

Supplemental File 1. Survey items

Screening questions.

What is your age? _____

What is your gender?

What is your ethnicity?

- Latino/Hispanic
- Non-Hispanic/non-Latino
- Other _____

Our team is doing a study to better understand women’s interest in learning different types of genetic information. We would like to hear your thoughts.

Section 1:

Nowadays, it is possible to predict whether or not a person is likely to develop certain diseases by analyzing their genes. This is called genetic testing. Genetic testing is currently available for a limited number of diseases, but it may be available for more diseases in the future.

Genetic testing could tell you about your risks of different types of diseases.

- **You could learn about your risk of developing a disease that may be able to be prevented or treated.** For example, you could learn that you are more likely to develop colon cancer. In this case, your doctor might recommend that you screen for colon cancer more often.
- **You could learn about your risk of developing a disease that cannot be prevented or treated.** For example, you could learn that you are more likely to develop a muscle disorder that gets worse over time or that you are more likely to develop early dementia from a disease that we don’t know how to prevent or treat.
- **You could also learn more about how you respond to a medication for a disease.** For example, you could learn that a certain treatment would not be helpful for you or that you need a different dose of a medicine in order for it to work. You might also learn that you are more or less likely to develop a side effect from a certain treatment.

Another type of information that you might learn from genetic testing **is about a variation in one of your genes that does not affect your health, but could cause health problems if passed on to a child.** For example, you could learn that you have a variation in the gene that causes cystic fibrosis or a variation in the gene that causes sickle cell disease. Having a variation in this type of gene would not cause any health problems for you. But if you were to have children with someone who also had a variation in the same gene, then your children could be born with these serious diseases.

On a scale from 1 to 7, where 1 means not at all interested, and 7 means very interested, if it were offered by a doctor how interested would you be in doing genetic testing to learn about:

	Not at all interested			Somewhat interested			Very interested
Q5_1 Your risk of developing a disease that may be able to be prevented or treated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1			4			7
Q5_2 Your risk of developing a <u>cancer</u> that may be able to be prevented or treated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1			4			7

Q8_3 Your risk of developing a disease that cannot be prevented or treated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q8_4 How you would respond to a medication for a disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q8_5 A gene variation that does not affect your health but might affect the health of your children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section 2:

For the next set of questions, we'd like to find out more about how you think about inherited risk.

On a scale from 1 to 7 where 1 is not at all worried, and 7 is extremely worried, please describe how worried you are about the following:

Q9_1 That your genes put you at increased risk for developing a common disease, like heart disease or diabetes.	Not at all worried <input type="radio"/> 1	<input type="radio"/>	<input type="radio"/>	Somewhat worried <input type="radio"/> 4	<input type="radio"/>	Extremely worried <input type="radio"/> 7
Q9_2 That you have a genetic variation that means you will certainly develop a disease.	<input type="radio"/> 1	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> 4	<input type="radio"/>	<input type="radio"/> 7
Q9_3 That your children could be affected with a genetic condition that you have passed on.	<input type="radio"/> 1	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> 4	<input type="radio"/>	<input type="radio"/> 7

On a scale from 1 to 5 where 1 is strongly disagree, and 5 is strongly agree, how much do you agree or disagree with the following statements:

Q10_1 I know how to assess the role of genes for health.	Strongly disagree <input type="radio"/> 1	Somewhat disagree <input type="radio"/> 2	Neither agree nor disagree <input type="radio"/> 3	Somewhat agree <input type="radio"/> 4	Strongly agree <input type="radio"/> 5
Q10_2. I know how to assess my genetic risk for disease.	Strongly disagree <input type="radio"/> 1	Somewhat disagree <input type="radio"/> 2	Neither agree nor disagree <input type="radio"/> 3	Somewhat agree <input type="radio"/> 4	Strongly agree <input type="radio"/> 5

Q10_3 I can explain genetic issues to people.	Strongly disagree ○ 1	Somewhat disagree ○ 2	Neither agree nor disagree ○ 3	Somewhat agree ○ 4	Strongly agree ○ 5
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Would you say that the following statements are true or false?

	True	False	Not sure
Q11_1 Some diseases are caused by genes, environment, and lifestyle.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_2 A gene is a disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_3 You can see a gene with the naked eye.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_4 Healthy parents can have a child with an inherited disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_5 A person with an altered (mutated) gene may be completely healthy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_6 All serious diseases are inherited.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_7 Genes are instructions for making proteins, which help the body grow and work properly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_8 The child of a person with an inherited disease will always have the same disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_9 A gene is a piece of DNA.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_10 Altered (mutated) genes can cause disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_11 Genes are inside of cells.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_12 A chromosome contains many genes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_13 Genes determine traits such as height, eye color, and facial appearance.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_14 A person has thousands of genes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_15 Identical twins have different sets of genes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_16 Humans have 20 pairs of chromosomes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q11_17 Parents pass both copies of each chromosome to their child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11_18 A genetic test can tell you if you have a higher chance to develop a specific disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q12_1. On a scale from 1 to 7 where 1 is not at all important, and 7 is very important, please mark how important it is to you to learn more about how your genes may affect your chance of getting cancer.

Not at all important		Somewhat important			Very important	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1		4				7

Q12_2. ...the health of any future children.

Not at all important		Somewhat important			Very important	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1		4				7

Section 3:

For the next set of questions, we'd like to find out more about how you think about health and health information.

On a scale from 1 to 5 where 1 is strongly disagree, and 5 is strongly agree, how much do you agree or disagree with the following statements:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Q14_1 Living life in best possible health is very important to me	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
Q14_2 Eating right, exercising, and taking preventive measures will keep me healthy for life	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
Q14_3 My health depends on how well I take care of myself	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
Q14_4 I actively try to prevent disease and illness	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5

Q14_5 I do everything I can to stay healthy	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
Q14_6 I make a point to read and watch stories about health	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
Q14_7 I really enjoy learning about health issues	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
Q14_8 To be and stay healthy it's critical to be informed about health issues	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
Q14_9) The amount of health information available today makes it easier for me to take care of my health	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
Q14_10) When I take medicine, I try to get as much information as possible about its benefits and side effects	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
Q14_11) I need to know about health issues so I can keep myself and my family healthy	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
Q14_12) Before making a decision about my health, I find out everything I can about this issue	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
Q14_13) It's important to me to be informed about health issues	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5

Q15) In the past 30 days, how often would you say you have looked for information about ways to stay healthy or to feel better?

- | | |
|---|---|
| <input type="checkbox"/> Very often | <input type="checkbox"/> Not very often |
| <input type="checkbox"/> Somewhat often | <input type="checkbox"/> Not at all |

Q16. Compared to other people your gender, age, and race, how likely do you think you are to get each of the following types of cancer in your lifetime?

	A lot less likely	Somewhat less likely	About as likely	Somewhat more likely	A lot more likely
Q16_1) Breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q16_2) Ovarian cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q16_3) Colon cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

On a scale from 1 to 7 where 1 is strongly disagree, and 7 is strongly agree, please mark how much you agree or disagree with the following statement:

Q17) The people who mean the most to me think I should learn more about ways I can keep myself healthy.

Strongly disagree			Neither agree nor disagree			Strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1			4			7

Q18) On a scale from 1 to 7 where 1 is not at all motivated, and 7 is very motivated, how motivated you would say you are to do what these people want you to do?

Not at all motivated			Somewhat motivated			Very motivated
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1			4			7

On a scale from 1 to 5 where 1 is not at all characteristic of me, and 5 is entirely characteristic of me, please check the best answer for the following statements:

	Not at all characteristic of me			Entirely characteristic of me	
Q19_1) Unforeseen events upset me greatly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5
Q19_2) It frustrates me not having all the information I need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5
Q19_3) One should always look ahead so as to avoid surprises.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5
Q19_4) A small, unforeseen event can spoil everything, even with the best of planning.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5

Q19_5) I always want to know what the future has in store for me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5
Q19_6) I can't stand being taken by surprise.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5
Q19_7) I should be able to organize everything in advance.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5
Q19_8) Uncertainty keeps me from living a full life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5
Q19_9) When it's time to act, uncertainty paralyzes me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5
Q19_10) When I am uncertain I can't function very well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5
Q19_11) The smallest doubt can stop me from acting.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5
Q19_12) I must get away from all uncertain situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	1	2	3	4	5

Section 4:

For the last set of questions, we'd like to ask more about you.

Q22) What is the highest level of school that you have completed?

- Junior high or some High school
- High school degree or GED
- Some college
- Associate degree
- College degree
- Graduate degree

Q24) What is your race? (Check all that apply)

- White/Caucasian
- African-American/Black
- Asian
- Pacific Islander/Native Hawaiian
- Native American/Alaska Native
- Other _____

Q25) Do your parents or grandparents have any Ashkenazi (Eastern European) Jewish ancestry?

- Yes
- No
- Not sure

Q26) What is your marital status?

- Married
- Living as married
- Divorced
- Separated
- Never been married
- Widowed

Q27) Do you have any biological children?

- Yes
- No

Q28) Are you planning to become pregnant in the next year?

- Yes
- No
- Not sure

Q29) What is your zip code? _____

Q30) Think about your household's total income. About how much did your household receive in the last year?

- Less than \$25,000
- \$25,000 - \$49,999
- \$50,000 - \$74,999
- \$75,000 - \$99,999
- \$100,000 or higher
- Prefer not to answer

Q31) Do you currently have health insurance?

- Yes, I have private insurance (for example, through my job, HMO)
- Yes, I have public insurance (for example, Medicaid, Medicare)
- No

Q32) Have you ever received genetic testing as part of your clinical care?

- Yes. {(Q33) if yes, what type_____}
- No
- Don't know

Q34) Have you ever been diagnosed as having cancer?

- Yes. {(Q35) if yes, what type_____}
- No

Q36) Have any of your family members ever had cancer?

- Yes. {(Q37) if yes, what type_____}
- No

Q43) How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
1	2	3	4	5

Q44) How often do you have problems learning about your medical condition because of difficulty understanding written information?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
1	2	3	4	5

Q45) How confident are you filling out medical forms by yourself?

Not at all	A little bit	Somewhat	Quite a bit	Extremely
1	2	3	4	5

That is the end of the questions. Do you have anything else that you would like to share with the research team?

Thank you again for agreeing to share this information with us.