

# Colorectal cancer screening barriers, facilitators, and promotion recommendations by Alaska Native people who are non-adherent to colorectal cancer screening

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## Abstract

**Purpose:** We examined barriers and facilitators to colorectal cancer (CRC) screening among Alaska Native individuals who had never been screened or were not up to date with screening guidelines.

**Methods:** As part of a larger study investigating the use of the multitarget stool DNA test in rural Alaska communities, we conducted focus groups and in-depth interviews with 28 never screened or not up-to-date Alaska Native people in two remote communities between November 2022 and July 2023. Participants shared their barriers to CRC screening and offered suggestions to improve programs to better reach those who are guideline discordant.

**Findings:** General screening barriers included lack of knowledge, fear of discovering you have cancer, and cultural health beliefs. Colonoscopy-specific barriers included embarrassment from knowing the local medical staff, having rectal area viewed or touched, fear of pain and injury, difficulty scheduling a procedure due to traditional food gathering activities, lack of provider referrals/reminders, and the high cost of air travel required to get to a colonoscopy facility. Stool DNA-specific concerns included not feeling that it was as good as colonoscopy, lack of privacy to do the test, and hesitancy collecting stool samples. Suggestions for increasing screening rates included increasing access via paid air transportation, using local indigenous languages, improving provider relationships and reminder systems, and providing CRC and screening education using trusted messengers.

**Conclusions:** This was the first exploration of the perceptions of CRC screening among guideline discordant Alaska Native people. Identified themes can be used to improve screening program outreach effectiveness in the future.

## KEYWORDS

Alaska Native, colorectal neoplasms, early detection of cancer, health promotion, qualitative research

## INTRODUCTION

Screening for colorectal cancer (CRC) can help prevent new cases of CRC and deaths due to the disease.<sup>1</sup> United States Preventive Services Taskforce (USPSTF) national guidelines recommend CRC testing for all adults ages 45–75 years old.<sup>2</sup> Between 2015 and 2020, American Indian and Alaska Native people in the United States experienced higher colorectal cancer incidence (48.6 vs. 35.7 per 100,000 people) and mortality (18.6 vs. 13.1 per 100,000) than the White population.<sup>3</sup> For Alaska Native people alone, rates are even higher. In 2018, the CRC incidence rate among Alaska Native people was 61.9 per 100,000 – the highest recorded rate in the world.<sup>4</sup> Due to concerted efforts within the Alaska Tribal Health System, CRC screening has increased among Alaska Native people, with 56.2% of Alaska Native people between the ages of 45–75 years up to date with CRC screening in 2021.<sup>5</sup> Despite improvements in screening rates, this is still well below the United States Healthy People 2030 goal (68.3%) and the 80% in Every Community National CRC Roundtable goal.<sup>6–9</sup> There is a critical need to understand why Alaska Native people might not choose to get screened, or are overdue for re-screening or surveillance exams. Previous studies have shown that offering different screening options can help improve screening uptake.<sup>10</sup> The primary screening option available in the Alaska Tribal Health System is colonoscopy, with limited use of fecal immunochemical stool testing. To expand the options for home stool testing, the multitarget stool DNA test (Cologuard®, Exact Sciences, Madison WI) is being considered but has not yet been adopted in the Alaska Tribal Health System.<sup>11</sup>

In 2017, Alaska Native people aged 40–75 years in three rural/remote regions in Alaska and their health care providers completed mailed questionnaires on their willingness to use mt-sDNA testing if offered, as well as their perspectives on how it might compare with colonoscopy for CRC screening. Over half of those surveyed stated a preference for colonoscopy over the mt-sDNA test. Primary mt-sDNA barriers included the belief that colonoscopy was a better test and not knowing how to do the mt-sDNA test since it had never been used in the region before. There were, however, barriers reported for colonoscopy including the cost of travel to endoscopy facilities and requirements for bowel preparation. That study concluded that adding mt-sDNA as a screening option could potentially raise screening rates among Alaska Native people if coupled with information about its effectiveness and education on how to complete the test.<sup>12</sup> A subsequent study which surveyed Tribal Health System providers noted provider turnover and the need for better screening reminder tools in the electronic health record system as barriers to effective CRC screening for this population.<sup>13</sup> However, no study to date has examined perspectives on CRC screening from the viewpoint of screening-eligible Alaska Native people who have never been screened or who are not up to date with screening guidelines.

