

**Appendix**  
**Engaging Patients in Decisions About Cancer Screening:**  
**Exploring the Decision Journey Through the Use of a Patient Portal**  
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**Appendix Table 1.** Responses to Questions in Informed Decision Making (IDM) Module

Questions (and response options)	Selected by respondents (%)
1. Have you previously heard that you should or should not have [cancer screening test]?	
Yes	76.9
No	23.1
2. How far along are you with making a decision about [cancer screening test]?	
I have not yet thought about the choice	16.4
I am thinking about the choice	17.8
I am close to making a choice	10.0
I have already made a choice	55.8
3. If you had to make a choice, what would you do next to decide whether to get [cancer screening test]?	
Talk to my health care provider	76.5
Talk to other people I trust: my family, friends, or someone who has been through this	16.3
Attend a lecture or seminar	1.9
Do my own reading and research	28.5
Let my gut feelings or instincts guide me	6.9
Do nothing	4.8
4. For the items below, select how important each is to you. <sup>a</sup>	
What are my options (choices) for getting screened or not getting screened?	70.1
How much would screening improve my chances of living longer?	78.0
Does one kind of screening test work better than another?	75.6
Are there problems that screening might cause, such as false test results, medical complications, or unnecessary treatments?	68.2
What are the screening guidelines of expert organizations, such as the American Cancer Society?	58.4
How is the screening test performed?	61.8
How common or how dangerous is the cancer?	73.3
What are the costs and what will my insurance cover?	56.5
Please specify what else you would like to know about cancer screening.	24.7
5. Choose the option that shows how you would want the topic explained and then adjust the slider to the level of detail you desire for the topic. <sup>b,c</sup>	
<u>Words</u> : Primarily in words, with sentences and paragraphs that explain the issues	86.9

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<u>Numbers</u> : Primarily with numbers (statistics), showing actual rates and probabilities	39.8
<u>Pictures</u> : Primarily with pictures, showing the information visually	25.3
<u>Stories</u> : As a story, to help me see how this affects a real person	7.3
6. When you do your own reading and research for a decision like cancer screening, how helpful are...? <sup>d</sup>	
Internet research or other online information (e.g., Mayo Clinic, WebMD, or Google)	93.2
Television programs or commercial videos about screening	42.3
Articles about screening in magazines or newspapers	73.0
Educational materials from a doctor's office or health organizations, such as pamphlets, brochures, flyers, or videos	87.4
Something else	17.4
7. What is the best way for you to use statistics, like numbers and percentages, to learn what to expect from different screening options? <sup>b</sup>	
<u>Tables</u> : Listed in data tables with rows and columns	28.6
<u>Plain English</u> : Explained in plain English or the spoken word	49.0
<u>Pictures</u> : Shown in pictures, such as pie charts or bar graphs—I'm a visual person	22.4
8. How important to you are your gut feelings or instincts about cancer screening compared with weighing the pros and cons?	
Gut feelings or instincts are most important	5.3
Gut feelings or instincts are somewhat important	10.9
Not sure or neutral	23.4
Weighing pros and cons are somewhat important	42.4
Weighing pros and cons are most important	18.0
9. How important are the following fears or worries to your decision about [cancer screening test]? <sup>a</sup>	
Getting cancer or not catching cancer early enough	79.5
The pain or embarrassment of the test	12.1
Getting bad news when the results come back or finding out I have cancer	41.0
The costs of screening	21.8
Having complications (risks and side effects) from the screening test	39.1
Going to health care providers	19.3
Regretting my decision	15.8
Please specify what else you would like to know about cancer screening.	9.1
10. What steps do you want to take next? <sup>e</sup>	
I want to give it more thought	38.5
I have already decided to get [cancer screening test]	50.1

