

Common survey items, eMERGE participant survey, follow up at 6-12 months 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 shared your genetic test result with your biological mother?

- ☐ Yes
- ☐ No

Have you shared your genetic test result with your biological father?

- ☐ Yes
- ☐ No

How many biological sisters do you have?

(Please include biological half-sisters.)

Have you shared your genetic test result with your biological sister(s)?

☐ Yes

☐ No

(Please include biological half-sisters.)

How many biological sisters have you shared your genetic test result with?

(Please include biological half-sisters.)

How many biological brothers do you have?

(Please include biological half-brothers.)

Have you shared your genetic test result with your biological brother(s)?

☐ Yes

☐ No

(Please include biological half-brothers.)

How many biological brothers have you shared your genetic test result with?

(Please include biological half-brothers.)

How many biological children do you have?

Have you shared your genetic test result with your biological children?

☐ Yes

☐ No

How many biological children have you shared your genetic test result with?

How many biological grandchildren do you have?

Have you shared your genetic test result with your biological grandchildren?

☐ Yes

☐ No

How many biological grandchildren have you shared your genetic test result with?

Thinking about the family members you DID share your genetic test result with, which of the following were important to your decision to share?

- ☐ I felt obligated to share my genetic test result
- ☐ I was encouraged by my health care provider
- ☐ I made an agreement to tell them before receiving my genetic test result
- ☐ I was encouraged by other family members to share the information
- ☐ I felt the information could help my family members in making medical decisions
- ☐ I was asked about my genetic test result by a family member
- ☐ I wanted to know if a family member had symptoms related to my genetic test result
- ☐ I needed emotional support from my family member
- ☐ I needed advice from my family member in making medical decisions
- ☐ I wanted to provide my family member information about their risk
- ☐ I wanted to encourage them to get tested
- ☐ Other

(Check all that apply to one or more of your family members that you shared with.)

Please specify: _____

Thinking about when you shared your genetic test result with any one of your family members, did you have problems telling any one of your family members about the genetic test result?

- ☐ Yes
- ☐ No

Thinking about problems you had when you shared your genetic test result with any one of your family members, what were those problems?

- ☐ I had trouble reaching people
- ☐ I didn't feel close to some of the family members
- ☐ I felt I didn't really understand the genetic test result
- ☐ I had a hard time explaining the genetic test result
- ☐ I felt that I was causing distress for my family members
- ☐ I felt that I was to blame for this genetic test result in our family
- ☐ Other

(Check all that apply to one or more of your family members that you shared with.)

Please specify: _____

If you did not disclose your genetic test results to SOME or ALL of your family members, which of the following were reasons for NOT sharing?

- ☐ I am not in contact with my family member/s
- ☐ I am not close to my family member/s
- ☐ My family member/s wouldn't care about the genetic test result
- ☐ My result would cause my family member/s distress
- ☐ I was having trouble accepting and coping with the genetic test result

- ☐ I did not know what to say to my family member/s about the genetic test result
- ☐ It is not my responsibility to share the genetic test result with my family member/s
- ☐ My family member/s were too young
- ☐ My family member/s were too old
- ☐ My family member/s were too sick
- ☐ Genetic information is private and personal
- ☐ I do not have a good relationship with my family member/s
- ☐ The information might hurt my family member/s' mental well being
- ☐ My family member/s have the right not to know
- ☐ The information might hurt my family member/s' chances to get married
- ☐ The information might hurt my family member/s' reputation in the community
- ☐ The information might hurt my family member/s' ability to obtain insurance
- ☐ Other

(Check all that apply.)

If 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 selecting from strongly agree to 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

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

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 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 made 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 recommend or implement medical care for a condition based on the genetic test result?

- ☐ Yes
- ☐ No

Please indicate what type of doctors or health care providers recommended or implemented medical care for a condition based on your 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: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
- ☐ Yes, followed the recommendation, but not in response to result
- ☐ No, have not followed the recommendation but plan to follow the recommendation
- ☐ No, and do not plan to follow the recommendation

Please indicate the number of visits: _____

See an oncologist.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

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

Please specify: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
- ☐ Yes, followed the recommendation, but not in response to result
- ☐ No, have not followed the recommendation but plan to follow the recommendation

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

Please indicate the number of visits: _____

See a cardiologist.

