

# Patient–Provider Discussions about Colorectal Cancer Screening: Who Initiates Elements of Informed Decision Making?

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**BACKGROUND:** Colorectal cancer (CRC) screening rates remain low among low-income minority populations.

**OBJECTIVE:** To evaluate informed decision making (IDM) elements about CRC screening among low-income minority patients.

**DESIGN:** Observational data were collected as part of a patient-level randomized controlled trial to improve CRC screening rates. Medical visits (November 2007 to May 2010) were audio-taped and coded for IDM elements about CRC screening. Near the end of the study one provider refused recording of patients' visits (33 of 270 patients). Among all patients in the trial, agreement to be audio taped was 43.5 % (103/237). Evaluable patient (n=100) visits were assessed for CRC screening discussion occurrence, IDM elements, and who initiated discussion of each IDM element.

**PARTICIPANTS:** Patients were African American (72.2 %), female (63.7 %), with annual household incomes <\$20,000 (60.7 %), without health insurance (57.0 %), and limited health literacy (53.7 %).

**KEY RESULTS:** Although CRC screening was mentioned during 48 (48 %) visits, no further discussion about screening occurred in 23 visits (19 times mentioned by the participant with no response from providers). During any visit, the maximum number of IDM elements was five; however, only two visits included five elements. The most common IDM element discussed in addition to the nature of the decision was the assessment of the patient's understanding in 16 (33.3 %) of the visits that included a CRC discussion.

**CONCLUSIONS:** A patient activation intervention initiated CRC screening discussions with health care providers; however, limited IDM occurred about CRC screening during medical visits of minority and low-income patients.

**KEY WORDS:** colorectal cancer; cancer screening; communication; decision making.

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## INTRODUCTION

Increased colorectal cancer (CRC) screening rates and advances in treatment are responsible for the decrease in CRC incidence and mortality rates reported in the United States (U.S.).<sup>1–3</sup> Certain segments of the population, however, have not benefitted equally from screening and continue to have elevated CRC incidence and mortality rates.<sup>1,3</sup> The U.S. Preventative Services Task Force (USPSTF) recommends routine screening for CRC by the fecal occult blood test (FOBT), sigmoidoscopy, or colonoscopy for average-risk adults ages 50 to 75.<sup>4</sup> These CRC screening tests, however, are associated with different risks, benefits, and need to be completed at different frequencies causing confusion for some patients.<sup>5</sup> Since CRC screening test options require different patient involvement (e.g. preparation, discomfort, time, cost), patient preference is important to consider for improving screening adherence.<sup>6–8</sup> As such, the USPSTF recommends that patients participate in the decision making process with their provider in order to collaboratively choose a CRC screening test consistent with their preference.<sup>4</sup> Despite this recommendation and that patients have expressed a desire to be involved in the CRC screening decision,<sup>7,8</sup> patient–provider discussions tend not to include all CRC screening test options, possibly reducing patients' likelihood of completing screening.<sup>9–12</sup>

One issue associated with the decision making process for CRC screening is the lack of one agreed definition of what constitutes an informed decision or how to measure it.<sup>13–17</sup> Most definitions include components that address the decision context (e.g. type of health decision), the decision maker (e.g. level of involvement preferred), and other influences (e.g. cost information). Interventions using decision aids to improve patients' decision making about CRC screening have demonstrated improved CRC knowledge and risk perception, have increased intention to be screened, and there are mixed results for improving CRC screening behaviors.<sup>18–26</sup> In addition, decision aids have demonstrated that CRC screening test preferences vary by screening test attributes.<sup>22</sup>

Patients making informed decisions about CRC screening should have information including: 1) the nature of the

clinical decision; 2) the patient's role; 3) alternatives; 4) pros and cons of alternatives; 5) uncertainties associated with the decision; 6) patient's understanding; and 7) patient's preferences.<sup>16,17</sup> In addition, the patients' desire for input from trusted others should be considered in the CRC screening informed decision making (IDM) process.<sup>12</sup> To date, however, only a limited number of studies focused on assessing the IDM elements in the decision about getting CRC screening<sup>9,10,12,27,28</sup> and only a few evaluated IDM elements from recorded patient-provider discussions.<sup>10,12,28</sup> Since a patient-provider discussion is critical for a patient to make an informed decision about CRC screening, the evaluation of patient-provider discussions is important to determine the value of informed decisions on improving CRC screening rates. To that end, the purpose of this study was to evaluate CRC screening discussions for IDM elements and to determine the initiator for each IDM element. Since no previous study has identified the person who initiated discussion of the IDM elements, we thought that this information may be important to develop effective interventions for patients and providers to improve CRC screening discussions, increase screening tests ordered, and increase CRC screening rates in the future.