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I have already decided not to get [cancer screening test]	11.4
<b>11. Which of the following would you like to do?</b>	
No next steps for now	50.6
Do more reading and research	13.0
Fill out a printed or online “decision aid” questionnaire that could help me weigh pros and cons	3.3
Talk with my regular health care provider	47.5
Talk with a specialist for a second opinion	4.0
Talk with my family, friends, clergy, or other people I trust	4.4
Prayer	5.0
Get a reminder to make this decision	16.3
Other next steps	6.3
<b>12. Please click the button that best describes how you feel about your decision.<sup>f</sup></b>	
I know the benefits and risks of each option for getting screened or not getting screened	85.8
I am clear about which benefits and risks from [cancer screening test] matter most to me	84.2
I have enough support and advice to make a decision about getting [cancer screening test]	81.7
I feel sure about the best choice for me	77.2
<b>13. Would you like to discuss [cancer screening decision] at your next appointment? <i>MyPreventiveCare</i><sup>TM</sup> can notify your health care provider.<sup>b</sup></b>	
Yes (if you choose this, <i>MyPreventiveCare</i> <sup>TM</sup> will send your answers to your provider)	47.2
No (if you choose this, <i>MyPreventiveCare</i> <sup>TM</sup> will NOT send your answers to your provider)	52.8
<b>14. What about [cancer screening test] would you like to discuss with your health care provider?<sup>b</sup></b>	
What are my options (choices) for getting screened or not getting screened?	55.4
How much would screening improve my chances of living longer?	27.0
Does one kind of screening test work better than another?	48.3
Are there problems that screening might cause, such as false test results, medical complications, or unnecessary treatments?	38.9
What are the screening guidelines of expert organizations, such as the American Cancer Society?	24.3
How is the screening test performed?	29.9
How common or how dangerous is the cancer?	23.9
What are the costs and what will my insurance cover?	35.0

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What do I need to know about logistics, such as preparation, where to go, scheduling, and transportation?	37.0
Something else (please specify)	13.7
15. For the [cancer screening test] decision, slide the slider to the phrase that reflects the role you would prefer with your health care provider. <sup>b</sup>	
I prefer to make the decision about [cancer screening test].	6.8
I prefer to make the final decision about [cancer screening test] after seriously considering my health care provider's opinion.	27.6
I prefer that my health care provider and I share responsibility for deciding which choice is best for me.	58.2
I prefer that my health care provider makes the final decision about [cancer screening test] but seriously considers my opinion.	4.5
I prefer to leave much of the decision regarding [cancer screening test] to my health care provider.	2.9
16. Can you help us? We want to see whether completing <i>MyQuestions</i> <sup>TM</sup> helps patients at their doctor's appointment. As part of a study, we are audio-recording about 30 appointments. All you would need to do is arrive a few minutes early for your next appointment to sign a consent form and allow your appointment to be recorded. In return we will thank you with a \$50 Target gift card. Want to learn more? Please enter your information and a coordinator will call with more details. <sup>b</sup>	
I am interested in learning more	13.5
I am not interested in learning more at this time	86.5
17. Please give us feedback on <i>MyQuestions</i> <sup>TM</sup> by indicating how much you agree or disagree. <sup>b,f</sup>	
The questions were clear and easy for me to understand	87.0
It took too long to answer the questions	46.7
Completing <i>MyQuestions</i> <sup>TM</sup> helped me with my decision about cancer screening	34.8
Completing <i>MyQuestions</i> <sup>TM</sup> could help other patients who have diabetes or other diseases and face complex medical choices	63.1

*Note:* Percentages refer to all respondents (in aggregate); preferences differed for patients considering breast, colorectal, and prostate cancer screening.

<sup>a</sup> Percentage of patients who rated this option "Very Important."

<sup>b</sup> Data from responses to these questions not reported in this article and will be reported elsewhere.

<sup>c</sup> Percentage of patients who chose this option for at least one topic is reported.

<sup>d</sup> Percentage of patients who chose "Somewhat Helpful" or "Most Helpful."

