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From Guideline to Practice: New Shared Decision-Making Tools for Colorectal Cancer Screening from the American Cancer Society

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The goal of the American Cancer Society (ACS) 2018 guideline update for colorectal cancer (CRC) screening is to reduce the incidence of and deaths from CRC for average-risk adults ages 45 and older through the use of screening tests that are selected to align with a patient's preferences and test availability.[1] Beginning screening at age 45 is a qualified recommendation, and regular screening of adults 50 years of age and older is a strong recommendation. The basis for the grading of these recommendations is described in the guideline update.[1] For adults in good health with at least a 10-year life expectancy, screening should continue to age 75, while the decision to screen individuals ages 76 through 85 years should be individualized based on patient preferences, life expectancy, health status, and prior screening history (qualified recommendation). Clinicians should discourage individuals over age 85 from continuing screening (qualified recommendation). The updated guideline includes details about the process for developing and rating the recommendations.[1]

In the updated guideline, the ACS Guideline Development Group placed greater emphasis on the importance of patient preferences and choice in selecting a screening test, with the goal of increasing CRC screening uptake and adherence. Six screening options are included in the new guideline, including three stool-based tests (fecal immunochemical test [FIT], high sensitivity guaiac-based fecal occult blood test [HSgFOBT], multi-target stool DNA test [mt-sDNA]) and three structural (visual) exams (colonoscopy, CT colonography [CTC], flexible sigmoidoscopy [FS]). Each option is associated with unique operational and performance attributes, as well as demands on patients, and there is an extensive literature demonstrating variability in how patients value the attributes of CRC screening options.[2–5] These attributes, which include the frequency of testing, test procedures, and required preparation, can, alone or in combination, impact a patient's preference for CRC screening tests.[3] Provider recommendations also strongly influence uptake of screening and choice of test.[6] Decision-making about CRC screening therefore involves the patient weighing the importance of the test attributes in making a decision with a health care provider about which test is right for them. In the absence of the provider's assessment of patient preferences, screening may not take place if the test offered is judged by the patient to be undesirable. There is evidence that screening intentions are higher among patients offered an option that is consonant with their preferences.[5,7]

The updated guideline emphasizes the importance of communication about CRC screening between health care providers and patients to improve CRC screening utilization.[8] Shared decision making is a collaborative process that allows patients and their health care providers to make decisions together, accounting for the best scientific evidence available, as well as the values and preferences of the patient.[9] With the release of its updated CRC screening guideline, the ACS has developed decision support tools to engage patients and health care providers in making shared decisions about screening (https://www.cancer.org/health-care-professionals/colon-md.html). Here we introduce these new tools for supporting shared decision making about CRC screening. In developing these decision support tools, we addressed three key questions.

First, which patients are most likely to benefit from decision support interventions? The ACS guideline notes one of the main challenges in lowering the rate of deaths from CRC is failure to initiate and remain up to date with screening.[1] Patients new to screening and those who, for a variety of reasons, have not initiated or remained current with screening are most likely to benefit from targeted decision support interventions. For average-risk patients who initiate screening at age 45 and remain up to date with screening, providing decision support may have less value than robust reminder systems. However, the value of initial decision support in choosing a CRC screening test is the possibility of greater adherence to screening in the future for better informed patients who initially chose tests closely aligned with their preferences.

There is growing evidence that vulnerable patients not up-to-date with screening benefit from decision support interventions encouraging CRC screening. A recent randomized trial conducted in community health center practices showed higher rates of CRC screening for patients receiving a decision aid and support from a navigator compared to patients receiving usual care.[10] Another randomized trial conducted in community-based primary care settings that serve many low health literacy and low income patients showed higher CRC screening rates among patients who received a digital health intervention including a patient decision aid and self-referral feature compared to patients receiving usual care.[11]

Second, how should the tools be used? We chose to develop decision support interventions that can be used to encourage deliberation between patients and health care providers during the clinical encounter when CRC screening is discussed and tests are ordered. Such “consult” interventions have been around for many years[12–15] and several are included in the most recent Cochrane systematic review of randomized trials of patient decision aids.[16] Stacey et al., make an important distinction about the timing of decision support interventions, noting that they can be delivered before, during, or after a clinical encounter.[16] Aids delivered before an encounter prepare patients for a consultation with a clinician, while aids used during the consultation directly support deliberation and shared decision making.

We have developed “conversation cards,” decision support tools that can be used during the clinical encounter. Recognizing the limited time clinicians can devote to this process, the conversation cards emphasize the most critical information about each screening test option necessary for an informed decision. Each card represents a single test option and describes its attributes in lay language. They are meant to be viewed during the clinical encounter and to facilitate discussion about the test attributes, address misconceptions about screening, provide an opportunity to explore barriers to screening, and help arrive at a decision about which option is best for the patient. In addition, we have developed a Clinician Summary which provides an overview of the ACS recommendations along with instructions for using the conversation cards and guidance on shared decision making with patients. A Patient Decision Aid has also been developed for patients to view on their own if they prefer to review additional information before making a decision.

Finally, which test options should be offered to patients? The ACS guideline suggests that rather than offering patients all screening test options, offering a limited choice of options based on access and availability of tests is optimal. Concerns about how patients make decisions and pragmatic concerns about test availability form the basis for this recommendation. The recommendation and guidance have implications for how decision support interventions are designed. Some patients may express a lack of acceptance of the options that are presented. For these individuals, other testing options included in the guideline should be presented.

There is strong evidence that patients want to know their options when facing health care decisions, and they want their preferences considered when choices are made.[17] Yet, there is concern that offering too many options may undermine decision-making. Schwartz[18] describes the problem of too much information in decision making, termed the paradox of choice, and its detrimental impact on choice. Few studies have evaluated the impact of offering multiple CRC screening options on patients’ interest and adherence. In one study, patients who were not adherent to screening reported greater confusion about different CRC screening options.[19] Another small pilot study found greater preference for colonoscopy when two options compared to five options were offered, but only when costs of screening were included in describing the attributes of the tests.[20] On the other hand, limiting the choices to a single option misses the opportunity for patients to select a test based on their personal preferences. A large, multi-ethnic, cluster randomized trial showed lower rates of completing screening when only colonoscopy was offered, compared to offering fecal occult blood test (FOBT) or a choice between colonoscopy and FOBT.[21] The problem of only offering colonoscopy as an option is that patients may not comply with screening if their preferences align better with another choice, such as a stool test. The ACS suggests that the patient have the opportunity to select either a structural (visual) exam (colonoscopy, CTC, or FS) or a high-sensitivity stool-based tests (FIT, HSgFOBT, or mt-sDNA), based on access and availability of test options.

While the updated guideline places importance on the role of patient preferences in decision-making about CRC screening, it also notes that test options as well as follow-up colonoscopy for positive test findings need to be accessible to the individual patient. Test availability is therefore a key consideration in determining which options to offer a patient. Several factors impact the availability of screening tests. Other than colonoscopy, each screening option requires a follow-up colonoscopy when there is a positive result, which may be associated with out-of-pocket costs depending on the patient's health care coverage. There may also be situations where the health care provider, based on the patient's health status or other factors, decides to offer only certain tests for screening. An example would be not recommending colonoscopy to an older patient because of the increased risk of bowel perforation. Finally, not all screening options may be currently available to the referring clinicians, such as access to CT colonography.

We designed a single conversation card for each screening test option. In this way, clinicians can select cards for those options that are available to the patient and use the cards to engage the patient in a dialogue about the test attributes and how the patient feels about the attributes and tradeoffs, in order to come to a decision about screening. Again, the guideline suggests that the patient have the opportunity to select either a structural (visual) exam or a high-sensitivity stool-based test.

Finally, we recognize that the recommendations about screening in individuals 76 to 85 years of age, including those with health conditions that impact longevity, should lead to discussions between patients and health care providers about continuing screening or when to stop. Such conversations are complex and the way life expectancy is communicated to patients must be done with care.[22] The guideline notes the potentially important role of patient decision aids in fostering shared decisions in this group. In the area of breast cancer screening, Schonberg et al., showed that a patient decision aid improved patients' knowledge of the benefits and risks of screening and decreased patients' intentions to be screened among women ages 75 to 89 years.[23] The guideline further suggests integrating life expectancy calculators in these decision support interventions, while offering a note of caution that none have been validated for cancer screening populations. Any validated life expectancy tool can be used. One in particular, the web-based ePrognosis life expectancy calculator, provides life expectancy information, integrating demographic, medical, and functional status (website: eprognosis.ucsf.edu/leeschonberg.php).

The goal of the updated ACS guideline for CRC screening is to reduce the incidence of and mortality from CRC. To achieve this goal, it is important that patients initiate screening at the recommended age of 45 years and that they remain up to date with the screening options they select with their health care providers. The conversation cards we have developed will promote shared decision making between patients and their health care providers, while also allowing clinicians to tailor which set of screening test options they present to their patients. Primary care clinicians and clinicians from other specialties may find value in using the cards with their patients who are not current with CRC screening. Patients with low health literacy should also benefit from conversations with their health care provider because the cards use simple graphics and can easily be reviewed side-by-side. We recognize tools for non-English speakers are needed. We encourage clinicians to have conversations with their eligible patients about the importance of CRC screening, and to provide them an opportunity to select and remain current with the screening option that aligns with their preferences. The new conversation cards can support this process.

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