Supplementary Online Content


eAppendix. Interview Guide and Participant Questionnaire

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

We are interested to know your opinions about cancer screening. There is no right or wrong answer. Please do not feel like you have to answer in a certain way.

The questions are also NOT specific about you, meaning we do not know what the right cancer screening decisions for you are, and all questions are hypothetical.

You may already know what a cancer screening test is. Examples of cancer screening tests include mammogram, colonoscopy, or a blood test for prostate cancer. These tests look for cancer early, before a person feels any symptoms. If a cancer is found early it can be easier to treat so it does not cause health problems for the person later on.

But there are also risks from screening tests, some can cause serious problems. For example colonoscopy can cause bleeding or a tear in the lining of the colon. Mammogram exposes a person to radiation.

Many cancers grow very slowly - it sometimes take 5 or 10 years before a cancer grows to the point of causing problems for a person’s health. If a person passes away in less than 5 or 10 years, a cancer may be there but may never have caused problems during a person’s life; screening for these cancers would not give a person benefit but can give a person harm from the screening test. If a person lives longer than 10 years then he/she likely will benefit from the screening test by finding the cancer early.

Do you have any questions about what I have told you so far?
1. Can you tell me about the last time you made a decision about cancer screening (either to get screened or to not get screened) and how you made that decision?

2. (If participant has had screening) Can you describe any scenarios in which you would consider stopping cancer screening?
   
   (If participant has already stopped cancer screening) Can you tell me how you came to decide to stop?

3. How would it make you feel if your regular doctor told you that you don’t need a cancer screening test anymore? What questions might you have? How would this make you feel towards your doctor?

4. What information should the doctor explain to the patient when deciding whether to get or not to get a cancer screening test?

5. Guidelines for cancer screening are often based on age. How important do you think it is to also consider whether a person is healthy or not, and how the person is functioning from day to day, when deciding whether to get or not to get a cancer screening test?

6. If someone is healthy and active but older, say past 80, should this person get screening tests if the doctor thinks screening would still be helpful but some guidelines may recommend stopping screening at this age? Why or why not?

7. If someone is not healthy, has a lot of health problems, needs help with day to day activities, but is younger, say in their 60s where guidelines usually recommend screening, should this person get screening tests if the doctor thinks that the tests would cause more harm than benefit? Why or why not?

8. Sometimes doctors don’t know the best way to talk to a patient about not needing a screening test. I’m going to pretend that I’m the doctor talking to a hypothetical patient. I will be using several different ways to tell this hypothetical patient (choose Mr. Jones for male participants, choose Ms. Jones for female participants) why (he/she) does not need
another screening test. I want you to tell me, if you were in this person’s place, what you would think of each of these ways of talking?

a. *Ms. Jones, knowing what I know about you, I think this screening test would harm you more than benefit you, so I don’t think we should get the test anymore.*

   How does that sound to you? What questions would you have?

b. This next way of talking has to do with how old Ms. Jones is.

   *Ms. Jones, when people get to be around your age, this screening test is not usually recommended anymore because it would cause more harm than benefit. I don’t think we should get the test anymore.*

   How does that sound to you? What questions would you have?

c. This next way of talking has to do with how healthy Ms. Jones is.

   *Ms. Jones, knowing what I know about you, thinking about the health problems you have - when people have these medical problems like you and need help with day to day activities like you, this test can cause more harm than benefit. I don’t think we should get the test anymore.*

   How does that sound to you? What questions would you have?

d. This next way of talking has to do with how long Ms. Jones may live:

   *Ms. Jones, knowing what I know about you, thinking about your age, your medical problems, and how much help you need from day to day, I think this test would not help you live longer, it would harm you more than benefit you. I don’t think we should get the test anymore.*

   How does that sound to you? What questions would you have?
e. What if instead of saying “this test would not help you live longer”, I said: “you may not live long enough to benefit from this test”? How does that sound to you? What questions would you have?

f. What are some suggestions you have for how doctors can talk to patients about not needing a screening test?

9. A doctor may consider a lot of different things when making a recommendation to a patient about cancer screening, such as how old the patient is, what health problems the patient has, what the family history is, etc. If one of the things the doctor considers is how long the patient has to live, do you think the doctor should then talk about how long the patient has to live with the patient when discussing whether or not to get cancer screening? Why or why not?

10. How well do you think doctors can predict how long someone may live?

11. Because cancers grow slow, in people who may not live very long, research shows that the harms may be more than the benefit, so some guidelines have said things like: “Don’t recommend cancer screening if patient is not likely to live 10 years.” What is your opinion or reaction to that statement?

12. Is there anything else I haven’t asked you about this topic that you would like to share?
Participant Questionnaire

The first set of questions asks about your health and if you have difficulty with certain activities.