<sup>e</sup> For patients eligible for colorectal cancer screening, the response options were: *I want to give it more thought, I have already decided to get a colonoscopy, I have already decided to get a stool blood test.*

<sup>f</sup> Percentage of patients who chose "Agree" or "Strongly Agree."

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**Appendix Table 2.** Priority Topics Identified by Respondents (N, Percentage)

Topic	Breast cancer screening (N=441)			Colorectal cancer screening (N=999)			Prostate cancer screening (N=361)			Total (N=1,801) Very
	Very important	Somewhat important	Not that important	Very important	Somewhat important	Not that important	Very important	Somewhat important	Not that important	
For each of the items below, select how important each is to you.										
How much would screening improve my chances of living longer?	<b>381 (86.4<sup>a</sup>)</b>	48 (10.9)	12 (2.7)	<b>749 (75.0)</b>	190 (19.0)	60 (6.0)	<b>274 (75.9)</b>	76 (21.1)	11 (3.0)	<b>1,404 (78.0)</b>
Does one kind of screening test work better than another?	<b>358 (81.2<sup>b</sup>)</b>	69 (15.6)	14 (3.2)	<b>731 (73.2)</b>	218 (21.8)	50 (5.0)	<b>273 (75.6)</b>	75 (20.8)	13 (3.6)	<b>1,362 (75.6)</b>
How common or how dangerous is the cancer?	<b>347 (78.7<sup>c</sup>)</b>	74 (16.8)	20 (4.5)	<b>712 (71.3<sup>d</sup>)</b>	225 (22.5 <sup>d</sup> )	61 (6.1 <sup>d</sup> )	<b>261 (72.3)</b>	91 (25.2)	9 (2.5)	<b>1,320 (73.3)</b>
What are my options for getting screened or not?	<b>328 (74.4)</b>	81 (18.4)	32 (7.3)	<b>688 (68.9)</b>	240 (24.0)	71 (7.1)	<b>247 (68.4)</b>	98 (27.1)	16 (4.4)	<b>1,263 (70.1)</b>
Are there problems that screening might cause?	<b>321 (72.8<sup>a</sup>)</b>	92 (20.9)	28 (6.3)	<b>652 (65.3<sup>e</sup>)</b>	270 (27.0)	77 (7.7)	<b>255 (70.6)</b>	93 (25.8)	13 (3.6)	<b>1,228 (68.2)</b>
How is the screening test performed?	<b>272 (61.7)</b>	119 (27.0)	50 (11.3)	<b>652 (65.3<sup>d,f</sup>)</b>	273 (27.4 <sup>d</sup> )	73 (7.3 <sup>d</sup> )	<b>189 (52.4<sup>g</sup>)</b>	128 (35.5)	44 (12.2)	<b>1,113 (61.8)</b>
What are screening guidelines of expert organizations?	<b>272 (61.7)</b>	135 (30.6)	34 (7.7)	<b>570 (57.1<sup>d</sup>)</b>	344 (34.5 <sup>d</sup> )	84 (8.4 <sup>d</sup> )	<b>210 (58.2)</b>	137 (38.0)	14 (3.9)	<b>1,052 (58.4)</b>
What are the costs and what will my insurance cover?	<b>293 (66.4)</b>	94 (21.3)	54 (12.2)	<b>563 (56.4<sup>d</sup>)</b>	305 (30.6 <sup>d</sup> )	130 (13.0 <sup>d</sup> )	<b>161 (44.6<sup>g</sup>)</b>	139 (38.5)	61 (16.9)	<b>1,017 (56.5)</b>
Please specify what else you would like to know. <sup>h</sup>	<b>99 (28.3)</b>	63 (18.0)	188 (53.7)	<b>194 (24.4)</b>	167 (21.0)	433 (54.5)	<b>61 (21.3)</b>	67 (23.3)	159 (55.4)	<b>354 (24.7)</b>
How important are the following fears or worries to your decision?	<b>Breast cancer screening (N=247)</b>			<b>Colorectal cancer screening (N=639)</b>			<b>Prostate cancer screening (N=280)</b>			<b>Total (N=1,166)</b>
Getting cancer or not catching cancer early enough.	<b>212 (85.8<sup>a</sup>)</b>	23 (9.3)	12 (4.9)	<b>499 (78.1)</b>	107 (16.7)	33 (5.2)	<b>216 (77.1)</b>	56 (20.0)	8 (2.9)	<b>927 (79.5)</b>

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Getting bad news when the results come back.	<b>123 (49.8<sup>a</sup>)</b>	68 (27.5)	56 (22.7)	<b>262 (41.0)</b>	192 (30.0)	185 (29.0)	<b>93 (33.2)</b>	108 (38.6)	79 (28.2)	<b>478 (41.0)</b>
Complications from the screening test.	<b>85 (34.4)</b>	81 (32.8)	81 (32.8)	<b>254 (39.7)</b>	276 (43.2)	109 (17.1)	<b>117 (41.8)</b>	121 (43.2)	42 (15.0)	<b>456 (39.1)</b>
Costs of screening	<b>64 (25.9)</b>	91 (36.8)	92 (37.2)	<b>144 (22.5)</b>	240 (37.6)	255 (39.9)	<b>46 (16.4)</b>	115 (41.1)	119 (42.5)	<b>254 (21.8)</b>
Going to health care providers	<b>54 (21.9)</b>	58 (23.5)	135 (54.7)	<b>118 (18.5)</b>	190 (29.7)	331 (51.8)	<b>53 (18.9)</b>	67 (23.9)	160 (57.1)	<b>225 (19.3)</b>
Regretting my decision	<b>44 (17.8)</b>	73 (29.6)	130 (52.6)	<b>107 (16.7)</b>	170 (26.6)	362 (56.7)	<b>33 (11.8)</b>	88 (31.4)	159 (56.8)	<b>184 (15.8)</b>
Pain/embarrassment of the test.	<b>24 (9.7)</b>	44 (17.8)	179 (72.5)	<b>100 (15.6<sup>a</sup>)</b>	177 (27.7)	362 (56.7)	<b>17 (6.1)</b>	65 (23.2)	198 (70.7)	<b>141 (12.1)</b>
Specify what else you are worried about. <sup>i</sup>	<b>13 (7.6)</b>	11 (6.4)	148 (86.0)	<b>38 (8.6)</b>	48 (10.9)	354 (80.5)	<b>22 (11.5)</b>	24 (12.5)	146 (76.0)	<b>73 (9.1)</b>

<sup>a</sup> $p < 0.001$  in comparison with the other two screening groups.

<sup>b</sup> $p = 0.005$  in comparison with the other two screening groups.

<sup>c</sup> $p = 0.013$  in comparison with the other two screening groups.

<sup>d</sup>Denominator=998.

<sup>e</sup>Lower than among women eligible for mammography and men eligible for PSA ( $p = 0.0010$ ).

<sup>f</sup>Differed significantly from other two screening groups; higher among women eligible for mammography than the PSA group ( $p < 0.001$ ).

<sup>g</sup>Differed significantly from patients eligible for mammography or CRC screening ( $p < 0.001$ ).

<sup>h</sup>Smaller denominators answered this question: breast (N=350), colorectal (N=794), prostate (N=287).

<sup>i</sup>Smaller denominators answered this question: breast (N=172), colorectal (N=440), prostate (N=192).

PSA, prostate-specific antigen test; CRC, colorectal cancer.