## METHODS

This observational study (November 2007 to May 2010) was part of a patient-level randomized controlled trial (RCT) designed to test patient activation to increase CRC screening rates.<sup>29</sup> The Institutional Review Board of The Ohio State University approved the protocol for this study.

Patient activation in this study was defined as providing patients with the skills and encouragement to ask their provider for a CRC screening test. Patients were randomized to CRC screening information only or CRC screening information plus patient activation. Findings from the RCT suggest that patient activation significantly increases patient-reported CRC screening discussions, CRC screening tests ordered, and CRC screening test completion.<sup>29</sup>

Briefly, the study was conducted in one federally qualified health center (FQHC) that serves a mostly minority and low socioeconomic status population. Medical records of patients scheduled for any non-acute medical visit were reviewed and patients were then called and asked to participate in a study evaluating two health educational programs. To be eligible, men and women had to be 50+ years old, average-risk for CRC, not within CRC screening guidelines, able to speak and understand English, and had to agree to come to the health center one hour prior to their scheduled appointment.

During the informed consent process, patients in both arms of the trial were asked if their medical visit could be

audio recorded to help develop strategies to improve patient-provider communication. Medical visits were only recorded if the patient and provider both agreed to the recording. Following a face-to-face baseline survey (demographics, medical history, CRC screening knowledge and attitudes, health literacy, desire for shared decision making), patients were randomized to one of two CRC screening educational programs that focused on the completion of the FOBT. Both interventions consisted of a ten minute CRC screening video, a brochure of CRC prevention tips, and time to answer patient questions. In addition, the intervention group video contained a narrative section that activated patients to ask their provider about CRC screening and patients in this group also received a brochure to reinforce the importance of asking their provider about CRC screening. After participants viewed the educational materials, a brief face-to-face survey was completed to measure changes in CRC screening knowledge and attitudes. If both the provider and the patient agreed to have the medical visit audio recorded, a research assistant placed an audio recorder in the examination room and the recorder was removed immediately after the patient's medical visit. Providers and staff were aware that a patient-level CRC screening intervention was being tested; however, they did not know the content of the intervention or that the CRC screening discussions were being analyzed for IDM elements.

In preparation for coding the CRC screening discussions, all audio recorded medical visits were reviewed by two team members for the presence of a CRC screening discussion (JK, KE). CRC screening discussions were transcribed verbatim by one team member (JK) and checked by a second team member (BBO). Two team members (MLK, BBO) met and agreed upon the definition of each IDM element. The eight IDM elements evaluated in this study were: 1) the nature of the clinical decision (CRC screening); 2) the patient's role (desire to participate in CRC screening decision); 3) alternatives (CRC screening test options including not completing screening); 4) pros and cons of alternatives (potential benefits and risks associated with CRC screening); 5) uncertainties associated with the decision (e.g. fear of cancer); 6) patient's understanding (importance of completing CRC screening and/or completing a specific screening test); 7) patient's preferences (CRC screening test options); and 8) input from trusted others (family member or friend).

After jointly coding a medical visit's CRC screening discussion, we independently coded CRC screening discussions from two medical visits. Differences in coding were discussed and a consensus was reached. The remaining patient visits were independently coded for IDM elements about CRC screening decisions by two study team members (MLK and BBO); who initiated the discussion for each IDM element during each discussion (patient, provider, or staff) was also noted.

### Data Analysis

Kappa statistics were calculated to assess agreements of the coding of the IDM elements by the two reviewers. Demographic characteristics of participants who agreed to be audio recorded were compared to participants who refused (or whose provider refused) to have their medical visit audio recorded. Statistical tests (t-tests and chi-square analysis) were used to determine if differences between means and proportions were significant (alpha set at 0.05). All statistical analyses were conducted using SAS version 9.2 (SAS Institute Inc., Cary, NC).

