



YOUR THOUGHTS AND OPINIONS ABOUT GENETIC RESEARCH RESULTS

If envelope is lost, return completed surveys to:

Pancreas Research Project Survey
Mayo Clinic, Charlton 6
200 First Street SW
Rochester, MN 55905

Thank you for taking this survey. It is divided into 9 sections. Once you are done with the survey, return it to us using the envelope provided.

Please complete the survey using a pen or pencil. Place a mark in the oval to indicate your answer. Ovals do not need to be filled in completely.



RESEARCH PARTICIPATION AND OPINIONS

ABOUT YOUR FAMILY

VIEWS ON GENES AND HEALTH

GENETIC TESTING EXPERIENCE

AN EXAMPLE FROM GENETIC RESEARCH

PRACTICAL CONSIDERATIONS IN GENETIC RESEARCH

HOW TO RETURN GENETIC RESEARCH RESULTS

GENETIC RESEARCH RESULTS AND PRIVACY

ABOUT YOU

1 Have you ever participated in the Mayo Clinic Biospecimen Resource for Pancreas Research? Participation includes giving a blood sample and/or filling out a questionnaire.

- Yes
- No
- Not Sure

2 Which of the following best describes what you expect to happen when you participate in a genetic research study? Studies include collection of a blood or saliva sample. (mark only one)

- I expect I will not learn anything about my own genetic results.
- I expect I will learn something about my own genetic results.

→ If you expect to learn something, please answer the following questions.

2a I expect I would be told if researchers found something bad (a health risk) in my blood sample.

- Yes
- No

2b I expect I would be told if researchers found something good (I did NOT have a particular health risk) in my blood sample.

- Yes
- No

3 Please tell us how much you disagree or agree with each statement.

	Strongly DISAGREE	DISAGREE	Neither Agree nor Disagree	AGREE	Strongly AGREE
Scientific research is essential for improving the quality of human lives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scientific research has created as many problems for society as it has solutions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New technology used in medicine allows people to live longer and better lives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New genetic discoveries can create a burden of worry where there wasn't one before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



RESEARCH PARTICIPATION AND OPINIONS

ABOUT YOUR FAMILY

VIEWES ON GENES AND HEALTH

GENETIC TESTING EXPERIENCE

AN EXAMPLE FROM GENETIC RESEARCH

PRACTICAL CONSIDERATIONS IN GENETIC RESEARCH

HOW TO RETURN GENETIC RESEARCH RESULTS

GENETIC RESEARCH RESULTS AND PRIVACY

ABOUT YOU

4 Are you adopted?

- Yes
- No

If yes, answer the following question.

4a How would you describe the contact/relationship you have/had with your biological family?

- I don't know my biological family
- Some contact
- Extensive contact

5 Is your biological mother still living?

- Yes
- No
- I don't know

6 Is your biological father still living?

- Yes
- No
- I don't know

7 Do you have any blood-related (biological) brothers or sisters who are still living?

- Yes
- No
- I don't know

8 Do you have any blood-related children who are still living?

- Yes
- No
- I don't know

9 Have you ever been diagnosed with pancreatic cancer?

- Yes
- No

If no, answer the following question.

9a How likely do you think it is that you will get pancreatic cancer sometime in your life?

- Very unlikely
- Somewhat unlikely
- Somewhat likely
- Very likely

10 To your knowledge, have any of your blood relatives (parent, child, sibling, aunt, uncle, grandparent, grandchild, niece, nephew, or cousin) ever been diagnosed with pancreatic cancer?

- Yes
- No

→ If no, answer the following question.

10a How likely do you think it is that one of your blood relatives will get pancreatic cancer sometime in his/her life?