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**Appendix Table 3.** Preferred Information Sources for Reading and Research

When you do your own reading and research for a decision like cancer screening, how helpful are...?	Breast cancer screening (N=282)				Colon cancer screening (N=720)				Prostate cancer screening (N=320)				TOTAL
	Most helpful	Somewhat helpful	Less helpful	Doesn't apply to me	Most helpful	Somewhat helpful	Less helpful	Doesn't apply to me	Most helpful	Somewhat helpful	Less helpful	Doesn't apply to me	
Internet research or other online information	161 (57.1)	109 (38.7)	7 (2.5)	5 (1.8)	400 (55.6)	261 (36.3)	25 (3.5)	34 (4.7)	176 (55.0)	125 (39.1)	13 (4.1)	6 (1.9)	737 (55.7)
Educational materials from a doctor's office or health organization.	138 (48.9)	116 (41.1)	20 (7.1)	8 (2.8)	311 (43.2)	304 (42.2)	62 (8.6)	43 (6.0)	152 (47.5)	134 (41.9)	23 (7.2)	11 (3.4)	601 (45.5)
Articles about screening in magazines or newspapers.	72 (25.5)	139 (49.3)	48 (17.0)	23 (8.2)	147 (20.4)	365 (50.7)	142 (19.7)	66 (9.2)	62 (19.4)	180 (56.3)	62 (19.4)	16 (5.0)	281 (21.3)
Television programs or commercial videos about screening.	43 (15.2)	96 (34.0)	112 (39.7)	31 (11.0)	58 (8.1)	246 (34.2)	319 (44.3)	97 (13.5)	21 (6.6)	95 (29.7)	170 (53.1)	34 (10.6)	122 (9.2)
Something else.	15 (6.7 <sup>a</sup> )	30 (13.5 <sup>a</sup> )	18 (8.1 <sup>a</sup> )	160 (71.7 <sup>a</sup> )	38 (6.5 <sup>b</sup> )	58 (10.0 <sup>b</sup> )	47 (8.1 <sup>b</sup> )	439 (75.4 <sup>b</sup> )	25 (10.0 <sup>c</sup> )	18 (7.2 <sup>c</sup> )	23 (9.2 <sup>c</sup> )	185 (73.7 <sup>c</sup> )	78 (7.4)

Notes: Television and commercial videos were more useful to women eligible for mammography (15.2%) than for patients eligible for colorectal cancer (8.0%) or prostate cancer (6.6%) screening ( $p=0.0003$ ).

<sup>a</sup>Denominator=223.

<sup>b</sup>Denominator=582.

<sup>c</sup>Denominator=251.

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**Appendix Figure 1.** Screen shot of Action Page.

You are here : MyQuestions

## Get Tested for Colon Cancer

**Your Information**

You had a colonoscopy on 2/27/2014.  
Talk with your doctor about getting another colonoscopy, sigmoidoscopy, or home stool test now.

You said you really wanted to know more about the following topics. [Click the tiles below to read more.](#)

- Options for getting screened
- Health benefits of screening
- Problems that screening can cause
- Costs and insurance coverage

[More information about Colon Cancer Screening](#)

**The Basics**  
Men and women age 50 to 75 should be screened regularly for colon cancer. Any one of three tests can be used: a **colonoscopy** every 10 years, a **sigmoidoscopy** every 5 years, or a **home stool test** every 1 year.

**The Benefits**  
If you act early, you can significantly reduce your chances of complications or death from colon cancer.

**The Risks**  
Screening isn't perfect and can produce a "false-positive" result when there is no cancer. This can cause anxiety and lead to additional tests. Also, a colonoscopy can sometimes cause bleeding, damage to the colon, or other serious complications.