### RESULTS

Near the end of the RCT, one provider refused to have their patients' medical visits recorded (n=33), resulting in 237 patients being asked to have their medical visit recorded. Among the 237 eligible participants, 103 (43.5 %) patients agreed to have their medical visits recorded. Participant agreement to have their medical visit recorded varied by research assistant (23.9 %–83.3 %). Three patients' medical visits could not be evaluated because the recorder malfunctioned. A CRC screening discussion occurred in 48 of the 100 evaluable recorded visits. There was good overall agreement between the two reviewers for the coding of the IDM elements (kappa .8991; p<0.01) and good agreement (p<0.01) for each individual IDM element (kappa: input from trusted others [0.5556]; patients' preferences [0.5556]; patients role in decision making [0.7392]; checking patients' understanding [0.7555]; pros and cons of alternatives [0.8835]; alternatives [0.9465]; and perfect agreement for the nature of the decision and uncertainties associated with the decision).

The healthcare providers included in this manuscript were six physicians and three certified nurse practitioners (CNP). The physicians were two males (one African American, non-Hispanic and one White, Hispanic) and four females (three White, non-Hispanic and one African American, non-Hispanic). The CNPs were three females (one Asian, two White, non-Hispanic). Data were not available for medical staff members.

### Study Participants

Baseline demographic characteristics according to patient (or provider) agreement with having the medical visit recorded are presented in Table 1. Participants were predominantly African American (72.2 %), female (63.7 %), with annual household incomes <\$20,000 (60.7 %), with a high school education (72.6 %), and without health insurance (57.0 %). Participants who agreed to have their medical visit recorded were more likely to report having an annual household income less than \$20,000 compared to participants

**Table 1. Demographic Characteristics of Participants by Agreement to Have or Not Have Their Medical Visit Audio Recorded**

Characteristic	Medical visit recorded (n=103)	Medical visit not recorded (n=167)
Age: years (mean)	55.2	56.5
Gender (% Females)	68 (66.0 %)	104 (62.3 %)
Race (% African Americans)	73 (70.9 %)	122 (73.1 %)
Marital status (% married or living as married)	14 (13.6 %)	24 (14.4 %)
Education (% < high school graduate)	25 (24.3 %)	49 (29.3 %)
Health Literacy (% below high school reading level by REALM)	56 (54.4 %)	89 (53.3 %)
Household Income (% annual <\$20,000)*	70 (68.0 %)	94 (56.3 %)
No Health Insurance	60 (58.3 %)	94 (56.3 %)
Patient activation arm of trial	55 (53.4 %)	83 (49.7 %)
Wants input into medical decisions	86 (83.5 %)	143 (85.6 %)

\*p<0.05

who did not have their medical visits recorded. This difference may be a reflection of low-income African Americans being more willing to have their visits recorded due to mistrust of the medical system stemming from a historical perspective of documented disparities in medical care and/or personal experiences of discrimination.<sup>30</sup>

### Informed Decision Making

The number of IDM elements and IDM elements discussed during the medical visits are listed in Tables 2 and 3. The nature of the decision (CRC screening) was mentioned during 48 medical visits (17 patients were randomized to the CRC screening information only arm and 31 patients were randomized to the CRC screening information plus activation arm). Although CRC screening was mentioned during the 48 visits, no further discussion about screening occurred in 23 visits (CRC screening was mentioned by the participant in 19 visits without a response from the

**Table 2. Number of Informed Decision Making (IDM) Elements About Colorectal Cancer Screening Discussed During Patients' Medical Visits**

Number of IDM Elements	Patients n=100
0	52
1	23*
2	12
3	7
4	4
5	2
6	0
7	0
8	0

\*Colorectal cancer screening mentioned but not discussed. Among the 23 medical visits, screening was mentioned by 19 patients and 4 providers with no further discussion

**Table 3. Informed Decision Making (IDM). Elements About Colorectal Cancer Screening with Provider, Clinical Staff, or Both Members of the Healthcare Team during patient visits (n=48)**

