

Common survey items, eMERGE participant survey, follow up at 0-1 month post disclosure

Please complete the survey below.

Thank you!

Please indicate how important each of the following statements is to you.

Doctors and other health care providers should be able to share your medical information with each other electronically.

- ☐ Very important
- ☐ Somewhat important
- ☐ Not important at all

You should be able to get to your own medical information electronically

- ☐ Very important
- ☐ Somewhat important
- ☐ Not important at all

How confident are you that safeguards (including the use of technology) are in place to protect your medical records from being seen by people who aren't permitted to see them? Having safeguards (including the use of technology) in place has to do with the security of your medical records.

- ☐ Very confident
- ☐ Somewhat confident
- ☐ Not confident

How confident are you in the security of genetic information that is in your electronic medical/health record?

- ☐ Very confident
- ☐ Somewhat confident
- ☐ Not confident

How confident are you that you have some say in who is allowed to collect, use, and share your medical information? Having a say in who can collect, use, and share your medical information has to do with the privacy of your records.

- ☐ Very confident
- ☐ Somewhat confident
- ☐ Not confident

How confident are you in the privacy of genetic information that is in your electronic medical/health record?

- ☐ Very confident
- ☐ Somewhat confident
- ☐ Not confident

Have you, or do you plan to, share your genetic test result with your biological mother?

- ☐ Yes
- ☐ No

Have you, or do you plan to, share your genetic test result with your biological father?

- ☐ Yes
- ☐ No

How many biological sisters do you have?

(Please include biological half-sisters.)

Have you, or do you plan to, share your genetic test result with your biological sister(s)?

☐ Yes

☐ No

(Please include biological half-sisters.)

How many biological sisters have you, or do you plan to, share your genetic test result with?

(Please include biological half-sisters.)

How many biological brothers do you have?

(Please include biological half-brothers.)

Have you, or do you plan to, share your genetic test result with your biological brother(s)?

☐ Yes

☐ No

(Please include biological half-brothers.)

How many biological brothers have you, or do you plan to, share your genetic test result with?

(Please include biological half-brothers.)

How many biological children do you have?

Have you, or do you plan to, share your genetic test result with your biological children?

☐ Yes

☐ No

How many biological children have you, or do you plan to, share your genetic test result with?

How many biological grandchildren do you have?

Have you, or do you plan to, share your genetic test result with your biological grandchildren?

☐ Yes

☐ No

How many biological grandchildren have you, or do you plan to, share your genetic test result with?

If you indicated you have not and do not plan to disclose your genetic test result to any of your family members, please choose reasons for not disclosing it.

- ☐ Genetic information is private and personal.
- ☐ I do not have a good relationship with my family members.
- ☐ The information will not contribute to my family members health.
- ☐ The information might hurt my family members mental wellbeing.
- ☐ My family members have the right not to know.
- ☐ The information might hurt my family members chances to get married.
- ☐ The information might hurt my family members reputation in the community.
- ☐ The information might hurt my family members ability to obtain insurance.
- ☐ Other

(Check all that apply.)

Other (please explain) _____

Please think about the decision you made to enroll in the study and receive results from the genetic test. Please show how you feel about these statements by circling a number from 1 (strongly agree) to 5 (strongly disagree).

It was the right decision

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree Nor Disagree
- ☐ Disagree
- ☐ Strongly disagree

I regret the choice that was made

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree Nor Disagree
- ☐ Disagree

- ☐ Strongly disagree

I would go for the same choice if I had to do it over again

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree Nor Disagree
- ☐ Disagree
- ☐ Strongly disagree

The choice did me a lot of harm

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree Nor Disagree
- ☐ Disagree
- ☐ Strongly disagree

The decision was a wise one

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree Nor Disagree
- ☐ Disagree
- ☐ Strongly disagree

The following questions ask about how you felt after receiving your genetic test results. Please indicate how much you had each specific feeling in the past week by checking one answer for each question: not at all, a little, somewhat, a good deal, or a great deal.