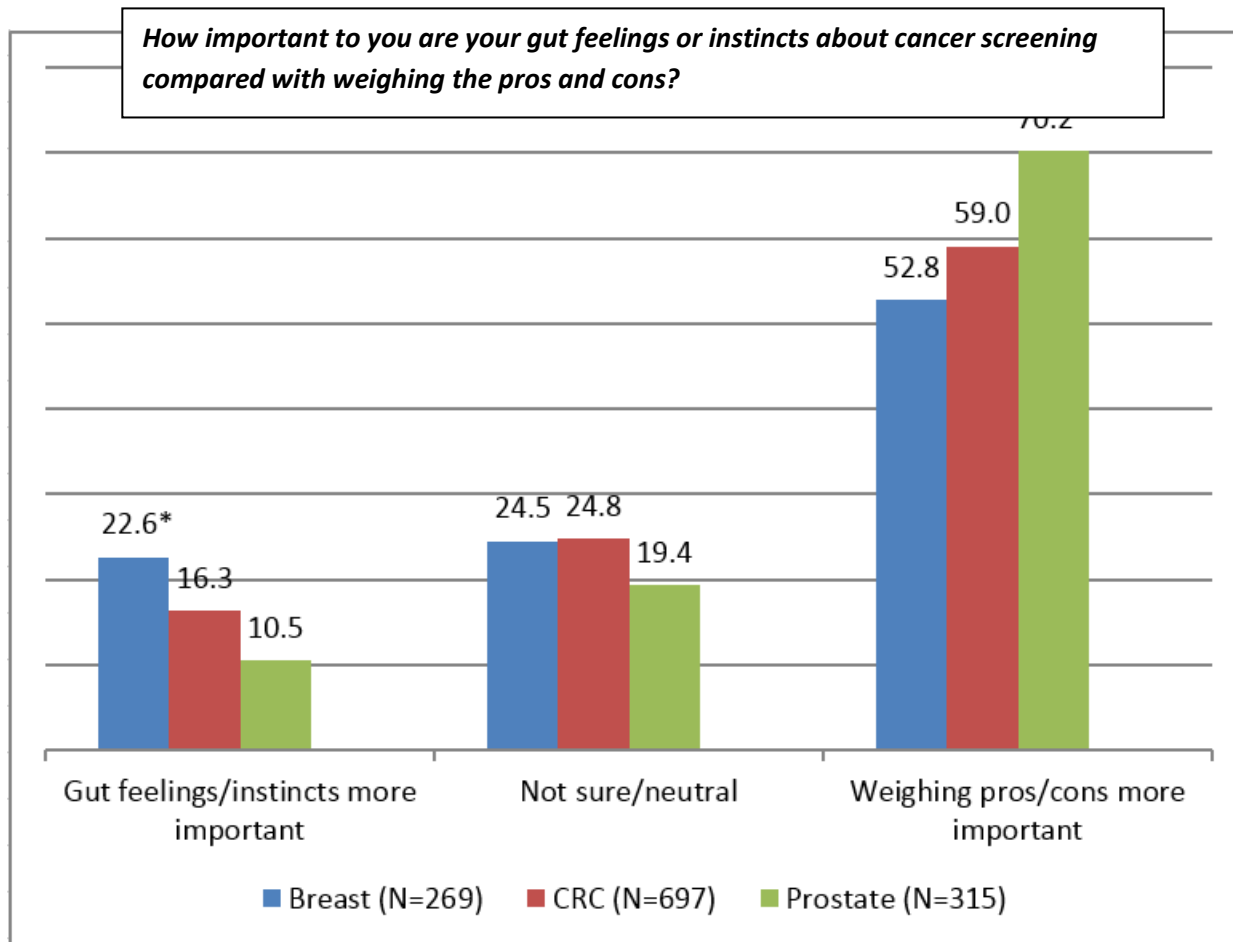
[Move to Next Steps >](#)

*Notes:* Screen shot of Action Page, which appeared midway through the Informed Decision-Making (IDM) module as an educational resource for patients. Apart from providing the date of prior testing (drawn directly from the electronic health record) and a text box with generic information about basics and the benefits and risk of screening, the Action Page featured four “tiles” corresponding to the four topics identified by respondent as “most important” to his or her decision. As indicated by the icons in the lower right-hand corner of the tiles, the information displayed after clicking the tile was presented in the format (words, pictures, numbers, or stories) the respondent said they preferred. Clicking the bottom tile gave patients access to a complete library of information resources.