## METHODS

As part of a larger study investigating the use of the multitarget stool DNA test (Cologuard®) in rural Alaska Native communities,<sup>14</sup> we con-

ducted focus groups and in-depth interviews with Alaska Native people ages 45–75 years old who had never had CRC screening or who were not up to date with screening (colonoscopy more than 10 years prior or stool testing greater than 12 months prior). Non-screened individuals were identified through an electronic health record query and contacted via telephone to participate in the focus groups. Interested persons who could not attend a focus group were offered the opportunity to take part in individual interviews in person or by telephone. All participants provided signed informed consent. The focus groups were co-facilitated by an Alaska Native staff member (DB) from the regional tribal health organization supported by a non-Alaska Native research consultant (MT). Focus group participants received a USD \$50 gift card and interview participants received a USD \$25 gift card in appreciation for their time. The study was approved by the Alaska Area Institutional Review Board (IRB #2019-04-038) and the Alaska Native Tribal Health Consortium and the Yukon-Kuskokwim Health Corporation tribal research review committees.

## Study setting and recruitment

The Yukon-Kuskokwim Delta region in southwest Alaska is about the size of the state of Oregon. It is not connected by roads to the rest of Alaska, and is an USDA Economic Research Service-defined Frontier and Remote (FAR) Level 4 Zip Code Area, in which the majority of the population is living more than 15 min away from urban areas of 2500 or more people.<sup>15</sup> Health care, including CRC screening, is provided by the Yukon-Kuskokwim Health Corporation to both Alaska Native and non-Native peoples in the region. Services include a regional hospital in the hub community of Bethel, subregional clinics in five communities, and 41 community clinics staffed by community health aides. CRC screening using colonoscopy requires travel to the hub community by boat, snow machine, or airplane, or flights to Anchorage if at risk for colonoscopy complications.

Alaska Native adults ages 45–75 who were due for screening and living in one remote community (population size ~800) only accessible by small aircraft or living in the larger regional hub community (population size ~6200) who had never been screened or were due for screening were invited to participate in the focus groups and interviews ( $n = 305$ ). Study staff were able to contact 203 people (67%) to invite them to participate in the study. Thirty individuals (15%) agreed and provided informed consent, and 28 (14% of those able to be contacted) participated in a focus group or in-depth interview.

## Data collection

The Reach Effectiveness Adoption Implementation Maintenance (RE-AIM) framework guided the overall study design,<sup>16,17</sup> while the focus group and key informant interview guides were informed and developed to elicit beliefs and preferences using the Health Belief Model.<sup>16,18,19</sup> The same guide was used for the focus groups and individual interviews and was composed of open-ended questions about

the mt-sDNA test and colonoscopy including discussion of multilevel barriers and facilitators for screening with each test, feedback on the mt-sDNA test instructions, and suggestions for how to improve programs to better reach non-guideline concordant Alaska Native community members. Focus groups were stratified by gender and each participant provided demographic information (gender, age, and community).

Previous studies indicate that 80%–90% of themes will be discovered in two to three focus groups.<sup>20,21</sup> We completed three focus groups, supplemented by 10 in-depth interviews to reach data saturation. The first focus groups were held in the hub community at the regional hospital in November 2022 during the COVID-19 pandemic. COVID-19 protocols required rapid COVID-19 testing of participants immediately before the focus group and the use of masks during the group discussion. Masks with a transparent plastic window were used to allow focus group participants and moderators to view facial expressions. Offering and sharing food is an important cultural value in the region. Participants were offered food before the focus group with space between each participant while eating according to COVID-19 protocols. For the men's focus group in the hub community, an Alaska Native male elder who is a Calricaraq Program leader assisted with the group discussion and provided cultural insight during the focus group debriefing. Calricaraq is a training program for health care staff in the region that uses Native values and teachings from elders to guide individuals and communities as they deal with trauma and seek healing.<sup>22</sup> The second set of focus groups in the hub community and the remote community were held in May 2023.

Given that participants were not currently up to date with CRC screening guidelines, the tribal health system asked that CRC screening options be offered to study participants at the completion of the focus group/interview. Two people were interested in colonoscopy after participating in the focus groups/interviews and were connected to a patient navigator for scheduling, although it is unknown whether they completed screening. Four never-screened individuals requested and were provided mt-sDNA kits of which two were completed and returned for laboratory processing.

## Data processing and analysis

The focus groups and interviews were recorded and transcribed verbatim using Temi software (version 2.4, [www.temi.com](http://www.temi.com)).<sup>23</sup> After transcription, the text was reviewed and corrected for errors by trained coders (MT and CF). We conducted an inductive analysis identifying thematic codes and grouped them into categories and subcategories<sup>24</sup> across the individual- and systems-level of the social-ecological model.<sup>25</sup> We then created a thematic codebook and analyzed the data using Dedoose qualitative analytic software.<sup>26,27</sup> An inter-rater reliability test conducted on a 10% subsample with two coders (MT and CF) resulted in a Cohen's kappa statistic of 0.88, indicating acceptable reliability and consistency in data excerpt coding.<sup>28</sup>

**TABLE 1** Study population characteristics ( $n = 28$ ).

	Participant count (%)
<b>Gender</b>	
Men	16 (57%)
Women	12 (43%)
<b>Age</b>	
Range	45–71 years
Mean	55 years
<b>Screening status</b>	
Never screened	24 (86%)
Due for screening	4 (14%)
<b>Place of residence</b>	
Hub community	18 (64%)
Remote community	10 (36%)
<b>Type of participation by gender</b>	
Focus group—men	10 (36%)
Focus group—women	8 (29%)
Interview—men	6 (21%)
Interview—women	4 (14%)

## RESULTS

### Study population

Of the study participants ( $n = 28$ ), 57% were men and 43% were women (Table 1). The age range for participants was 45–71 years; mean age 55 years. Eighty-six percent (86%) of participants had never been screened before and the remaining 14% were overdue for re-screening. Two-thirds (64%) were from the rural hub community, and one-third (36%) lived in the smaller remote community. Ten men (36%) and eight women (29%) participated in focus groups, and six men (21%) and four women (14%) completed individual interviews.

### Study themes and subthemes

Several themes and subthemes emerged from this qualitative inquiry on CRC screening among screening guideline discordant Alaska Native people, including general individual- and system-level barriers to screening, as well as individual- and system-level barriers specifically for colonoscopy and mt-sDNA. Participants also noted multiple facilitators that might be used to help increase screening rates among unscreened and overdue individuals (Table 2).

### Individual-level general barriers to CRC screening

#### Lack of knowledge

Participants had extensive questions about CRC and screening, including: What is cancer in general, what causes it, what are the risk factors,

**TABLE 2** Themes and subthemes of provider and system barriers and facilitators to CRC screening with colonoscopy or multitarget stool DNA.

Theme	Subtheme
<b>Individual-level barriers to CRC screening in general</b>	
Lack of knowledge	<ul style="list-style-type: none"> <li>• Not knowing that CRC can have serious consequences</li> <li>• Not knowing what a screening involves</li> </ul>
Fear of cancer diagnosis	<ul style="list-style-type: none"> <li>• Afraid they won't be able to continue to be active if they have cancer</li> <li>• Afraid of what happens if they have cancer</li> <li>• Yup'ik word for cancer means it is incurable</li> </ul>
Cultural beliefs and practices	<ul style="list-style-type: none"> <li>• Inner strength and stoicism and living simply to prevent illness (screening not needed)</li> <li>• Mistrust of western medicine and providers</li> <li>• Subsistence activities more important than screening</li> </ul>
<b>Individual-level barriers to colonoscopy</b>	
Embarrassment	<ul style="list-style-type: none"> <li>• Medical staff being friends or family in a small community</li> <li>• Having rectal area viewed/touched</li> </ul>
Fear of pain or injury	<ul style="list-style-type: none"> <li>• Fear of not waking up from the anesthesia</li> <li>• Fear related to painful medical incidents in the past</li> <li>• Having an unpleasant experience with a colonoscopy in the past</li> </ul>
<b>System-level barriers to colonoscopy</b>	
Cost of travel	<ul style="list-style-type: none"> <li>• Costly travel to screening colonoscopies not covered by Medicaid or the tribal health system</li> </ul>
Provider recommendations and reminders	<ul style="list-style-type: none"> <li>• Not all providers discuss screening with their patients</li> <li>• Some participants had not received a reminder letter</li> <li>• Some participants misplaced the reminder letter</li> </ul>
<b>Individual-level barriers to mt-sDNA</b>	
Embarrassment	<ul style="list-style-type: none"> <li>• Embarrassment at handling stool sample</li> <li>• Not having privacy in their home to do the test</li> </ul>
<b>System-level barriers to mt-sDNA</b>	
Lack of confidence in successfully mailing kit	<ul style="list-style-type: none"> <li>• Fear that weather will delay the mail and prevent kit from being processed in time</li> <li>• Not wanting to repeat test if it doesn't reach the destination in time</li> </ul>
<b>Screening facilitators in general</b>	
Patient/provider collaboration	<ul style="list-style-type: none"> <li>• Providers engaging with community members</li> </ul>
Community education	<ul style="list-style-type: none"> <li>• Outreach in local Alaska Native language</li> <li>• Use local community distribution channels to share screening message</li> <li>• Use local leaders as trusted messengers</li> <li>• Include screening message in community and high school health care classes</li> </ul>
<b>Colonoscopy facilitators</b>	
	<ul style="list-style-type: none"> <li>• Paid air travel to endoscopy facilities</li> <li>• Translators available for procedures</li> <li>• Supportive clinic staff, including choice of male or female provider</li> <li>• Incentives for test completion</li> </ul>
<b>Mt-sDNA facilitators</b>	
	<ul style="list-style-type: none"> <li>• Local test kit distribution</li> <li>• Improve kit instructions and verbiage</li> <li>• Show how-to videos in the clinic</li> <li>• Alternate methods of stool collection</li> </ul>

The bold refers to the topic area. The first one is general barriers, then the second is individual-level barriers to colonoscopy and then system-level barriers to colonoscopy, and then individual-level barriers to mt-sDNA, and so on.

and is it hereditary? What are CRC symptoms, signs, and location in the body? Who is at high risk for CRC? How do you prevent CRC? How do you get scheduled for a colonoscopy, what does it test for, and when should you get screened? How accurate is the mt-sDNA test, how long has it been used, and has it been tested? Participants noted that more knowledge about CRC and colonoscopy in the community would be helpful. One person said that he went with his father to get a colonoscopy, and he still did not know what it was. He also said: "That is

*the one main thing that I think is keeping people from taking that stool test or having a colonoscopy [is not knowing] the seriousness of this disease. We should educate the villagers and let them know that it is a life and death situation... education is the key, and having a translator there with educators is important."*

When asked if people in their community talk about cancer, one woman said, "No, not from what I see nobody talks about it." Another woman said that the lack of knowledge about what the procedure

entails can cause fear: “*Maybe more information would help [...]. I was afraid, and I brought my daughter [to have a colonoscopy], and that really alleviated most of my fears.*”

### Reluctance to get screened or fear of cancer diagnosis

Some participants reported a general reluctance to get screened, despite knowing that it might be beneficial. One man in the remote community, when asked if he would get screened, responded: “*Everything in my body and in my mind is saying ‘no.’ But I know I have to. Sooner or later, I might as well get it done and over with.*”

Participants also said that people did not get screened because they were afraid to learn they had cancer: “[*People*] don’t want to take the test. [*They are*] scared that they might have it or afraid that if they do have it, what’s going to happen—that they won’t be able to do the things that they used to do.” One person explained that the local Yup’ik Alaska Native word for cancer means incurable and that the word was created at a time when having cancer almost always led to death.

### Protection provided by traditional lifestyles and beliefs

Male participants, in particular, noted that feeling healthy and living an active, traditional lifestyle makes people feel that they are not at risk and that CRC would not happen to them: “*We live in such a way culturally... if you are a subsistence hunter and so physically active, getting out in the boat, out riding a snow machine, running through the forest chasing down moose, running up on top of the ice to chase down walrus or a seal, whatever. The last thing you are thinking about is a colonoscopy.*” One male participant noted that culturally, Alaska Native people believe in an inner strength and stoicism that works to overcome things with simplicity. He said that Alaska Native people have faced many physical and medical challenges, and they strongly believe in their own system of healing and living that prevents ill health, which could make people think there is not a need for screening.

Related to these cultural beliefs and practices, several participants said that men specifically are reluctant to visit the local clinic. One woman said, “*I know a lot of stubborn guys here that wouldn’t go to the clinic for nothing.*” Discussion in the women’s remote community focus group included a feeling that only women are “supposed” to use the health clinic.