IDM Element	Patient Visits n (%)	Health Care Team					
		Provider		Clinical Staff*		Provider and Clinical Staff*	
Nature of decision to be made	48 (100 %)	34	(71 %)	3	(6 %)	11	(23 %)
Assessment of patient's understanding	16 (33.3 %)	7	(44 %)	4	(25 %)	5	(31 %)
Alternatives	13 (27.1 %)	12	(92 %)	1	(8 %)	0	
Patient's role in decision making	5 (10.4 %)	5	(100 %)	0		0	
Pros and cons of alternatives	5 (10.4 %)	4	(80 %)	0		1	(20 %)
Patient's desire for input from trusted others	4 (8.3 %)	2	(50 %)	2	(50 %)	0	
Asking Patient Preference	3 (6.3 %)	2	(67 %)	0	(20 %)	1	(33 %)
Uncertainties Associated with the Decision	0	0		0		0	

\*Clinical staff includes nurses and medical assistants

healthcare team and in four visits the healthcare provider mentioned CRC screening but there was no further discussion). The maximum number of IDM elements per medical visit was five of the eight possible IDM elements; however, only two visits included five elements. Among the medical visits that mentioned CRC screening, the most common IDM element discussed, assessment of the patient understanding, was included in 16 (33.3 %) visits. Checking for patient preference was only discussed during three (6.3 %) of the 48 visits and uncertainties associated with the decision was not discussed during any recorded visits.

IDM elements included in CRC screening discussion were further explored to evaluate if discussions occurred between patients and their providers, patients and the clinical staff (medical assistant, nurse), or with both members (healthcare provider and clinical staff) of the healthcare team (Table 3). Interactions between patients and providers were the dominant source of each IDM element discussed during patient visits. During three medical visits; however, the patient mentioned CRC screening with the staff member and did not discuss screening with the provider.

Initiation of IDM elements by patients or healthcare team members was evaluated for each IDM element in the CRC screening discussions (Table 4). Patients initiated the conver-

sation about CRC screening in the majority of discussions with providers (33 of the 45 times) and staff members (13 of the 14 times). Among the 16 visits that discussed patients' understanding of the CRC screening test, the majority of the time the patients initiated checking their understanding with providers (9 of 12 visits) and staff members initiated checking for patient understanding (7 of 9 visits) after a CRC screening test had been ordered. Alternatives were mentioned during 13 patient visits, with providers initiating the majority of the discussions (10 of 13 visits). Although the frequency of other IDM elements were rarely discussed, providers initiated the majority of discussions on the patient's role in the decision making process (4 of 5 visits). Patients' preference for which CRC screening test option was only discussed in three medical visits, and it was initiated by the patient in two of those visits. Examples of CRC screening discussions for each IDM element are listed in Table 5.

## DISCUSSION

The increase in CRC screening rates among average-risk adults is a significant reason for the decline in CRC

**Table 4. Informed Decision Making (IDM) Element Occurrence Initiated in Patient-Provider or Patient-Staff Colorectal Cancer Screening Discussions\***

IDM Element	Provider		Clinical Staff	
	Patient to Provider	Provider to Patient	Patient to Clinical Staff	Clinical Staff to Patient
Nature of decision to be made	33	12	13	1
Assessment of patient's understanding <sup>†</sup>	9	3	2	7
Alternatives	2	10	1	0
Patient's role in decision making	1	4	0	0
Pros and cons of alternatives	2	3	1	0
Patient's desire for input from trusted others <sup>‡</sup>	2	0	2	0
Asking patient preference	2	1	0	1
Uncertainties associated with the decision	0	0	0	0

\*Initiation of an IDM element was evaluated separately for patient-provider and patient-staff (nurses and medical assistants) discussions

<sup>†</sup>Two patients checked their understanding of screening test with staff member before meeting with the provider and had their understanding checked by the staff member after the provider visit. Both patients are only counted as patient to staff interactions

<sup>‡</sup>One patient asserted his desire for input from a trusted other to a provider, engaged in another conversation, and then had his desire for input from a trusted other assessed by a provider. This was counted as a patient to provider interaction

Table 5. Colorectal Cancer (CRC) Screening Discussions for Each Informed Decision Making (IDM) Element

IDM Element	Patient Initiated	Provider Initiated
Nature of the Decision to be Made	<b>Patient:</b> "Okay, let me ask you a question." <b>Provider:</b> "Uh huh." <b>Patient:</b> "Do you see any need for me to do a colon screening test?"	<b>Provider:</b> "Have you ever had a colonoscopy?" <b>Patient:</b> "No."
Assessment of the Patient's Understanding	<b>Patient:</b> "You have to do it three times in a row. I don't have a bowel movement every day." <b>Provider:</b> "That's fine. You just need three separate bowel movements." <b>Patient:</b> "So it doesn't have to be each day?" <b>Provider:</b> "No."	<b>Provider:</b> "Here are the stool blood cards." <b>Patient:</b> "Yes." <b>Provider:</b> "Okay. So you know what to do?" <b>Patient:</b> "Right."
Alternatives	<b>Patient:</b> "Send one home with me." <b>Provider:</b> "Okay. We'll do that." <b>Patient:</b> "Anything to keep the camera from going up there..."	<b>Provider:</b> "I think you should. You need screening for colon cancer. Okay? So, we can also, I mean, that's the gold standard, colonoscopy. It's done once every ten years. I mean you can also do, um, we can give you stool cards to screen for colon cancer as well."
Patient's Role in Decision Making	<b>Patient:</b> "Uh, do you check for any type of cancer on there?" <b>Provider:</b> "No." <b>Patient:</b> "Because, I'm going through that colon cancer screening [educational program]. And they wanted to know if, something about. They check for cancer in my blood or something." <b>Provider:</b> "No we don't check for cancer with blood. All you can do is, we can give you three cards, have you put stool in the..."	<b>Provider:</b> "So I'm going to have them give you the test for your stool, okay" <b>Patient:</b> "Yeah." <b>Provider:</b> "It's called a hemoccult. Okay?"  <b>Patient:</b> "Yup."
Pros and Cons of the Alternatives	<b>Patient:</b> "Now, is there such a thing as a false negative?" <b>Provider:</b> "Um, I'm going to say no for you." <b>Patient:</b> "Okay." <b>Provider:</b> "There may have been cases where that could certainly be possible, but not very likely." <b>Patient:</b> "Okay." <b>Provider:</b> "Not very likely at all."	<b>Provider:</b> "No big deal to do the stool." <b>Patient:</b> "You think I need a colonoscopy?" <b>Provider:</b> "Well, that would be more accurate..."
Assessment of Patient's Desire for Input from Trusted Others	<b>Patient:</b> "She told me she was going to call the colon cancer police out on me." <b>Provider:</b> "Oh no." <b>Patient:</b> "Because I should get one too."	N/A
Asking for the Patient Preference	<b>Patient:</b> "Uh, there was some mention about colon cancer screening. I'd like to get that." <b>Provider:</b> "A colonoscopy?" <b>Patient:</b> "No. Those little cards." <b>Provider:</b> "Oh, you want the stool cards."	<b>Patient:</b> "Oh yeah. And I wanted to talk to you too, about the colon, um, the fecal..." <b>Provider:</b> "The occult blood?" <b>Patient:</b> "Yeah. I'd like to do that, um." <b>Provider:</b> "Okay. Would you like to do a colonoscopy or do you want a..." <b>Patient:</b> "No, no, no. I don't think I need colonoscopy."
Uncertainty Associated with the Alternatives	N/A	N/A

mortality in the U.S.<sup>1,3</sup> Unfortunately, CRC disparities exist among minority and low-income populations partially due to lower CRC screening rates.<sup>31</sup> To reduce CRC disparities, it is imperative to increase CRC screening rates among underserved populations. Patient-provider CRC screening discussions are central to this issue since a healthcare providers' recommendation is the single most important factor to get individuals to complete CRC screening.<sup>32,33</sup> In this study, evaluated audio recordings were from medical visits of average-risk minority and low-income patients who were in need of CRC screening and who participated in a RCT of two CRC screening educational interventions.<sup>29</sup>