How upset did you feel about your genetic test result?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat

- ☐ A good deal
- ☐ A great deal

How happy did you feel about your genetic test result?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A good deal
- ☐ A great deal

How anxious or nervous did you feel about your genetic test result?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A good deal
- ☐ A great deal

How relieved did you feel about your genetic test result?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A good deal
- ☐ A great deal

The following questions ask about how you felt after receiving your genetic test results. Please indicate how much you had each specific feeling in the past week by checking one answer for each question: not at all, a little, somewhat, a good deal, or a great deal.

How sad did you feel about your genetic test result?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat

- ☐ A good deal
- ☐ A great deal

How frustrated did you feel that there are no definite disease prevention guidelines for you?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A good deal
- ☐ A great deal

How uncertain did you feel about what your genetic test results means for you?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A good deal
- ☐ A great deal

How uncertain did you feel about what your genetic test result means for your child(ren) and/or family's risk of disease?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A good deal
- ☐ A great deal

How much did you feel that you understood clearly your choices for disease prevention or early detection?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A good deal
- ☐ A great deal

How concerned did you feel that your genetic test result would affect your health insurance status?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A good deal
- ☐ A great deal

How helpful was the information you received from your genetic test result in planning for the future?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A good deal
- ☐ A great deal

How concerned did you feel that your genetic test result would affect your employment status?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A good deal
- ☐ A great deal

Please indicate whether you PLAN to make any of the following changes in response to learning about your genetic test result.

Changing your job

- ☐ Yes
- ☐ No

Retiring

☐ *Yes*

☐ *No*

Moving to a different state or country

☐ *Yes*

☐ *No*

Getting married or divorced

☐ *Yes*

☐ *No*

Having a biological child

☐ *Yes*

☐ *No*

Adopting a child

☐ *Yes*

☐ *No*

Buying new or buying more life insurance

☐ *Yes*

☐ *No*

Buying new or buying more disability insurance

☐ *Yes*

☐ *No*

Buying new or buying more long term care insurance

☐ *Yes*

☐ *No*

Any other major change or event in your life

☐ Yes

☐ No

Any other major change or event in your life, please specify:

Did you discuss your genetic test result with any other doctors or health care providers?

☐ Yes

☐ No

Please indicate what doctors or health care providers you discussed your genetic test result with:

☐ Primary Care provider

☐ Oncologist (Cancer specialist)

☐ Cardiologist (Heart specialist)

☐ Geneticist or Genetic counselor

☐ Another Specialist

(Check all that apply.)

Please specify: _____

Did any doctor or health care provider make recommendations based on the genetic test result?

☐ Yes

☐ No

Please indicate what type of doctors or health care providers made recommendations based on the genetic test result.

- ☐ Primary Care provider
 - ☐ Oncologist (Cancer specialist)
 - ☐ Cardiologist (Heart specialist)
 - ☐ Geneticist or Genetic counselor
 - ☐ Another specialist
- (Check all that apply.)

Please specify: _____

Please indicate recommendations made by a provider in response to learning about your genetic test result.

See a primary care provider.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

- ☐ Oncologist
- ☐ Cardiologist
- ☐ Geneticist or Genetic Counselor
- ☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
 - ☐ Yes, plan to follow the recommendation
 - ☐ No, do not plan to follow the recommendation
-

Please indicate recommendations made by a provider in response to learning about your genetic test result.

See an oncologist.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

- ☐ Primary Care Provider
- ☐ Cardiologist
- ☐ Geneticist or Genetic Counselor
- ☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
- ☐ Yes, plan to follow the recommendation
- ☐ No, do not plan to follow the recommendation

Please indicate recommendations made by a provider in response to learning about your genetic test result.

See a cardiologist.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

- ☐ Primary Care Provider

- ☐ Cardiologist
- ☐ Geneticist or Genetic Counselor
- ☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
- ☐ Yes, plan to follow the recommendation
- ☐ No, do not plan to follow the recommendation

Please indicate recommendations made by a provider in response to learning about your genetic test result.

See a geneticist or genetic counselor.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

- ☐ Primary Care Provider
- ☐ Oncologist
- ☐ Cardiologist
- ☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
- ☐ Yes, plan to follow the recommendation

- ☐ No, do not plan to follow the recommendation

Please indicate recommendations made by a provider in response to learning about your genetic test result.

See another specialist.

- ☐ Yes
☐ No

Please specify: _____

What type of provider made the recommendation?

- ☐ Primary Care Provider
☐ Oncologist
☐ Cardiologist
☐ Geneticist or Genetic Counselor
☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
☐ Yes, plan to follow the recommendation
☐ No, do not plan to follow the recommendation

Please indicate recommendations made by a provider in response to learning about your genetic test result.

Have a colonoscopy, an evaluation of the colon for cancer.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

- ☐ Primary Care Provider
- ☐ Oncologist
- ☐ Cardiologist
- ☐ Geneticist or Genetic Counselor
- ☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
- ☐ Yes, plan to follow the recommendation
- ☐ No, do not plan to follow the recommendation

Please indicate recommendations made by a provider in response to learning about your genetic test result.

Have a mammogram, an x-ray of the breast to screen for cancer.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

- ☐ Primary Care Provider
- ☐ Oncologist
- ☐ Cardiologist
- ☐ Geneticist or Genetic Counselor
- ☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
 - ☐ Yes, plan to follow the recommendation
 - ☐ No, do not plan to follow the recommendation
-

Please indicate recommendations made by a provider in response to learning about your genetic test result.

Have a PSA (prostate-specific antigen) blood test to screen for prostate cancer.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

- ☐ Primary Care Provider
- ☐ Oncologist
- ☐ Cardiologist
- ☐ Geneticist or Genetic Counselor
- ☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
- ☐ Yes, plan to follow the recommendation
- ☐ No, do not plan to follow the recommendation

Please indicate recommendations made by a provider in response to learning about your genetic test result.

Have an echocardiogram, an ultrasound of the heart.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

- ☐ Primary Care Provider
- ☐ Oncologist
- ☐ Cardiologist
- ☐ Geneticist or Genetic Counselor
- ☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
- ☐ Yes, plan to follow the recommendation
- ☐ No, do not plan to follow the recommendation

Please indicate recommendations made by a provider in response to learning about your genetic test result.

Have your cholesterol checked.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

- ☐ Primary Care Provider
- ☐ Oncologist
- ☐ Cardiologist
- ☐ Geneticist or Genetic Counselor
- ☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
- ☐ Yes, plan to follow the recommendation
- ☐ No, do not plan to follow the recommendation

Please indicate recommendations made by a provider in response to learning about your genetic test result.

Have an ECG, a test that measures the rhythm of the heart using “sticky pads”.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

- ☐ Primary Care Provider
- ☐ Oncologist
- ☐ Cardiologist
- ☐ Geneticist or Genetic Counselor
- ☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
 - ☐ Yes, plan to follow the recommendation
 - ☐ No, do not plan to follow the recommendation
-

Please indicate recommendations made by a provider in response to learning about your genetic test result.

Have another exam.

- ☐ Yes
- ☐ No

Please specify: _____

What type of provider made the recommendation?

- ☐ Primary Care Provider
- ☐ Oncologist
- ☐ Cardiologist
- ☐ Geneticist or Genetic Counselor
- ☐ Other

Please specify: _____

Do you plan to follow, or have you already followed, the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, already have followed the recommendation
- ☐ Yes, plan to follow the recommendation

- ☐ No, do not plan to follow the recommendation
-

Do you plan to, or have you already made, any of the following lifestyle changes in response to learning about your genetic test result?

Eat a healthier diet

- ☐ Yes, already have
- ☐ Yes, plan to
- ☐ No, have not and do not plan to
- ☐ No, I was already doing this

Start exercising or exercise more

- ☐ Yes, already have
- ☐ Yes, plan to
- ☐ No, have not and do not plan to
- ☐ No, I was already doing this

Get a full night's sleep

- ☐ Yes, already have
- ☐ Yes, plan to
- ☐ No, have not and do not plan to
- ☐ No, I was already doing this

Start taking (more) vitamins or other supplements

- ☐ Yes, already have
- ☐ Yes, plan to
- ☐ No, have not and do not plan to
- ☐ No, I was already doing this

Consume less/no alcohol

- ☐ Yes, already have

- ☐ Yes, plan to
- ☐ No, have not and do not plan to
- ☐ No, I was already doing this

Reduce stress

- ☐ Yes, already have
- ☐ Yes, plan to
- ☐ No, have not and do not plan to
- ☐ No, I was already doing this

Stop smoking

- ☐ Yes, already have
- ☐ Yes, plan to
- ☐ No, have not and do not plan to
- ☐ No, I was already doing this

Did a provider recommend genetic testing and/or other evaluations for your family members based on your genetic test result?

- ☐ Yes
- ☐ No

DEMOGRAPHIC QUESTIONS

What is your age (years)? _____

Are you male or female?

- ☐ Male
- ☐ Female
- ☐ Other
- ☐ Prefer not to answer

Which one or more of the following would you say is your race? (Check all that apply.)

- ☐ White or Caucasian
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Pacific Islander
- ☐ Other
- ☐ Don't know

Are you Hispanic or Latino/a?

- ☐ Yes
- ☐ No
- ☐ Don't know

What is your current marital status?

- ☐ Married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated
- ☐ Never married / Single

What is the highest level of education you have completed?

- ☐ Never attended school
- ☐ Grade school (Grade 1 to 8)
- ☐ Some high school (Grade 9 to 12)
- ☐ High school graduate (or GED)
- ☐ Post high school training other than college (vocational, technical, or other types of training)
- ☐ Some college
- ☐ Bachelor's degree or equivalent

- ☐ Post graduate work or graduate degree (MS, MBS, MFA, MBA, PhD, MD, JD, or other)

What is your current work situation? (Check all that apply.)

- ☐ Working
- ☐ Looking for work, unemployed
- ☐ Homemaker
- ☐ Disabled, permanently or temporarily
- ☐ Only temporarily laid off, sick leave or maternity leave
- ☐ Student
- ☐ Retired
- ☐ Other

What is your current household income?

- ☐ Less than \$15,000
- ☐ \$15,000 to \$29,999
- ☐ \$30,000 to \$44,999
- ☐ \$45,000 to \$59,999
- ☐ \$60,000 to \$89,999
- ☐ \$90,000 to \$149,999
- ☐ \$150,000 to \$199,999
- ☐ \$200,000 or above
- ☐ Prefer not to answer

Including yourself, how many people currently live in your household?

Do you have health insurance or a health coverage plan? (Check all that apply.)

- ☐ Yes, through employer
- ☐ Yes, through someone else's employer
- ☐ Yes, a plan that I or someone else buys

- ☐ Yes, through Medicare
- ☐ Yes, through Medicaid or Medical Assistance
- ☐ Yes, through military, Tricare, CHAMPUS, or the VA Yes, through some other source
- ☐ No I don't have any coverage
- ☐ Don't know
- ☐ Choose not to answer

How religious do you consider yourself to be?

- ☐ Not at all religious
- ☐ Not very religious
- ☐ Somewhat religious
- ☐ Very religious
- ☐ Don't know
- ☐ Decline to answer

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

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Occasionally
- ☐ Never

How often do you have someone help you read materials about health care (for example, the materials that you might receive if you're in the hospital or at your doctor's office)?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Occasionally
- ☐ Never

How confident are you filling out medical forms by yourself?

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

How much do you agree or disagree with the following statement? In general, I depend on numbers and statistics to help me make decisions about my health?

- ☐ Strongly agree
- ☐ Somewhat agree
- ☐ Somewhat disagree
- ☐ Strongly disagree

Which of the following numbers represents the biggest risk of getting a disease?

- ☐ 1 in 100
- ☐ 1 in 1000
- ☐ 1 in 10

People can talk about the chance of something happening using either words, like "It rarely happens" or numbers, like "There's a 5% chance." When people tell you the chance of something happening, do you prefer they use words or numbers?

- ☐ Generally prefer words
- ☐ Generally prefer numbers
- ☐ No preference