- Very unlikely
- Somewhat unlikely
- Somewhat likely
- Very likely

11 Do or did you have a spouse/partner who was ever diagnosed with pancreatic cancer?

- Yes
- No
- No spouse/partner

12 Pancreatic cancer seems to run in my family.

- Strongly disagree
- Disagree
- Neither agree or disagree
- Agree
- Strongly agree



RESEARCH PARTICIPATION AND OPINIONS

ABOUT YOUR FAMILY

VIEWS ON GENES AND HEALTH

GENETIC TESTING EXPERIENCE

AN EXAMPLE FROM GENETIC RESEARCH

PRACTICAL CONSIDERATIONS IN GENETIC RESEARCH

HOW TO RETURN GENETIC RESEARCH RESULTS

GENETIC RESEARCH RESULTS AND PRIVACY

ABOUT YOU

13 Please mark either “true,” “false,” or “not sure” for each statement. Mark only one answer for each statement.

	TRUE	FALSE	NOT SURE
If a person has a genetic mutation for a disease, the person will always get the disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Only mothers can pass on genetic diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People can be healthy even if they have a genetic mutation for a disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic testing can be used in adults to find out if they have a greater than average chance of developing certain kinds of cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic testing can be used during pregnancy to find out whether the baby will develop sickle cell disease or cystic fibrosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14 Please tell us how much you disagree or agree with each statement.

	Strongly DISAGREE	DISAGREE	Neither Agree nor Disagree	AGREE	Strongly AGREE
Genes are the most important contributor to health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can influence the impact of my genes on my health through prayer or spiritual practice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The main thing that affects my health is what I myself do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Regarding my health, I can only do what my doctor tells me to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Luck plays a big part in determining how soon I will recover from an illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am in control of my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having regular contact with my physician is the best way for me to avoid illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most things that affect my health happen to me by accident	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I take the right actions, I can stay healthy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health professionals control my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My good health is largely a matter of good fortune	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



RESEARCH PARTICIPATION AND OPINIONS

ABOUT YOUR FAMILY

VIEWS ON GENES AND HEALTH

GENETIC TESTING EXPERIENCE

AN EXAMPLE FROM GENETIC RESEARCH

PRACTICAL CONSIDERATIONS IN GENETIC RESEARCH

HOW TO RETURN GENETIC RESEARCH RESULTS

GENETIC RESEARCH RESULTS AND PRIVACY

ABOUT YOU

15 Have you ever received genetic counseling or met with a genetic counselor?

- Yes
- No
- Unsure

16 Genetic testing involves giving a sample of your blood or saliva. Please tell us whether you have had the following kinds of tests.

	YES	NO	UNSURE
Genetic testing through an internet website to determine your disease risk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic testing through an internet website to determine your ancestry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic testing during pregnancy (prenatal) to determine your child's risk of having a specific health condition (For men, answer for the mother of your child)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic testing prior to pregnancy (pre-conception) to determine your risk of having a child with a specific health condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic testing for a specific disease that was ordered by your doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic testing to determine what kind or amount of medication you should take	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



RESEARCH PARTICIPATION AND OPINIONS

ABOUT YOUR FAMILY

VIEWS ON GENES AND HEALTH

GENETIC TESTING EXPERIENCE

AN EXAMPLE FROM GENETIC RESEARCH

PRACTICAL CONSIDERATIONS IN GENETIC RESEARCH

HOW TO RETURN GENETIC RESEARCH RESULTS

GENETIC RESEARCH RESULTS AND PRIVACY

ABOUT YOU

Please use this story to answer the questions on the next page.

PAT'S STORY: PART 1

Pat, who is 58 years old, was diagnosed with pancreatic cancer in 2009. Pancreatic cancer is difficult to detect early, spreads rapidly, and is often fatal. Pat has a spouse and 2 biologically-related children, a daughter age 22 and a son age 24. Pat volunteered to participate in the “Mayo Clinic Biospecimen Resource for Pancreas Research.” The purpose of this research registry is to collect information and blood samples from many people with the goal of making discoveries that will help cancer patients in the future. As a participant in the research registry, Pat completed questionnaires and gave a blood sample.