1. Which best describes your health in general?
   _____Excellent
   _____Very Good
   _____Good
   _____Fair
   _____Poor

2. During the past 12 months, how many times have you been hospitalized overnight?
   _____Zero
   _____One
   _____Two or more times

3. Do you have difficulty walking ¼ mile (several city blocks) without help from other people or special equipment?
   _____Yes
   _____No

4. Do you need the help of others in everyday household chores, doing necessary business, shopping, or getting around, because of a physical, mental or emotional problem?
   _____Yes
   _____No

5. Do you have difficulty managing money - such as paying bills and keeping track of expenses, because of a health or memory problem?
   _____Yes
   _____No

6. Do you have difficulty with bathing or showering because of a health or memory problem?
   _____Yes
   _____No

7. Do you have difficulty pushing or pulling large objects like a living room chair because of a health problem?
   _____Yes
   _____No

8. Have you ever had cancer (excluding skin cancer)?
   _____Yes Please indicate what type: __________________
   _____No

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9. **For women**
Have you ever been screened for breast cancer using one of the tests listed here? If YES, choose the most recent time when you had the test? If NO, leave blank.

- **Breast exam (yourself or a doctor)**
  - within the last year
  - within the last 2 years
  - >2 years ago

- **Mammogram**
  - within the last year
  - within the last 2 years
  - >2 years ago

- **Breast ultrasound or MRI**
  - within the last year
  - within the last 2 years
  - >2 years ago

- **Breast biopsy**
  - within the last year
  - within the last 2 years
  - >2 years ago

- **Other**
  - within the last year
  - within the last 2 years
  - >2 years ago

Not sure if I have had any of these

- **At this time, I would still consider getting screened for breast cancer.**
- **At this time, I have decided to stop getting screened for breast cancer.**
- **Not applicable because I have a history of breast cancer.**

**For men**
Have you ever been screened for prostate cancer using one of the tests listed here? If yes, choose the most recent time when you had the test? If no, leave blank.

- **Rectal exam**
  - within the last year
  - within the last 2 years
  - >2 years ago

- **Blood test**
  - within the last year
  - within the last 2 years
  - >2 years ago

- **Prostate biopsy**
  - within the last year
  - within the last 2 years
  - >2 years ago

- **Other**
  - within the last year
  - within the last 2 years
  - >2 years ago

Not sure if I have had any of these

- **At this time, I would still consider getting screened for prostate cancer.**
- **At this time, I have decided to stop getting screened for prostate cancer.**
- **Not applicable because I have a history of prostate cancer.**
For women and men
Have you ever been screened for cancer in your colon or rectum?
If yes, choose the most recent time when you had the test? If no, leave blank.

Stool sample
_____within the last year ____within the last 2 years _____>2 years ago

Colonoscopy
_____within the last year ____within the last 2 years _____>2 years ago

Other_______
_____within the last year ____within the last 2 years _____>2 years ago

Not sure if I have had any of these __________

_____At this time, I would still consider getting screened for colon cancer.
_____At this time, I have decided to stop getting screened for colon cancer.
_____Not applicable because I have a history of colon cancer.

The next set of questions asks about you.
10. Do you usually have someone accompany you to doctors' visits?
   _____Yes
   _____No

11. How often do you have someone help you read hospital materials?
   _____Always
   _____Often
   _____Sometimes
   _____Occasionally
   _____Never

12. How confident are you in filling out medical forms by yourself?
   _____Extremely
   _____Quite a bit
   _____Somewhat
   _____A little bit
   _____Not at all

13. How often do you have problems learning about your medical condition because of difficulty understanding written information?
   _____Always
   _____Often
   _____Sometimes
   _____Occasionally
   _____Never

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14. How good are you at working with fractions?

Not good at all                                                                                             Extremely good
1                2                3                4                5                6

15. How good are you at figuring out how much a shirt will cost if it is 25% off?

Not good at all                                                                                             Extremely good
1                2                3                4                5                6

16. How often do you find numerical information to be useful?

Never                                                                                                       Very often
1                2                3                4                5                6

17. What is the percent chance that you will live to be (patient’s age + 10) or more?

Absolutely no chance                                                                                      Absolutely certain
00              10                20                30                40                50                60                70                80                90                100

18. All in all, you have complete trust in your doctor.

Strongly disagree                                                                                           Strongly agree
1                2                3                4                5

19. Which category best describes your race? (check all that applies)

_____ American Indian/Alaska Native
_____ Asian
_____ Black or African American
_____ Native Hawaiian/Other Pacific Islander
_____ White
_____ Other, please specify: ________________

20. Which category best describes your ethnicity?

_____ I am of Hispanic, Latino, or Spanish origin
_____ I am NOT of Hispanic, Latino, or Spanish origin

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21. Which category best describes your financial status?
   ______ Comfortable
   ______ Enough to make ends meet
   ______ Not enough

22. What is the highest grade of education that you completed?
   ______ I did not finish high school, the highest grade that I completed: ______ th grade
   ______ I completed high school or have a GED
   ______ <4 years of college
   ______ I completed 4 years of college or have a higher post-graduate degree

Any additional comments: