

Version A

The screenshot shows a web browser window with the address bar displaying "NHGRI: Social Genomics Proj". The page header features the "genome.gov" logo and the "National Human Genome Research Institute" name, along with a "National Institutes of Health" tagline. A search bar with "Google Search" and a "SEARCH" button is present. A navigation menu includes links for "Research Funding", "Research at NHGRI", "Health", "Education", "Issues in Genetics", "Newsroom", "Careers & Training", "About", and "For You", along with social media icons for Facebook, Twitter, and YouTube.

NHGRI Division of Intramural Research
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Will Genome Sequence Information Change How You View Yourself?

In this study we ask you to imagine receiving genome sequence information and to answer a series of questions about whether the information may change the ways you view yourself.




We estimate that this survey will take 10 minutes, including the time for reviewing instructions, consenting, and completing the survey.

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OMB # 0925-NEW
Expiration Date: xx/xxxx

Thank you for your interest in this research. To participate you must be 18 years or older.

I verify that I am 18 years old or older




Yes

No

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OMB # 0925-NEW
Expiration Date: xx/xxxx

These surveys are being conducted by researchers at the National Human Genome Research Institute of the National Institutes of Health.

The surveys are being conducted to help researchers understand how people think and feel about issues related to genetics and health. You may complete as many or as few of the surveys as you wish.

Your response to the surveys is completely voluntary. You may end your participation at any time. Any reports or publications based on this research will use only group data and will not identify you individually. We will not store any personally identifying information within the survey. Your responses will remain secure to the extent permitted by law. The privacy and confidentiality of all collected information will be maintained at all times during the study process.

By clicking on the Accept button below you are indicating that you consent to participate in this research.

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First, we are going to ask you some questions about yourself. Please remember that there are no right or wrong answers; your honest answer is your best answer. If the question has a blank, fill in the blank. If the question has a list of choices, please select the response that best reflects your answer.

What is your gender?

Male
 Female

What is your current age?

years

Which country do you live in?

If US, which state do you live in?

What is your zip code?

Are you Hispanic or Latino?

Yes
 No
 Don't Know

Which one or more of the following would you say is your race?

Black or African
 Native Hawaiian or other Pacific Islander
 White
 Asian
 Indian or Alaska Native
 Don't Know



What is your highest level of completed education?

- Less than 8th grade
- 8th grade
- Some high school (no diploma or ged equivalent)
- High school diploma or ged equivalent
- Some college (no degree)
- Technical or Associate degree
- Bachelors Degree (BA, BS, AB)
- Masters Degree (RN,MS,MA)
- Professional Degree (JD, PhD, MD, ED)

What is your favorite food?

Are you adopted?

- Yes
- No
- I don't know

In general, would you say your health is:

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Poor | Fair | Good | Very Good | Excellent |
| 0 | 1 | 2 | 3 | 4 |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

On a scale from 1 to 7, where 1 is not at all happy and 7 is very happy, how happy do you feel in general?

- | | | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Not at all
happy | | | | | | Very
happy |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

On a scale from 1 to 7, where 1 is not at all stressed and 7 is very stressed, how stressed do you feel in general?

- | | | | | | | |
|------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Not at all
stressed | | | | | | Very
stressed |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Have you ever had a genetic screening?

- Yes
- No
- I don't know

Next >

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Will Genome Sequence Information Change How You View Yourself?

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Genes are the main instructions that tell the body how to develop and work. Your 'genome' includes all of your genetic information. Using a new technology called "sequencing", we can read the instructions your genome uses to make your body function. Currently we know some of the ways these instructions affect your future health.

The following questions ask about how your views of yourself might be affected if you learned new information about yourself from your genome. Our views of ourselves come from our life experiences, values, accomplishments, family and friends. Views of yourself might also come from information you receive from your doctor. We are interested in hearing from you how learning about your genome sequence might compare.


Imagine that you have the instructions in your genome read. The results reveal something new about your health that you did not know. Please read the items below and indicate how much this might change your views of yourself as compared to information that you might hear from your doctor. Rate how much more from 1 (much less) to 5 (much more).

Compared to learning about a risk to my future health from my doctor, if my genome sequence identified a new risk to my future health...




	Much Less	Somewhat Less	The Same	Somewhat More	Much More
	1	2	3	4	5
It may change whether I view myself as a healthy person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My ideas about who I am are not likely to change	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I may feel more vulnerable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It may complicate my understanding of who I really am	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It may help to clarify aspects of how I think about myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It may enlighten me about who I will be in the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It may change how I think of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It may broaden my ideas about myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Thank you for your time!

We are required by law to make you aware of the following:

Public reporting burden for this collection of information is estimated to average 10 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-NEW). Do not return the completed form to this address.

Done

Version B

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Thank you for your interest in this research. To participate you must be 18 years or older.




I verify that I am 18 years old or older

- Yes
- No

Continue >>

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What is your gender?

Male
 Female

What is your current age?

years

Which country do you live in?

If US, which state do you live in?

What is your zip code?

Are you Hispanic or Latino?

Yes
 No
 Don't Know

Which one or more of the following would you say is your race?

Black or African
 Native Hawaiian or other Pacific Islander
 White
 Asian
 Indian or Alaska Native
 Don't Know

What is your highest level of completed education?

- Less than 8th grade
- 8th grade
- Some high school (no diploma or ged equivalent)
- High school diploma or ged equivalent
- Some college (no degree)
- Technical or Associate degree
- Bachelors Degree (BA, BS, AB)
- Masters Degree (RN,MS,MA)
- Professional Degree (JD, PhD, MD, ED)

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- Yes
- No
- I don't know

In general, would you say your health is:

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Poor | Fair | Good | Very Good | Excellent |
| 0 | 1 | 2 | 3 | 4 |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

On a scale from 1 to 7, where 1 is not at all happy and 7 is very happy, how happy do you feel in general?

- | | | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Not at all
happy | | | | | | Very
happy |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

On a scale from 1 to 7, where 1 is not at all stressed and 7 is very stressed, how stressed do you feel in general?

- | | | | | | | |
|------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Not at all
stressed | | | | | | Very
stressed |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Have you ever had a genetic screening?

- Yes
- No
- I don't know

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Will Genome Sequence Information Change How You View Yourself?

Genes are the main instructions that tell the body how to develop and work. Your 'genome' includes all of your genetic information. Using a new technology called "sequencing", we can read the instructions your genome uses to make your body function. These instructions are passed down from parents to children. By looking at patterns in the instructions, we can tell where in the world our ancestors came from.

The following questions ask about how your views of yourself might be affected if you learned new information about your origins from your genome. Our views of ourselves come from our life experiences, values, accomplishments, family and friends. Views of yourself might also come from information about your family history that you receive from a relative. We are interested in hearing from you how learning about your ancestry through genome sequence might compare to learning your family history from a relative.

Imagine that you have the instructions in your genome read. The results reveal something new about your ancestry that you did not know. Please read the items below and indicate how much this might change your views of yourself as compared to information that you might hear from your relative. Rate how much more or less this might change your self-concept as rated from 1 (much less) to 5 (much more).

Compared to learning about my family history from a relative, if my genome sequence identified new information about my ancestry...

	Much Less	Somewhat Less	The Same	Somewhat More	Much More
	1	2	3	4	5
It may change whether I view myself as a healthy person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My ideas about who I am are not likely to change	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I may feel more vulnerable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It may complicate my understanding of who I really am	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It may help to clarify aspects of how I think about myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It may enlighten me about who I will be in the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It may change how I think of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It may broaden my ideas about myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Now we ask generally about your views of your self.

Indicate below the extent to which you agree with each statement from 1 to 7. Please answer as honestly as you can even if you feel unsure.

	Strongly Disagree	Disagree	Disagree Somewhat	Neutral	Agree Somewhat	Agree	Strongly Agree
	1	2	3	4	5	6	7
When I learn about my ancestors, it boosts my self- esteem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing something I know is wrong makes me lose my self- respect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whenever I follow my moral principles, my sense of self- respect gets a boost	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My self worth would suffer if I ignored my family origins	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I couldn't respect myself if I didn't live up to a moral code	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I lose my self-respect when I think about negative aspects of where my ancestors came from	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My self-esteem would suffer if I did something unethical	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wouldn't respect myself if I didn't honor my ancestry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My self-esteem depends on whether I follow my moral/ethical principles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>


Indicate below the extent to which you agree with each statement from 1 to 5. Please answer as honestly as you can even if you feel unsure.

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
	1	2	3	4	5
My beliefs about myself conflict with one another	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that I am not really the person I appear to be	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My beliefs about myself seem to change	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I were asked to describe my personality, my description might end up being different today compared to another day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>




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Thank you for your time!

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