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**Appendix Figure 2.** Cancer screening decisions: the importance of gut feelings or instincts compared to weighing pros and cons.

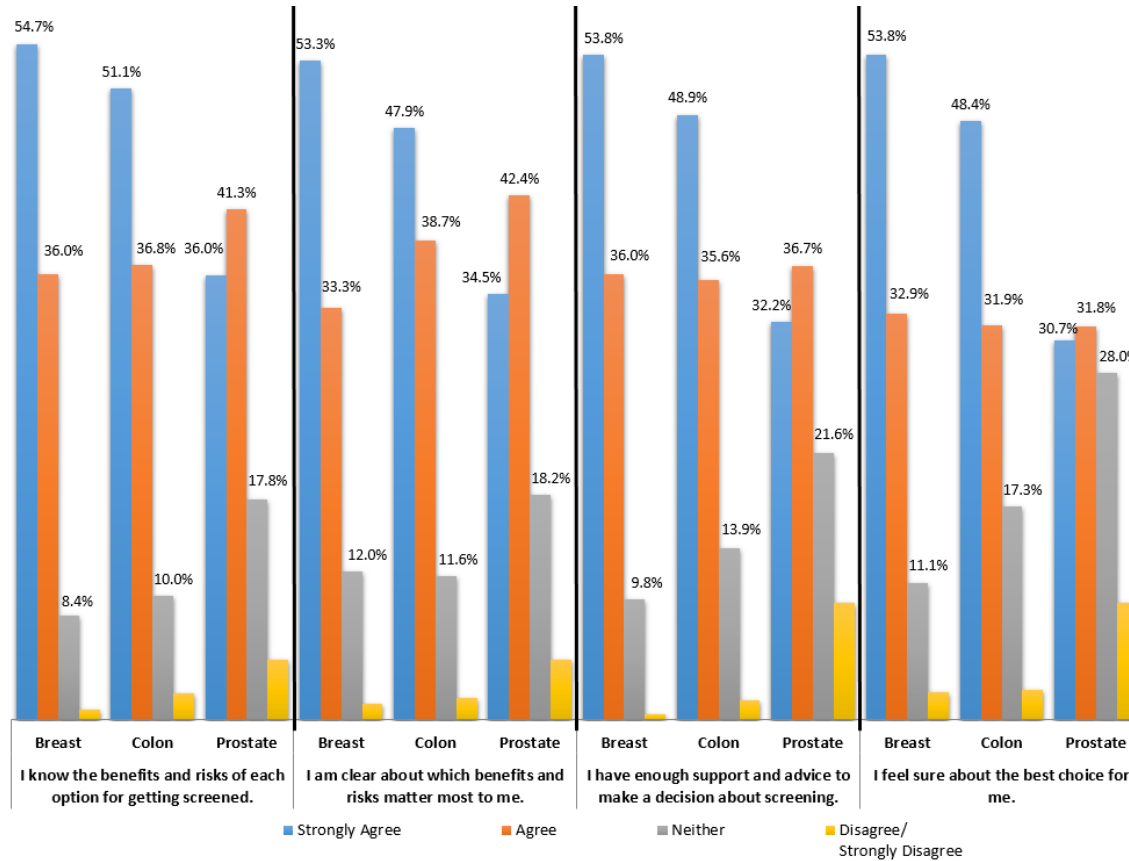


*Notes:* \*Greater than for two other comparison groups ( $p < 0.001$ ). Percentages reflect respondents choosing moderate or strong agreement.

CRC, colorectal cancer.

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**Appendix Figure 3.** Confidence in decision.



*Note:* Adapted from SURE (Legare et al., 2010). On all four questions, strong agreement was less likely among men eligible for PSA screening than among the other two groups, whereas these men were more likely to take neutral stances ( $p < 0.001$ ).

SURE, 4-item screening test (Sure of myself; Understand information; Risk-benefit ratio; Encouragement); PSA, prostate-specific antigen