In 2010, after analyzing many blood samples in the research registry, researchers discovered a new gene that is related to pancreatic cancer risk. This new gene was present in the blood sample Pat provided. Since genes run in families, Pat’s blood relatives might also have the new gene. At the time of this discovery, there were no proven ways to prevent the development of pancreatic cancer in people who have the gene.





For the following questions, please remember that “offering” results means that the person is given the option of saying “yes” or “no” to actually learning the result. The result is not provided unless the person says “yes” to the offer.

17 After reading Part 1 of Pat’s story, tell us how much you disagree or agree with each statement.

	Strongly DISAGREE	DISAGREE	Neither Agree nor Disagree	AGREE	Strongly AGREE
Researchers should offer Pat the information about the pancreatic cancer gene discovered in Pat’s blood sample	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pat should be able to keep information about the pancreatic cancer gene private from others in the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pat, not the researchers, is responsible for sharing the information about the pancreatic cancer gene with blood relatives (biologically-related family members)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Researchers should ONLY offer Pat’s information about the pancreatic cancer gene to blood relatives if Pat has given EXPLICIT PERMISSION to share genetic research results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the new discovery is made AFTER PAT’S DEATH, the information about the pancreatic cancer gene should be offered to Pat’s spouse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If Pat’s spouse REFUSES the offer of information about the pancreatic cancer gene, researchers should offer the results directly to Pat’s children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the new discovery is made AFTER PAT’S DEATH, and Pat’s wishes about sharing genetic information are UNKNOWN, the information about the pancreatic cancer gene should be offered to Pat’s blood relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the new discovery is made AFTER PAT’S DEATH, and Pat previously said NOT TO SHARE genetic information, the information about the pancreatic cancer gene should NOT be offered to Pat’s blood relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please use this story to answer the questions on the next page.

PAT'S STORY: PART 2

As the researchers continued to look for genetic causes of pancreatic cancer, they discovered that some patients in the registry also have mutations in genes that may increase risk for having other diseases. At Mayo Clinic, three examples have already been found in the research registry: genes for breast/ovarian cancer, melanoma, and cystic fibrosis. It is likely that in the future, advances in genetic research will reveal even more information about disease risk.

In 2012, researchers found a mutation in a gene called “BRCA2” in Pat’s blood sample. Women who have a BRCA2 mutation are about 3-4 times more likely than the average woman to get breast cancer during their lives, often at young ages. They are 10 times more likely to get cancer of the ovary. Men also can get breast cancer, and both men and women can pass on the gene mutation to their children. Since genes run in families, Pat’s blood relatives might also have the BRCA2 gene mutation. For example, Pat’s daughter has a 50/50 chance of having inherited the BRCA2 mutation. If she carries the BRCA2 mutation, she could get breast cancer screening earlier in her life and more often than the average woman. Also, some women with the BRCA2 mutation decide to have their ovaries removed.





For the following questions, please remember that “offering” results means that the person is given the option of saying “yes” or “no” to actually learning the result. The result is not provided unless the person says “yes” to the offer.

18 After reading Part 2 of Pat’s story, tell us how much you disagree or agree with each statement.

	Strongly DISAGREE	DISAGREE	Neither Agree nor Disagree	AGREE	Strongly AGREE
Researchers should offer Pat the information about the BRCA2 mutation discovered in Pat’s blood sample	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pat should be able to keep information about the BRCA2 mutation private from others in the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pat, not the researchers, is responsible for sharing the information about the BRCA2 mutation with blood relatives (biologically-related family members)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Researchers should ONLY offer Pat’s information about the BRCA2 mutation to blood relatives if Pat has given EXPLICIT PERMISSION to share genetic research results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the BRCA2 discovery is made AFTER PAT’S DEATH, the information about the BRCA2 mutation should be offered to Pat’s spouse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If Pat’s spouse REFUSES the offer of BRCA2 results, researchers should offer the results directly to Pat’s children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the BRCA2 discovery is made AFTER PAT’S DEATH, and Pat’s wishes about sharing genetic information are UNKNOWN, the information about the BRCA2 mutation should be offered to Pat’s blood relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the BRCA2 discovery is made AFTER PAT’S DEATH, and Pat previously said NOT TO SHARE genetic information, the information about the BRCA2 mutation should NOT be offered to Pat’s blood relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please use the following story to answer the questions on the next page.

PAT'S STORY: PART 3

In 2013, as the research continued, Mayo Clinic researchers found that some pancreatic cancer patients in the registry also carry the gene for cystic fibrosis. Cystic fibrosis is a severe chronic lung disease in children and young adults that can lead to early death. Treatments are available but do not cure the disease.

The patients in the registry who carry the gene for cystic fibrosis can pass the disease on to their children. To have the disease, a child must inherit 2 copies of the cystic fibrosis gene mutation, one from each parent. Children who inherit one copy will be “carriers.” They will not have the disease, but they can pass it along to their children.

Couples who are concerned about having a child with cystic fibrosis can be screened for the gene mutation before becoming pregnant. If both parents are found to have the cystic fibrosis mutation and the woman is pregnant, prenatal testing can be done to see if the baby will have cystic fibrosis. Couples whose unborn child receives a positive diagnosis of cystic fibrosis can choose to prepare for having a child with the disease or end the pregnancy.

Pat's blood sample tested positive for the cystic fibrosis mutation. Pat does not have the disease, but Pat's children may have inherited the mutation. If they did inherit Pat's mutation, they would be carriers. A carrier has a chance of passing on the mutation or of having a child with cystic fibrosis. If Pat's son or daughter has a partner who also carries the gene, the couple has a 1 in 4 chance of having a child with cystic fibrosis.





For the following questions, please remember that “offering” results means that the person is given the option of saying “yes” or “no” to actually learning the result. The result is not provided unless the person says “yes” to the offer.

19 After reading Part 3 of Pat’s story, tell us how much you disagree or agree with each statement.

	Strongly DISAGREE	DISAGREE	Neither Agree nor Disagree	AGREE	Strongly AGREE
Researchers should offer Pat the information about the cystic fibrosis mutation discovered in Pat’s blood sample	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pat should be able to keep information about the cystic fibrosis mutation private from others in the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pat, not the researchers, is responsible for sharing the information about the cystic fibrosis mutation with blood relatives (biologically-related family members)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Researchers should ONLY offer Pat’s information about the cystic fibrosis mutation to blood relatives if Pat has given EXPLICIT PERMISSION to share genetic research results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the discovery that Pat carries the cystic fibrosis mutation is made AFTER PAT’S DEATH, the information should be offered to Pat’s spouse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If Pat’s spouse REFUSES the offer of information, researchers should offer the information about the cystic fibrosis mutation directly to Pat’s children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the discovery about the cystic fibrosis mutation is made AFTER PAT’S DEATH, and Pat’s wishes about sharing genetic information are UNKNOWN, the information should be offered to Pat’s blood relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the discovery about the cystic fibrosis mutation is made AFTER PAT’S DEATH, and Pat previously said NOT TO SHARE genetic information, the information should NOT be offered to Pat’s blood relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



For the following questions, assume that genetic research results would be **MEDICALLY USEFUL**.

20 What if one of your **BIOLOGICAL PARENTS** participated in a research registry as Pat did? Please tell us how much you disagree or agree with each statement.

	Strongly DISAGREE	DISAGREE	Neither Agree nor Disagree	AGREE	Strongly AGREE
I would want to know about genetic research results discovered in my parent's sample	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am a blood relative, my parent has an OBLIGATION to share genetic research results with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My parents' genetic research results should be kept PRIVATE , including after their death	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would expect to be offered my parents' results, even if they had not granted explicit permission and no longer could give permission	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am certain my parents would want their genetic results offered to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All of my blood relatives would probably have the same opinion about being OFFERED genetic research results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All of my blood relatives would probably have the same opinion about ACTUALLY LEARNING genetic research results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21 What if **YOU** were the one who provided a blood sample for a research registry? Please tell us how much you disagree or agree with each statement.

	Strongly DISAGREE	DISAGREE	Neither Agree nor Disagree	AGREE	Strongly AGREE
I would want to know about genetic research results discovered in my sample	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would NOT want my blood relatives to know about my genetic research results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would want researchers to inform my health care provider about genetic results discovered in my research sample	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would feel OBLIGATED to share my genetic research results with my blood relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would want my genetic research results to be kept PRIVATE , even after my death	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would be OK with sharing my genetic research results with blood relatives who wanted to know them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Mayo Clinic researchers could discover information about your genetic risk for one of two reasons: 1) because a blood relative was a research participant and gave a sample (blood, tissue), or 2) because you volunteered to be a research participant and gave a sample. Please answer the following questions.

22 If researchers discovered that you might be at increased genetic risk for PANCREATIC CANCER, would you want this information OFFERED to you?

- Yes
- No

If yes, answer the following question.

22a Do you think you would want genetic testing to find out whether you carry the gene mutation?

- Yes
- No
- Not Sure

23 If researchers discovered that you might be at increased genetic risk for BREAST CANCER, would you want this information OFFERED to you?

- Yes
- No

If yes, answer the following question.

23a Do you think you would want genetic testing to find out whether you carry the gene mutation?

- Yes
- No
- Not Sure

24 If researchers discovered that you might be a carrier of the CYSTIC FIBROSIS mutation, would you want this information OFFERED to you?

- Yes
- No

If yes, answer the following question.

24a Do you think you would want genetic testing to find out whether you carry the gene mutation?

- Yes
- No
- Not Sure

25 Please tell us how much you disagree or agree with each statement.

	Strongly DISAGREE	DISAGREE	Neither Agree nor Disagree	AGREE	Strongly AGREE
Learning genetic research results can help you plan for the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic information belongs to all blood relatives, not just the person who gave the blood sample	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Learning genetic research results can only lead to worry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic knowledge is power	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



RESEARCH PARTICIPATION AND OPINIONS

ABOUT YOUR FAMILY

VIEWS ON GENES AND HEALTH

GENETIC TESTING EXPERIENCE

AN EXAMPLE FROM GENETIC RESEARCH

PRACTICAL CONSIDERATIONS IN GENETIC RESEARCH

HOW TO RETURN GENETIC RESEARCH RESULTS

GENETIC RESEARCH RESULTS AND PRIVACY

ABOUT YOU

26 Please tell us how much you disagree or agree with each statement.

	Strongly DISAGREE	DISAGREE	Neither Agree nor Disagree	AGREE	Strongly AGREE
Researchers should NOT be required to offer genetic results because it's not their job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
No matter how much money it costs, researchers SHOULD offer results to research participants	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When entering a research registry, participants should be given the choice to receive or not receive genetic results from their research sample	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When entering a research registry, participants should be given the choice to say whether or not their research results may be offered to biological family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People who do not want to know their research results should not participate in research studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An expert national advisory group should determine what genetic research results should be offered to research participants or their blood relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Since genes are shared among blood relatives, a person who participates in a genetic research study is obligated to share genetic results with blood relatives who want to know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Blood relatives of research participants should be given access to genetic research results if having the results will help them get insurance payment for their own personal genetic testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27 Please tell us which ONE of the following two statements better reflects your opinion about offering results.

- Not offering results to any research participants, in order to protect those who do not want to know genetic research results, is the right thing to do.
- OR
- Offering genetic research results to all research participants, even at the risk of upsetting those who may not want to be offered results, is the right thing to do.

28 Please tell us which ONE of the following two statements better reflects your opinion about offering results.

The most important factor to consider in returning genetic research results is the wishes of the person who provided the blood sample.

OR

The most important factor to consider in returning genetic research results is whether blood relatives will benefit.

29 Please tell us whether each of the following genetic research results should not or should be offered to research participants or family members.

	Definitely SHOULD NOT be offered	Could be offered	Definitely SHOULD be offered
The research result came from a genetic test that has NOT been approved by a government agency, such as the Food and Drug Administration (FDA)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The genetic research result shows an increased risk for a disease that is NOT TREATABLE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The genetic research result shows an increased risk for a disease that COULD BE PREVENTED	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The genetic research result shows an increased risk for a disease that is related to COGNITIVE DECLINE, like Alzheimer's disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The genetic research result shows an increased risk for a disease that can be PASSED TO CHILDREN	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The genetic research result shows increased risk for a disease that is FATAL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The genetic research result shows there is ONLY A SMALL CHANCE of developing the disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The genetic research result provides information a person can ACT ON	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The genetic finding was only recently discovered and is NOT FULLY UNDERSTOOD yet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30 What if a research participant dies without saying whether his/her genetic information can be offered to family members? Who should make decisions about the genetic information obtained from the blood sample? (Please mark only one)

- The research participant's spouse/partner
- The research participant's blood relatives
- The research participant's personal representative/executor of estate (whether or not a blood relative)
- The research participant's primary care physician
- The researcher
- Other (please specify): _____



RESEARCH PARTICIPATION AND OPINIONS

ABOUT YOUR FAMILY

VIEWS ON GENES AND HEALTH

GENETIC TESTING EXPERIENCE

AN EXAMPLE FROM GENETIC RESEARCH

PRACTICAL CONSIDERATIONS IN GENETIC RESEARCH

HOW TO RETURN GENETIC RESEARCH RESULTS

GENETIC RESEARCH RESULTS AND PRIVACY

ABOUT YOU



This section considers how information should be shared with research participants and biological family members if Mayo Clinic decides to do so.

If you would NEVER want to be offered genetic research results from your sample or a family member's sample, check this box and skip to the  before question 37.

31 Please tell us which ONE of the following two statements better reflects your opinion about the kind of information that should be included in a FIRST communication.

- GENERAL information, such as: “We have found something that might be important to your health or your family’s health.” You could then choose to learn specific results later.
- OR
- SPECIFIC information, such as: “We have found that you or a family member has a genetic mutation that significantly increases breast cancer risk compared to the average woman.”

32 Genetic information can affect decisions about having children. Do you think health implications for future children should be included in a FIRST communication about genetic research results?

- Yes
- No
- No opinion

33 There are a variety of ways to contact someone to offer genetic research results. Please tell us if the following ways of being contacted are not acceptable or acceptable.

	NOT ACCEPTABLE	ACCEPTABLE
A. Receiving a letter in the mail	<input type="radio"/>	<input type="radio"/>
B. Being given access to a secure Internet portal	<input type="radio"/>	<input type="radio"/>
C. Receiving an email	<input type="radio"/>	<input type="radio"/>
D. Receiving a phone call	<input type="radio"/>	<input type="radio"/>

34 Which ONE of the options above would you most prefer? Write the letter (A, B, C, or D) of your top choice in the box below.

My most preferred method of initial contact is

35 There are different professionals who can deliver genetic research results to participants who want to learn results. Please tell us if the following people are not acceptable or acceptable.

	NOT ACCEPTABLE	ACCEPTABLE
A. The research participant's own primary care doctor	<input type="radio"/>	<input type="radio"/>
B. The researcher who discovered the genetic result	<input type="radio"/>	<input type="radio"/>
C. A specialist in medical genetics	<input type="radio"/>	<input type="radio"/>
D. Anyone with medical training who could explain the result	<input type="radio"/>	<input type="radio"/>
E. A certified genetic counselor	<input type="radio"/>	<input type="radio"/>

36 Which ONE of the options above would you most prefer? Write the letter (A, B, C, D, or E) of your top choice in the box below.

The person I would most prefer to deliver results is



Another potential way researchers could handle genetic research results is to describe new findings in a newsletter that is mailed or emailed to all participants. This would mean that Mayo Clinic would not contact you personally about a genetic research result, but you could initiate contact with Mayo Clinic and find out if any results are available from your own blood sample. You could also read about the new findings in the newsletter and choose not to initiate contact or learn anything about your own sample.

37 Would the newsletter approach be acceptable or not acceptable?

- Acceptable
- Not acceptable

38 Please tell us which ONE of the following two statements better reflects your own viewpoint about offering genetic research results.

- The responsibility should rest with the RESEARCH PARTICIPANT to ask for genetic research results found in his or her blood sample.
- OR
- The responsibility should rest with the RESEARCHER to offer genetic research results to research participants.



RESEARCH PARTICIPATION AND OPINIONS

ABOUT YOUR FAMILY

VIEWS ON GENES AND HEALTH

GENETIC TESTING EXPERIENCE

AN EXAMPLE FROM GENETIC RESEARCH

PRACTICAL CONSIDERATIONS IN GENETIC RESEARCH

HOW TO RETURN GENETIC RESEARCH RESULTS

GENETIC RESEARCH RESULTS AND PRIVACY

ABOUT YOU

- 39 How concerned would you be if your biological family members learned your genetic research results?
- Not at all concerned
 - Slightly concerned
 - Quite concerned
 - Extremely concerned
- 40 How concerned would you be if an employer learned your or your biological family member's genetic research results?
- Not at all concerned
 - Slightly concerned
 - Quite concerned
 - Extremely concerned
- 41 How concerned would you be if your health insurance company learned your or your biological family member's genetic research results?
- Not at all concerned
 - Slightly concerned
 - Quite concerned
 - Extremely concerned
- 42 How concerned would you be if your disability, long-term care, or life insurance providers learned your or your biological family member's genetic research results?
- Not at all concerned
 - Slightly concerned
 - Quite concerned
 - Extremely concerned



RESEARCH PARTICIPATION AND OPINIONS

ABOUT YOUR FAMILY

VIEWS ON GENES AND HEALTH

GENETIC TESTING EXPERIENCE

AN EXAMPLE FROM GENETIC RESEARCH

PRACTICAL CONSIDERATIONS IN GENETIC RESEARCH

HOW TO RETURN GENETIC RESEARCH RESULTS

GENETIC RESEARCH RESULTS AND PRIVACY

ABOUT YOU

43 Are you?

- Male
- Female

44 What year were you born? _____

45 Are you Hispanic, Latino, or of Spanish origin?

- Yes
- No

46 Which of the following do you consider yourself? (Mark all that apply)

- White
- Black or African American
- Asian
- Native Hawaiian or Pacific Islander
- American Indian or Alaskan Native
- Some other race

47 What is the highest level of education you completed?

- Never attended school
- 8th Grade or less
- Some high school
- High School graduate or GED
- Vocational, technical or business school
- Some college or Associate's degree (including community college)
- Four year college graduate (Bachelor's degree)
- Graduate or Professional school

48 As of today, what is your employment status? (Please mark all that apply)

- Employed more than or equal to 32 hours per week
- Employed less than 32 hours per week
- Employed but on medical leave
- Full time student
- Part time student
- Unemployed
- Homemaker
- Unable to work due to disability
- Retired

49 Are you currently?

- Married
- Partnered in a marriage-like relationship
- Separated
- Divorced
- Widowed
- Single, never married

50 Are you currently covered by health insurance (including coverage through a spouse, partner, or parent)?

- No
- Yes, through an employer
- Yes, purchased privately
- Yes, through a government program (such as Medicare, Medicaid or a state program)

THANK YOU SO MUCH FOR YOUR PARTICIPATION!

When we complete our work, a summary of what we have learned will be mailed to all those completing the survey.

Place ID Label Here