

Supplementary Online Content

Piper MS, Maratt JK, Zikmund-Fisher BJ, et al. Patient attitudes toward individualized recommendations to stop low-value colorectal cancer screening. *JAMA Netw Open*. 2018;1(8):e185461. doi:10.1001/jamanetworkopen.2018.5461

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This supplementary material has been provided by the authors to give readers additional information about their work.

eAppendix. Final Survey Instrument

Dear Veteran,

This survey is part of a research project of the Health Services Research and Development (HSR&D) Center for Clinical Management Research at the Ann Arbor VA Medical Center. **This survey asks about your beliefs and opinions about personalized screening for colon cancer, including how you feel about stopping screening in some instances. You will learn about a hypothetical (not real) calculator that predicts your chances of getting colon cancer.**

It will take about 15-20 minutes to complete the survey. As you go through the survey, please do not read ahead or go back and change your answers. Your answers will help us understand the best way to talk to patients like you who might face these situations in real life in the future.

Even though we ask you questions about hypothetical situations, some of the information in this survey may relate to your life. If you have questions or concerns about your personal health, please talk to your doctor.

All of your responses will be kept completely anonymous and confidential. Your participation is completely voluntary, and you will not lose any of your benefits if you choose not to take our survey. If you do want to take our survey, you can stop at any time or choose not to answer any of the questions.

If you have questions or concerns about this survey please contact:

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Thank you for taking the time to complete this survey.

Sincerely,

A handwritten signature in black ink, appearing to read 'Sameer D. Saini', with a long horizontal flourish extending to the right.

Sameer D. Saini, MD, MS

To start off, we'd like to tell you a little about colon polyps, colon cancers, and colonoscopies.

Colon cancer is a medical condition where a tumor or growth forms in the lining of the colon, part of the digestive system where stool or poop is made. Colon cancer is the second-leading cause of cancer deaths in the United States, making it a common cancer. If we find colon cancer at an early stage *before* symptoms start, it's usually curable. If we detect it at a later stage, *after* symptoms have already started (like blood in the stool or belly pain), it's a lot harder to treat.

Most colon cancers start out as small growths in the lining of the colon, called **colon polyps**. Patients who have colon polyps are more likely to get colon cancer than those who don't. However, even patients who have colon polyps don't usually get colon cancer.

Screening is when we look for cancer or polyps in someone who doesn't have any symptoms. Experts agree that screening for colon cancer can be beneficial because it detects cancer early when it can be cured. However, most people will never get colon cancer. This means that most patients who are screened don't get any personal benefit from screening even though they go through all of the effort.

A **colonoscopy** is a type of screening test in which doctors insert a flexible tube into the colon to look for cancer or polyps. To get a colonoscopy, you first need to drink a "prep" solution to clean out your colon the day before the procedure. This "prep" gives you severe diarrhea and is usually the part patients dislike the most. On the day of the procedure, you get an intravenous line ("IV") and are given some medication to make you sleepy and comfortable for the procedure. Most patients don't remember much about the actual procedure.

If the doctor gets a good, clear look at the lining of your whole colon and doesn't see any polyps or growths, your colonoscopy is considered "normal". This is the case with most patients. Right now, doctors will usually recommend that someone with a normal colonoscopy get a repeat colonoscopy in 10 years. Unfortunately, we don't know if this is the best thing for all patients.

**AS YOU GO THROUGH THE REST
OF THE SURVEY, PLEASE DO NOT
READ AHEAD OR GO BACK AND
CHANGE YOUR ANSWERS.**

Questions About You:

Now we will ask you a few questions about you.

18. What is your age?

- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90 or above

19. What is your gender? Male Female Other/Transgender

20. What is the **highest** grade or level of schooling and/or training you completed?
(check one)

- Less than 8 years
- 8-11 years
- 12 years or completed high school or GED
- Vocational, technical, or business training
- 1-3 years of college/junior/community college
- 4 or more years of college or graduated from college
- Graduate or professional school
- Other (please specify): _____

21. What is your current marital status? (check one)

- Married, or living as married
- Widowed
- Divorced
- Separated
- Never married

Questions About You:

22. Do you consider yourself to be Hispanic or Latino? (*check one*)

- Yes No

23. Do you consider yourself to be of Middle Eastern or Arab origin? (*check one*)

- Yes No

24. Which of these best describes your race? NOTE: Mark all that apply.

- White
 Black or African American
 Asian
 Native Hawaiian or other Pacific Islander
 American Indian or Alaskan Native
 Other (please specify): _____

25. In general, would you say your health is (*check one*):

- Excellent
 Very good
 Good
 Fair
 Poor

For the next set of questions we will ask you about your experience with colon cancer and screening. **If you are not sure of an answer please give your best guess.**

26-28. When was the last time you had a ...	Within the last year	Between 1 and 5 years ago	Between 5 and 10 years ago	More than 10 years ago	Never
Colonoscopy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sigmoidoscopy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Test for blood in the stool ("stool cards," "stool vials," or FOBT)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

38. Overall, how would you rate your **knowledge** of colon cancer before taking this survey?

- ₀ ₁ ₂ ₃ ₄ ₅ ₆
- Did Not Know Knew A Lot
Anything About About
Colon Cancer Colon Cancer

For the next set of questions we will ask you about **your experience with health-related information**.

39. How often do you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read hospital materials?

- Always
 Often
 Sometimes
 Occasionally
 Never

40. How confident are you filling out medical forms by yourself?

- Extremely
 Quite a bit
 Somewhat
 A little bit
 Not at all

41. How often do you have problems learning about your medical condition because of difficulty understanding written information?

- Always
 Often
 Sometimes
 Occasionally
 Never

42. In general, how **likely** are you to trust your doctor's medical recommendations?

- ₀ ₁ ₂ ₃ ₄ ₅ ₆
- Not At All Extremely
Likely Likely

Thank you for participating in this survey!

eTable 1. Attitudes Toward Using Age to Decide When to Start/Stop Colorectal Cancer Screening

Questions (see supplemental for full questions)	Total Participants in survey, No. (%)
<i>“How reasonable does it seem to you that experts recommend using age to decide when to start screening?”</i>	
1 (Not at all)	50 (4.9)
2	20 (1.9)
3	38 (3.7)
4	125 (12.1)
5	166 (16.1)
6	285 (27.6)
7 (Extremely)	347 (33.7)
<i>“How reasonable does it seem to you that experts recommend using age to decide when to STOP screening?”</i>	
1 (Not at all)	227 (22.0)
2	76 (7.4)
3	74 (7.2)
4	159 (15.4)
5	128 (12.4)
6	198 (19.2)
7 (Extremely)	171 (16.6)
<i>“At what age do YOU think doctors should stop screening patients who have had a normal screening colonoscopy in the past?”</i>	
Before 75	65 (6.3)
At 75	278 (26.9)
After 75	180 (17.4)
Should never use age	509 (49.3)

eTable 2. Attitudes Toward Using Risk Calculators to Inform Colorectal Cancer Screening Decisions

Questions (see supplemental for full questions)	Total Participants in survey, No. (%)
<i>“How reasonable does it seem to you that doctors would use a calculator that predicts life expectancy to decide whether to stop screening?”</i>	
1 (Not at all)	332 (31.7)
2	87 (8.3)
3	105 (10.0)
4	144 (13.7)
5	136 (13.0)
6	130 (12.4)
7 (Extremely)	115 (11.0)
<i>“How reasonable does it seem to you that doctors would use a calculator that predicts colon cancer risk to decide whether to stop screening?”</i>	
1 (Not at all)	255 (24.3)
2	97 (9.3)
3	101 (9.6)
4	159 (15.2)
5	164 (15.6)
6	154 (14.7)
7 (Extremely)	119 (11.3)

eTable 3. Attitudes Toward Stopping Low-Value Colorectal Cancer Screening and Likelihood to Follow Recommendations to Stop Colorectal Cancer Screening

Questions (see supplemental for full questions)	Total Participants in survey, No. (%)
<i>“If you personally had serious health problems that were likely to shorten your life, and your doctor did not think screening would be of much benefit based on the calculator, how comfortable would you be with not getting any more screening colonoscopies?” (Primary Outcome)</i>	
1 (Not at all)	300 (28.7)
2	88 (8.4)
3	89 (8.5)
4	146 (13.9)
5	121 (11.6)
6	166 (15.9)
7 (Extremely)	137 (13.1)
<i>“In the end, how likely do you think you’d be to follow the doctor’s recommendation to stop screening for colon cancer (whether or not you are comfortable with it)?”</i>	
1 (Not at all)	298 (28.8)
2	98 (9.5)
3	99 (9.6)
4	138 (13.3)
5	131 (12.6)
6	138 (13.3)
7 (Extremely)	134 (12.9)