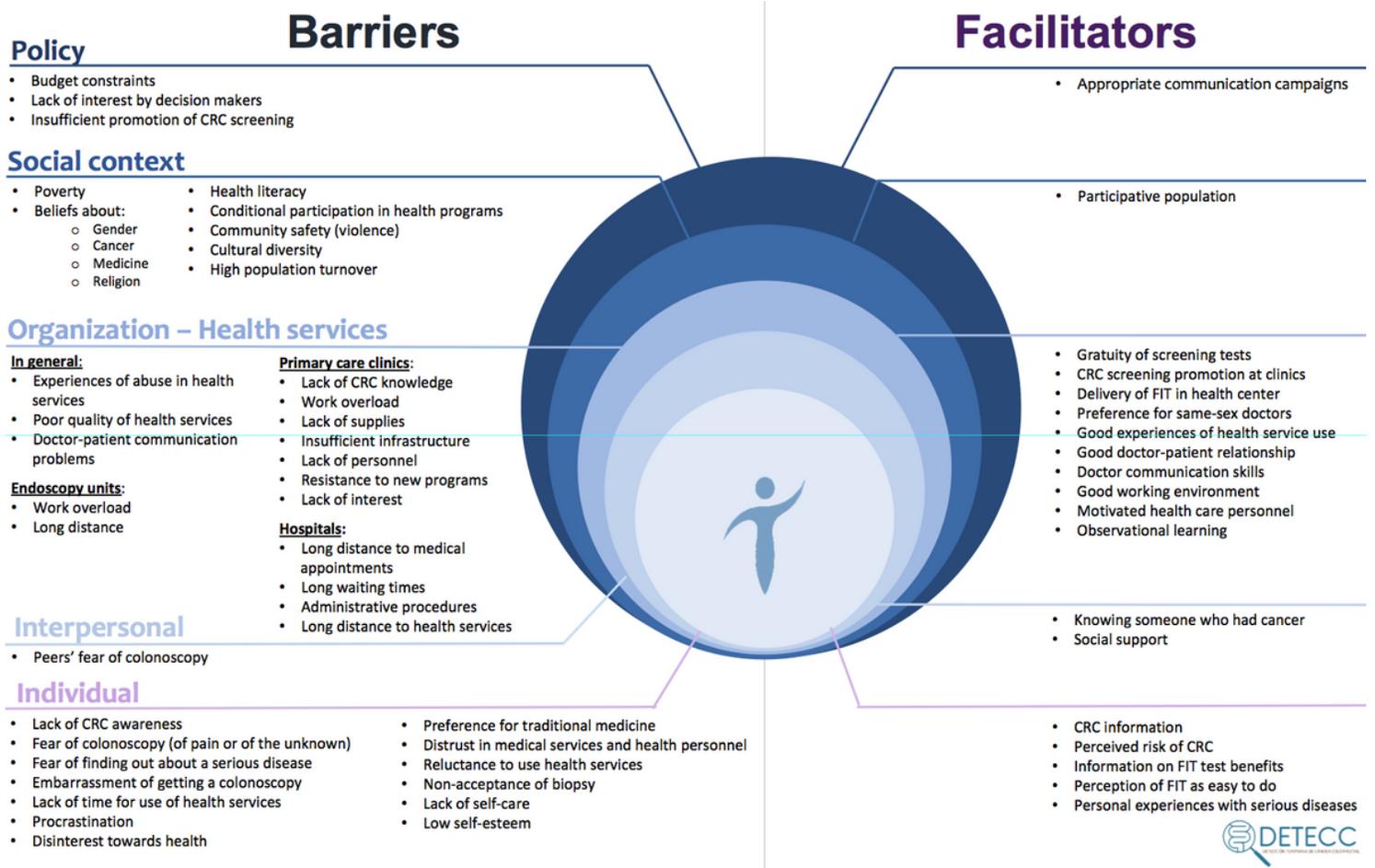
Perception of FIT as easy to do Female lay participant The test is not difficult, I can do it by myself and nobody will know, nobody will notice. I take my test where I have to and done.

Information on FIT test benefits Female lay participant It is a very, very effective and necessary test because if we do not find out that there is such a test, we can not prevent cancer

Perceived risk of CRC Female lay participant Anyone can get the illness, anyone can get sick right?, I do not know the reasons, sometimes there is no reason and people get cancer, so if we have the opportunity to get information about the disease, well, it is good to know what is happening.

Previous experiences with serious diseases Male lay participant With what I already suffered with a disease that I had, the truth is that I would do the colonoscopy.

# Figures



**Figure 1**

summarizes our findings. It represents the perceived barriers and facilitators for participation in a CRC screening program in this community at the different levels of the Social Ecological Model, where all levels interact with each other. Representative examples of participants' quotes for the most relevant codes are

## Supplementary Files

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- [StandardsforReportingQualitativeResearchA.21.pdf](#)