- ☐ Yes
☐ No

What type of provider made the recommendation?

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

Please specify: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
☐ Yes, followed the recommendation, but not in response to result
☐ No, have not followed the recommendation but plan to follow the recommendation
☐ No, and do not plan to follow the recommendation

Please indicate the number of visits: _____

See a geneticist or genetic counselor.

- ☐ Yes
☐ No

What type of provider made the recommendation?

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

Please specify: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
- ☐ Yes, followed the recommendation, but not in response to result
- ☐ No, have not followed the recommendation but plan to follow the recommendation
- ☐ No, and do not plan to follow the recommendation

Please indicate the number of visits: _____

See another specialist.

- ☐ Yes
- ☐ No

Please specify:

What type of provider made the recommendation?

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

Please specify: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
- ☐ Yes, followed the recommendation, but not in response to result
- ☐ No, have not followed the recommendation but plan to follow the recommendation
- ☐ No, and do not plan to follow the recommendation

Please indicate the number of visits: _____

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

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

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

Please specify: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
- ☐ Yes, followed the recommendation, but not in response to result
- ☐ No, have not followed the recommendation but plan to follow the recommendation

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

Please indicate the number of visits: _____

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
☐ Geneticist or Genetic Counselor
☐ Other

Please specify: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
☐ Yes, followed the recommendation, but not in response to result
☐ No, have not followed the recommendation but plan to follow the recommendation
☐ No, and do not plan to follow the recommendation

Please indicate the number of visits: _____

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
☐ Cardiologist
☐ Geneticist or Genetic Counselor
☐ Other

Please specify: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
☐ Yes, followed the recommendation, but not in response to result
☐ No, have not followed the recommendation but plan to follow the recommendation
☐ No, and do not plan to follow the recommendation

Please indicate the number of visits: _____

Have your blood pressure checked.

- ☐ Yes
☐ No

What type of provider made the recommendation?

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

Please specify: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
- ☐ Yes, followed the recommendation, but not in response to result
- ☐ No, have not followed the recommendation but plan to follow the recommendation
- ☐ No, and do not plan to follow the recommendation

Please indicate the number of visits: _____

Have your cholesterol checked.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

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

Please specify: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
- ☐ Yes, followed the recommendation, but not in response to result

- ☐ No, have not followed the recommendation but plan to follow the recommendation
- ☐ No, and do not plan to follow the recommendation

Please indicate the number of visits: _____

Have your blood sugar (glucose) checked.

- ☐ Yes
- ☐ No

What type of provider made the recommendation?

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

Please specify: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
- ☐ Yes, followed the recommendation, but not in response to result
- ☐ No, have not followed the recommendation but plan to follow the recommendation
- ☐ No, and do not plan to follow the recommendation

Please indicate the number of visits: _____

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: _____

Did you follow the recommendation made by the provider in response to learning about your genetic test result?

- ☐ Yes, followed the recommendation in response to the result
- ☐ Yes, followed the recommendation, but not in response to result
- ☐ No, have not followed the recommendation but plan to follow the recommendation
- ☐ No, and do not plan to follow the recommendation

Please indicate the number of visits: _____

Did you make 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

Please indicate how much you agree or disagree with the following statements regarding your genetic test result.

Came as a surprise to me

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Was important to me

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Helped explain a condition that I have

- ☐ Strongly Disagree

- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Helped explain a family history of disease

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Reassured me that I am taking the right healthcare actions

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Confirmed information that I already know

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Please indicate how much you agree or disagree with the following statements regarding your genetic test result.

Encouraged me to take specific action to reduce my risk

- ☐ Strongly Disagree

- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Taught me more about the risk of passing on a disease to my children.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Accurately predicted my disease risks

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Was stored securely to protect my privacy

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Influenced what treatment I may receive for current or future medical problems

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Influenced my or my child's reproductive decisions

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree