

Genetics Forum Survey Packet 3



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Survey Instructions

In this survey you will read about different outcomes that can occur when the human genome is sequenced.

This survey contains questions regarding your thoughts and opinions about possible policies for genome sequencing. A policy is a set of rules or regulations meant to guide the future actions of an institution such as a business, government, or hospital. Our aim is to use your responses to make recommendations that would guide future health care policy decisions.

These proposed policies will look familiar to you from the other surveys you received. Please answer the questions as to how you feel about these policies right now. Your answers on this survey do not have to be the same as your answers on the previous surveys or the views you expressed during the deliberation. If you feel the same way that you did when you answered the other surveys that is fine too.

In this packet you will find descriptions of three possible outcomes that might occur as a result of human genome sequencing. After reading through each possible outcome, you will be asked to answer a number of questions. Please answer each question to the best of your ability, but you may choose not to answer any questions you don't want to answer. At the end of the survey, we will ask for your opinions of the healthcare system and some information about yourself.

There are no right or wrong answers, so simply answer each question to the best of your ability.

PROCEED TO THE NEXT PAGE FOR
THE FIRST POSSIBLE OUTCOME

1. Medically actionable results

Please read the information below and answer the questions on the following pages.

When someone has their genome sequenced for one medical condition, it can also reveal information about other medical conditions. Some of these results can be medically actionable.

- What is a **medically actionable result**?
 - A change in a person's DNA that increases the risk of developing a specific health condition
 - A medical result where actions can be taken to prevent, delay, or reduce symptoms of the health condition
 - Examples: Certain types of heart conditions (e.g., high risk of heart attack), cancers (e.g., colon, breast, prostate), neurological conditions (e.g., Parkinson's Disease)

What does it mean if a person has a medically actionable result?

- It **does** mean that a person has a higher risk of developing the health condition than people without the DNA change
- It **does not** mean that the person will definitely develop the health condition

Consider this scenario where a patient might have a medically actionable result:

A patient has a heart condition that the patient's cardiologist (heart doctor) thinks might be due to a DNA change. To help make a diagnosis and determine whether any treatment options exist, the cardiologist suggests that the patient have his genome sequenced. The doctor tells the patient that genome sequencing could reveal *additional* and *unexpected* medically actionable results (not related to the heart condition). The doctor also discusses the risks and benefits of learning this information with the patient.

If you had your genome sequenced for a specific health condition...

1. Would you want to be told **medically actionable results** that were not related to the reason for the sequencing?

Definitely no No Probably no Probably yes Yes Definitely yes

Please explain your answer in the space below.

What you think is best for you might not be what you think is best for other people in general, that is, it may not be the best general policy.

The proposed genome sequencing policy regarding medically actionable results is that:

- Patients **are given** medically actionable results that are not related to the reason for the sequencing

AND

- Patients **have a choice**: They can ask to NOT be given these results

2. Should this be the genome sequencing policy regarding **medically actionable results**?

Definitely no No Probably no Probably yes Yes Definitely yes

Please explain your answer in the space below.

3. The policy you just read about says that patients **are given** medically actionable results that are not related to the reason for the sequencing. Do you agree with this part of the policy?

No Yes

4. The policy you just read about also says that patients **have a choice** about whether they are given medically actionable results that are not related to the reason for the sequencing. Do you agree with this part of the policy?

No Yes

If you had your genome sequenced for a specific health condition...

5. Would you pay to receive a report of medically actionable results that are not related to the reason for the sequencing if a report of these results was NOT covered by your insurance?

No Yes

If yes, how much would you be willing to pay?

I would be willing to pay \$_____

6. How worried would you be that the sequencing of your genome would reveal a medically actionable result?

| | | | | | | | | |
|--------------------------|---|---|---|---|---|---|---|----------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Not worried at all | | | | | | | | Extremely worried |

7. In your opinion, how likely is it that the sequencing of your genome would reveal a medically actionable result?

| | | | | | | | | |
|--|---|---|---|---|---|---|---|-------------------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Would definitely not reveal a result | | | | | | | | Would definitely reveal a result |

8. If a medically actionable result was discovered during the sequencing of your genome, to what extent do you think you would be able to do prevent, delay, or reduce the symptoms associated it?

| | | | | | | | | |
|------------|---|---|---|---|---|---|---|------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Not at all | | | | | | | | Completely |

PROCEED TO THE NEXT PAGE FOR
THE SECOND POSSIBLE OUTCOME

2. Adult-onset conditions

Please read the information below and answer the questions on the following pages.

Genome sequencing is not just for adults; **children can also have their genome sequenced.**

When a child has their genome sequenced for one medical condition, it can also reveal information about other medical conditions. Some of these conditions may be adult-onset.

- What is an **adult-onset condition**?
 - A change in a person's DNA that increases his or her risk for developing a specific health condition later in life, often in their 40s or older
 - Some of these health conditions are treatable, while others are not
 - Examples: high cholesterol, breast cancer, prostate cancer, Alzheimer's Disease

What does it mean if a child has a result for an adult-onset condition?

- It **does** mean that:
 - The child has a higher risk of developing the health condition than people without the DNA change
 - If the child develops the disease it is not likely to develop until the child becomes an adult.
- It **does not** mean that the child will definitely develop the health condition at any point in his/her life

Consider this scenario where a child might have a result for an adult-onset condition:

A child has developmental delays that the child's pediatrician thinks may be due to a DNA change. To help make a diagnosis and determine whether any treatment options exist, the pediatrician suggests to the child's parents that the child should have her genome sequenced. In addition to the genetic results related to the developmental delays, the pediatrician may learn that the child also has DNA changes that increase that child's risk of developing an adult-onset condition.

For the following question, if you don't have a child, imagine what you would do if you did have a child.

If your child had their genome sequenced for a specific health condition...

1. Would you want to be told whether **your child** had an increased risk of developing an **adult-onset condition** that is not related to the reasoning for the sequencing?

Definitely no No Probably no Probably yes Yes Definitely yes

Please explain your answer in the space below.

What you think might be best for you might not be what you think is best for other people in general, that is, it might not be the best general policy.

The proposed genome sequencing policy regarding adult-onset conditions is that:

- Children and their parents **are not given** results for adult-onset conditions that are not related to the reason for the sequencing

AND

- Children and their parents **have no choice**: They will not be given these results even if they want them

2. Should this be the genome sequencing policy regarding **adult-onset conditions**?

Definitely no No Probably no Probably yes Yes Definitely yes

Please explain your answer in the space below.

3. The policy you just read about says that children and parents **are not given** results for adult-onset conditions that are not related to the reason for the sequencing of the child's genome. Do you agree with this part of the policy?

No Yes

4. The policy you just read about also says children and parents **do not have a choice** about whether to be given results for adult-onset conditions that are not related to the reason for the sequencing of the child's genome. Do you agree with that part of the policy?

No Yes

You may or may not have a child. For the following questions, if you don't have a child, imagine what you would do if you did have a child.

If your child had their genome sequenced for a specific health condition...

5. Would you pay to receive a report of results for adult-onset conditions that are not related to the reason for the sequencing if a report of these results was NOT covered by your insurance?

No Yes

If yes, how much would you be willing to pay?

I would be willing to pay \$_____

6. How worried would you be that genome sequencing would reveal that your child has an increased risk of developing a health condition as an adult?

| | | | | | | | | |
|--------------------------|---|---|---|---|---|---|---|----------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Not worried at all | | | | | | | | Extremely worried |

7. In your opinion, how likely is it that the sequencing of your child's genome would reveal that your child has an increased risk of developing a health condition as an adult?

1 2 3 4 5 6 7 8 9

Would definitely
not reveal a result

Would definitely
reveal a result

8. If a result for an adult-onset condition was found for your child, to what extent do you think you would be able to prevent, delay, or reduce the symptoms associated it?

| | | | | | | | | |
|------------|---|---|---|---|---|---|---|------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Not at all | | | | | | | | Completely |

PROCEED TO THE NEXT PAGE FOR
THE THIRD POSSIBLE OUTCOME

3. Carrier Status Results

Please read the information below and answer the questions on the following pages.

When someone has their genome sequenced for one medical condition, it can also reveal information about other medical conditions, such as a person's carrier status.

- What is a **carrier status result**?
 - A change in a person's DNA that could be passed onto their children
 - The person generally will not exhibit the health condition linked to the DNA change
 - The person's children might exhibit the health condition if their other parent is also a carrier
 - Other members of his or her family, like siblings, could have the health condition
 - Can be unrelated to the reason for the sequencing
 - Examples: cystic fibrosis, sickle cell anemia, Fragile X Syndrome and hemophilia.

What does it mean if a person has a carrier status result?

- It **does** mean that:
 - There is usually little to no effect on the person who is a carrier
 - The person can learn information that could be useful to his or her family members who may also be carriers or have the health condition
 - The person can learn information that is helpful for making decisions about having children
- It **does not** mean that the person's children will definitely get the health condition

Consider this scenario where a patient might have a carrier-status result:

A young woman has recently been diagnosed with thyroid cancer that the woman's oncologist (cancer doctor) thinks may be due to a DNA change. To help determine which treatment options might be effective, the oncologist suggests that the woman have her genome sequenced. In addition to the genetic results related to the thyroid cancer, the oncologist may learn that the woman also has DNA changes that show that she is a carrier for a health condition(s). The woman is thinking about having a child after her cancer is treated.

If you had your genome sequenced for a specific health condition...

1. Would you want to be told **carrier status results** that were not related to the reason for the sequencing?

Definitely no No Probably no Probably yes Yes Definitely yes

Please explain your answer in the space below.

What you think might be best for you might not be what you think is best for other people in general, that is, it might not be the best general policy.

The proposed genome sequencing policy regarding carrier status results is that:

- Patients **are not given** carrier status results that are not related to the reason for the sequencing

AND

- Patients have **no choice**: They will not be given these results even if they want them

2. Should this be the genome sequencing policy regarding carrier status results?

Definitely no No Probably no Probably yes Yes Definitely yes

Please explain your answer in the space below.

3. The policy you just read about says that patients **are not given** any carrier status results that are not related to the reason for the sequencing. Do you agree with this part of the policy?

No Yes

4. The policy you just read about also says that patients **do not have a choice** about whether they are told about any carrier status results that are not related to the reason for the sequencing. Do you agree with this part of the policy?

No Yes

If you had your genome sequenced for a specific health condition...

5. Would you pay to receive a report of carrier status results that are not related to the reason for the sequencing if a report of these results was NOT covered by your insurance?

No Yes

If yes, how much would you be willing to pay?

I would be willing to pay \$_____

6. How worried would you be that genome sequencing would reveal a carrier status result?

| | | | | | | | | |
|--------------------------|---|---|---|---|---|---|---|----------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Not worried at all | | | | | | | | Extremely worried |

7. In your opinion, how likely is it that the sequencing of your genome would reveal a carrier status result?

| | | | | | | | | |
|--|---|---|---|---|---|---|---|-------------------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Would definitely not reveal a result | | | | | | | | Would definitely reveal a result |

If a carrier status result was discovered during the sequencing of your genome...

8. Would you have a prenatal (before your child is born) medical test done to determine if anything can be done to reduce the chance that your child would develop the health condition linked to the carrier result, even if there was a slight increase in the risk of a miscarriage?

Definitely no No Probably no Probably yes Yes Definitely yes

9. To what extent do you think you would be able to do something after your child is born to prevent, delay, or reduce your child's risk of developing the health condition as an adult?

1 2 3 4 5 6 7 8 9
Not at all Completely

Experience with Genetics

1. How confident are you in your ability to understand information about genetics?

| | | | | |
|-------------------------|---|---|---|------------------------|
| 1 | 2 | 3 | 4 | 5 |
| Not confident at all | | | | Extremely confident |

2. How well do you think you understand information about how genes might influence your health?

| | | | | |
|-----------------------------|---|---|---|--------------------------|
| 1 | 2 | 3 | 4 | 5 |
| Do not understand at all | | | | Understand completely |

3. How knowledgeable do you think you are about genetics?

| | | | | |
|-------------|---|---|---|-------|
| 1 | 2 | 3 | 4 | 5 |
| Very little | | | | A lot |

4. How do you think your knowledge of genetics compares to other people?

| | | | | |
|---------------------------|---|-----------------|---|----------------------------|
| 1 | 2 | 3 | 4 | 5 |
| Much lower than others | | Equal to others | | Much higher than others |

5. In your own words, describe how having your genome sequenced for one medical condition can also reveal information about other medical conditions (i.e. describe the steps involved in genome sequencing)?

Genetics Knowledge

*Below are a number of questions that measure your knowledge about key genetic concepts. **Information about these concepts can be found in the brochure that was included with this survey packet.** Feel free to use the brochure as you answer the questions. Please answer each question to the best of your ability.*

1. Your DNA can uniquely identify you.

False True

2. Most DNA changes do not lead to disease.

False True

3. If a healthy person has their genome sequenced they will almost certainly find out they have a disease causing DNA change.

False True

4. Genes determine everything about you, your current health, and your future health.

False True

5. Scientists understand what most of the genes in our body do.

False True

6. Once a DNA change for a disorder is identified in a person, the disorder can always be prevented or cured.

False True

7. Genes can influence how well certain medications will work for you.

False True

8. A person who is a carrier of a DNA change may be completely healthy.

False True

9. Some of the inherited disorders express themselves later in adult life.

False True

Genome Sequencing

Genome sequencing has the potential to identify DNA changes for thousands of health conditions in an individual. Some individuals may learn about their risk for developing as few as one or two health conditions; others might learn that they are at risk for more than one hundred. Imagine you were thinking about having your genome sequenced.

1. What information would you want to know about all of the health conditions that genome sequencing could identify **BEFORE** agreeing to have your genome sequenced?

Please check only one response:

- Nothing. The decision should be up to the doctor.
- The general categories of conditions that could be tested for (e.g., cancer, neurological conditions, heart disease).
- Some examples of conditions that could be tested for (e.g., breast cancer, Parkinson's).
- The name of every single condition that could be tested for (e.g., hypertrophic cardiomyopathy, lobular carcinoma in situ).
- Detailed information about every condition being test for (see below).

If you selected "Detailed information" please check what specific information you would want to know (*please check all that apply*):

- How likely someone with the DNA change will develop the health condition
- Typical age when the health condition begins to develop
- How much this health condition might decrease a person's lifespan
- Whether treatment is available
- Risk and benefits associated with any available treatment
- Other _____

2. What information sources would you use to help you make a decision about whether to have your genome sequenced (*circle all that apply*)?

Google or another search engine

WebMD or another online medical website

Medical pamphlet about genome sequencing

Videos about genome sequencing

Recommendations from a national health organization

Medical helpline (phone)

Health care provider (e.g., doctor)

Family and friends

Other: _____

Attitudes towards the Health Care System

The next questions are about your opinion of the health care system in general. When we refer to the health care system, we mean hospitals, health insurance groups, and medical research. For each statement below, please indicate how strongly you agree or disagree.

1. Medical experiments can be done on me without my knowing about it.

| | | | | |
|-------------------|---|---|---|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | | | | Strongly agree |

2. My medical records are kept private.

| | | | | |
|-------------------|---|---|---|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | | | | Strongly agree |

3. People die every day because of mistakes by the health care system.

| | | | | |
|-------------------|---|---|---|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | | | | Strongly agree |

4. When my blood is taken, individuals in the health care system do tests they don't tell me about.

| | | | | |
|-------------------|---|---|---|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | | | | Strongly agree |

5. If a mistake were made in my health care, the health care system would try to hide it from me.

| | | | | |
|-------------------|---|---|---|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | | | | Strongly agree |

6. People can get access to my medical records without my approval.

| | | | | |
|-------------------|---|---|---|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | | | | Strongly agree |

7. The health care system cares more about holding costs down than it does about doing what is needed for my health.

| | | | | |
|-------------------|---|---|---|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | | | | Strongly agree |

8. I receive high-quality medical care from the health care system.

| | | | | |
|-------------------|---|---|---|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | | | | Strongly agree |

9. The health care system puts my medical needs above all other considerations when treating my medical problems.

| | | | | |
|-------------------|---|---|---|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | | | | Strongly agree |

10. Some medicines have things in them that they don't tell you about.

| | | | | |
|-------------------|---|---|---|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly disagree | | | | Strongly agree |

Have you had any major changes in your health since the deliberation session on October 25?

No Yes

If yes, please describe:

Have you received any results from genetic testing since the deliberation session on October 25?

No Yes

If yes, please describe:

How often have you seen genetics or genome sequencing brought up or discussed in the media since the deliberation on October 25?

| | | | | |
|------------|---|---|---|-----------------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all | | | | All of the time |

Compared to before the deliberation on October 25, how much does it seem like the media brings up or discusses genetics or genome sequencing?

| | | | | |
|-----------|---|---|---|-----------|
| 1 | 2 | 3 | 4 | 5 |
| Much less | | | | Much more |

Thank you for your participation in the Genetics Forum!