### Colonoscopy individual-level barriers

#### Embarrassment

Some participants reported that a barrier to getting screened via colonoscopy is embarrassment caused by having a provider see or touch their rectal area, as well as the invasiveness of the test. This embarrassment can be amplified by the fact that in small communities, people often know or are related to clinical staff: “*We basically know*

*everybody here, and it is kind of embarrassing. Especially people here in the hospital, the nurses, and some providers we know. I was supposed to get one myself—I’m not going to do it here.*”

### Fear of pain and being hurt

Participants mentioned fear of being hurt by the procedure as a barrier to colonoscopy: “*Probably [people fear] the doctors, needles, or that they might not wake up from anesthesia or whatever they are given. One of my closest friends, when I was a child, she passed away from surgery.*” A few participants previously had a colonoscopy and said they would not do it again because of pain and discomfort: “*I’ve gone through the process. It’s horrible. I don’t ever want to do that again. I was told at the time the results were fine except that they brought me back in five years. I didn’t go back. I don’t plan on it.*” She went on to explain that the prep was uncomfortable and interfered with her getting rest, and the sedation given during the procedure knocked her out for the entire day. Another participant said she would not do it again because there was pain and leakage afterward.

### Subsistence activities interfere with scheduling colonoscopies

Participants mentioned that participation in subsistence activities, which provide food for their family for the entire year, can prevent community members from scheduling an appointment: “*There is a life cycle of our Native subsistence. There’s a peak of opening where people could probably have their check-up. You need to find that fine line where that time is to schedule it. The hospitals have to be ready, they got to leave that one period open.*”

### Colonoscopy system-level barriers

#### High cost of travel

Many respondents noted the cost of travel as a barrier to screening. Although the tribal health system covers the cost of the colonoscopy itself, airfare and lodging and food for the patient and their escort is not covered: “*That is the number one thing outside of the cultural context. You can only get to these places by air travel. The cost is crazy. You are talking about people living in third and fourth world type of socioeconomic situation and you’ve got costs that are just phenomenal for air travel.*” Another participant said: “*I’m up for it, you know, I’m ready [to get a colonoscopy]. I’m due for one. It’s just I’m not working at the moment. So, I can’t afford the fare over and back.*”

### Provider recommendations and reminders not consistently reaching community members

Several participants said their provider had asked if they had had a colonoscopy: “*I went in for something else, and someone said to me, [W]ell*

...sir, you're a little over 50 years old. When's the last time you had your guts checked and lower guts checked, and your rectum for colonoscopy.' And I was like, 'What the heck is a colonoscopy.' He explained it to me and once I understood accurately what was going to happen, I went: 'Let's get this done.'" Other participants said that their providers had not talked to them about screening: "I did ask for a colonoscopy test, but I never got a response from anyone. Not from the provider that I saw at the time—they never responded. I never got word. I'm still waiting."

The local tribal health organization sends out patient reminder letters to alert people to the need for CRC screening. Some participants said that they received a letter and that it was helpful. Others did not receive a letter, and some received it but didn't act on it: "I think I did get a letter about it, but then I misplaced the letter. When you get a lot of mail, I sometimes forget to reread the letters, and I trash them."

## Mt-sDNA individual-level barriers

### Embarrassment

Some participants stated that they did not want to have to take a sample of their stool or do the test at home: "In a village, having to do that in a family setting would be kind of embarrassing. So, I think that would need to be done in a clinic." A participant mentioned that in some Alaska Native communities the lack of running water or flushing toilets in the home would make it difficult to use the stool kit successfully, with one suggestion given to add disposable gloves to the kit to help people feel more comfortable handling the kit materials and their stool.

## Mt-sDNA system-level barriers

### Lack of confidence in successfully mailing kit

Many participants expressed concerns about the arrival of the mt-sDNA test kit to the lab within the allotted time limit. In rural and remote Alaska areas, it is common for plane travel to be delayed by the weather. One woman said, "Sometimes we don't even get mail out of here for nothing. See, that's why I think the colonoscopy would be better than the kit being stuck in the clinic for one week and then you got to do it all over again."

## Differences in reported barriers between men and women

Both men and women reported similar barriers, although men mentioned more barriers overall than women. Reasons for not getting CRC screening mentioned by men but not women included not using the medical system, being too proud, stubborn, or feeling shame, or having to fill out required paperwork. Barriers to getting a colonoscopy stated by men but not women included that Alaska Native people may lack motivation to get the test, that the extensive prep may be a barrier, and

that test scheduling may be difficult because of having to do traditional subsistence activities, as well as feeling that colonoscopies are not consistent with Alaska Native culture. When asked about barriers to using the mt-sDNA test to get screened, the only additional barrier that men had that was not reported by women was being worried about the kit being delivered too late to the laboratory due to slow mail service.

## Screening test preference

When participants were asked which screening test they preferred, the responses were mixed. Some preferred the stool test to colonoscopy because they would not have to go to the hospital or pay for travel to have it done, and it is not invasive: "...[A] lot more people are gonna do this more than they are the colonoscopies. Because colonoscopies is totally foreign to our bodies. This is a normal bodily function." A participant who had a colonoscopy in the past said that they would prefer to be screened with the mt-sDNA test instead of doing another colonoscopy because "the tube was like a foot long—I couldn't do that again. I felt violated."

However, others preferred colonoscopy because they didn't trust that the mt-sDNA test was as good, they did not want to collect the stool sample, or the test would be "too much work." One participant explained: "It would really depend on somebody's experience. Number one: what has their experience been? I mean, if they're really independent like myself, they'd rather do it themselves. And then if there are people who are the codependent types of thinking, they're going to want somebody else to do it [colonoscopy] saying, 'I don't want anything to do with that [stool kit].' So, realistically it's what your norm is? In terms of being able to get this done one way or another, I would have both on the table as an option."

## Facilitators to promote screening

### Collaborate instead of lecturing

One participant relayed a story about seeking medical care for frostbite. After an unsuccessful interaction with one physician, he was treated by an Alaska Native doctor who collaborated with him rather than lectured him, an approach that he felt would be most helpful when trying to encourage people to get CRC screening.

## Increase knowledge in the community about CRC and screening

Many participants suggested that screenings would increase if people learned more about CRC prevention through community outreach. It was suggested that this outreach should be in both English and Yup'ik, and should use the following methods and distribution channels: Local radio talk shows; public service announcements; videos in the clinic; posters at the local grocery store; information in the tribal health organization newsletter, local newspapers, Facebook and other social media sites; notifications to family members of those with CRC; mailed

informational pamphlets; and phone calls and reminder letters to those due for screening. Participants noted that the “messenger” should be influential spokespersons such as community leaders, local people who have done the test, or Alaska Native people who have survived cancer. Participants also suggested that the tribal health organization board should be involved with outreach, that health care classes in the community should be offered that cover CRC and screening options, and that teenagers should learn about cancer screening in school.

### Facilitators for screening with colonoscopy

Participants suggested the following facilitators for screening using colonoscopy: pay for air transportation, room, and board for the person and medical escort; have translators present or translation available; train staff so they are supportive, kind, and encouraging to alleviate fear; have the choice to schedule with a male or female provider; and offer incentives for test completion, such as inclusion in a raffle for airline tickets.

### Facilitators for screening with the mt-sDNA test

Participants suggested that mt-sDNA kits could be distributed at the local clinic, store, and community events. They suggested sending people home with kits and telling them to do the test if the weather is good to ensure that the mail goes out on the next plane, so the kit gets to the lab on time. If the weather is bad, they suggested telling people to wait to do the test. Some participants felt the instructions were clear and understandable, and the pictures were good. However, some felt that the instructions needed to be shorter with less steps, the font needed to be bigger, and the content should be translated into the local indigenous language in addition to English. It was also suggested that English medical words such as “bowel movement” could be changed to something more commonly used, like “poop.” Participants also suggested that clinic staff could demonstrate the kit, or people could be shown a short video on how to do the test. Some participants felt that people should have the choice to do the kit in the clinic, and the staff could carry out the other steps once a person had a bowel movement in the sample container.

## DISCUSSION

This qualitative study among non-screening guideline concordant Alaska Native people found individual-level barriers that if addressed could help increase CRC screening, such as increasing general knowledge in the community about the significant impact of CRC and the benefits of CRC prevention as part of a healthy Alaska Native lifestyle, as well as addressing concerns about the invasiveness of colonoscopy and handling stool samples. There were also system-level factors that could be addressed, including paying for airfare for required travel to obtain colonoscopy, more providers strongly recommending screening

during health care visits, and improvements in screening outreach letters to help engage people to seek out screening. The focus groups and in-depth interviews demonstrated that adding the mt-sDNA test as an option for CRC screening could also attract people not currently concordant with screening recommendations who are reluctant to get a colonoscopy if issues like test viability and sample handling could be resolved.

Of note, there were several concrete suggestions for intervention provided by participants that if implemented might increase screening in this population. For example, including disposable gloves in stool kits may help allay concerns about handling stool samples. Holding a concerted campaign to encourage age-eligible community members to complete stool testing during months with anticipated better weather like the springtime might address issues around mail service and weather-related flight delays. System improvements which facilitate patients traveling together for colonoscopy to reduce the number of people required for medical escorts would also help with travel and financial concerns. Lastly, having local survivors and peers who had been screened share their stories or lived experiences would help to help reduce the fear of cancer and increase understanding of the importance of screening and early intervention. Men especially noted more barriers to screening including not accessing the medical system or being busy engaging in traditional subsistence activities. Patient navigation which includes asking questions about the best time to schedule screening, offering tests that are non-invasive, or providing assistance completing paperwork, might help address some of these barriers more effectively.

The individual-level results in our study align with studies among other US tribal and non-tribal communities which have found a lack of knowledge about CRC and screening, lack of provider recommendation/reminder system, lack of transportation, fear of cancer being found, fear of embarrassment/pain, and mistrust of western medicine as barriers to screening.<sup>29-33</sup> Men, especially, in our study reported many of the same barriers reported in other studies, including fear of embarrassment/pain, less engagement with the medical system, and concern over mailed samples getting back to the lab in a timely manner. In contrast to a study of American Indians in North Dakota,<sup>31</sup> the present study did not find a focus on other health problems or a lack of CRC tailored health promotion as barriers to screening. Our study findings that differ from other studies include self-reported Alaska Native cultural beliefs around preventing illness, a desire to collaborate with clinicians, and the importance of scheduling screening around traditional subsistence activities. The system-level barrier of community members not being reminded to get screened was also noted in our previous work interviewing Alaska Tribal Health System providers within the same region.<sup>13</sup> Other studies have also noted that screening could be increased if barriers like requiring medical escorts and a person to drive someone home after colonoscopy could be eliminated.<sup>34</sup> This has not been examined in the Alaska Native context but would be a good topic for future research.

This exploration is valuable because it gathered suggestions from Alaska Native people who are due for a screening on how to successfully promote and facilitate screening for themselves and their



neighbors. This is important because rural and remote areas have unique characteristics due to culture, geography, and access to resources, which make it essential to design screening approaches that match local needs. Suggestions for promoting screening such as having translators present, supportive and encouraging colonoscopy clinic staff, and offering incentives for screening as well as distributing stool tests at different locations in the community and putting the instructions in a video and/or the local indigenous language were comparable to findings from tribal communities in Oklahoma and New Mexico which provided similar suggestions regarding education, patient reminders, transportation, and patient/provider relationships.<sup>35,36</sup>

There were some study limitations. These include the small overall number of participants and that the study was conducted in only one region in Alaska. Hence, the ability to generalize to other areas and populations is limited. Additionally, more data was collected in the larger hub community as compared to the remote community. There may be more themes that could have been found if the sample from remote areas was larger. Furthermore, all the interviews and focus groups were conducted in English. Richer culturally relevant information may have been elicited in the focus groups if they had been conducted in the local Yup'ik indigenous language.

This was the first exploration of the perceptions of CRC prevention among Alaska Native people who were never screened or due for re-screening. Participants provided valuable suggestions which can be used to implement better screening programs and outreach to increase screening rates among rural and remote Alaska Native people in the future.

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## CONFLICT OF INTEREST STATEMENT

Dr. Rutten provides scientific input to research studies through a contracted services agreement between Mayo Clinic and Exact Sciences. Dr. Kisiel is listed as an inventor of Mayo Clinic intellectual property, licensed to Exact Sciences (Madison, Wisconsin), for which he may receive royalties, paid to Mayo Clinic. He consults and receives research support under a sponsored research agreement between Mayo Clinic and Exact Sciences. All other authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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