Based on previous studies which have shown that provider recommendation and patient preference are important for completing CRC screening, IDM about CRC screening has been recommended by the USPSTF.<sup>6-8,32,33</sup> Our study corroborates other studies that indicate that either no CRC screening discussion occurs or that limited information is exchanged in patient-provider discussions about CRC screening,<sup>9-12,17,27,28</sup> however, only a few studies have analyzed recorded patient-provider discussions.<sup>10,12,28</sup>

In the current study, the IDM element discussed most often (48 %) was the nature of the decision. Among the 48 patients, sixteen patients had their understanding assessed, a

screening test was ordered for 13 patients, with nine of the 16 (56.3 %) patients completing CRC screening. Among 32 patients who did not have their understanding assessed, a screening test was ordered for 17 patients, and nine of the 32 (28.1 %) patients completed screening ( $p=0.058$ ). This is similar to findings from Ling and colleagues, where 6 % of 91 patients had their understanding assessed and those patients completed more tests than patients who did not have their understanding assessed (100 % vs. 35 %;  $p=0.002$ ).<sup>12</sup> In addition, Ling and colleagues found a negative association with completing CRC screening and discussing pros and cons of screening (12 % when discussed vs. 46 % when not discussed;  $p=0.01$ ) and addressing patient preferences for screening (6 % when discussed vs. 47 % when not discussed;  $p=0.001$ ).<sup>12</sup> In two additional studies analyzing recordings of patient-provider CRC screening discussions, a limited number of IDM elements were evaluated and occurred during recorded discussions.<sup>10,28</sup>

Overall, it is difficult to make definitive conclusions about the value of IDM to improve CRC screening rates based on findings from these few studies. In the current study, since the discussion of IDM elements was very limited and the CRC screening rate was low (14.8 %), it is difficult to conclude if specific IDM elements, the number of IDM elements included, or who initiates discussion of a specific IDM element other than the nature of the decision to be made may lead to improved CRC screening rates. There is a suggestion that a patient or provider checking the patient's understanding of CRC screening may be important. Results from our study suggest that patients may mention CRC screening to providers; however, that action may not always lead to CRC screening discussions or the ordering of CRC screening tests.<sup>29</sup> This finding is especially disappointing and may reflect providers' barriers to recommending CRC screening, especially their attitudes about recommending CRC screening tests other than colonoscopy.<sup>33</sup>

The results of this study focused not only on IDM elements discussed during patient visits but also on who initiated the IDM elements during the discussion. This analysis demonstrated that patients may mention CRC screening to healthcare providers (especially if they were activated to discuss screening with providers) but that many of the other elements involved in the IDM process are initiated by the healthcare providers. These findings suggest that patients do not want to bring up other IDM elements for some unknown reason(s) or, more likely, that patients lack awareness of the different issues associated with undergoing CRC screening (e.g. pros and cons of CRC screening tests). This finding may be critical when planning the content of CRC screening interventions for patients versus interventions for healthcare providers.

This study is not without limitations. First, participants were from a RCT testing two educational interventions about CRC screening. Thus, the number of IDM elements

about CRC screening initiated by patients may be artificially increased compared to other adults coming for non-acute medical visits. Second, there were a limited number of evaluable CRC screening discussions that occurred in the study. One provider near the end of the study no longer permitted recording of their patients' medical visits without providing a reason for this decision. Although the analysis of the CRC screening discussion was not the primary outcome of the RCT, recorded discussions provide valuable process information. Initially, it was thought that the patient population was suspicious of researchers wanting to record their medical visits. However, since patient agreement rates varied among the three research assistants, patient refusals were more likely due to assistants' experience and comfort working with patients. Although the number of discussions evaluated is small, distinct patterns emerged for the IDM elements and who initiated each element. Third, the study was cross-sectional and CRC screening discussions may have occurred during patients' previous medical visits. Finally, the generalizability of findings is limited since the study was conducted among mostly minority patients who spoke English in one FQHC.

In spite of limitations, this study documented the IDM elements about CRC screening that were initiated by patients or members of the healthcare team. This information may be useful to plan effective interventions to increase CRC screening among a mostly minority and low-income population. Additionally, since some IDM elements identified in CRC screening discussions occurred with staff members and not providers, it is important to test new strategies aimed at multiple levels (patient, provider, clinic) related to the CRC screening process and that include the entire healthcare team.

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