

## Screening Questions

1. What is your gender?
  - Male
  - Female
  - Other
  - Refuse to answer
2. What is your age?
3. Are you of Hispanic, Latino, or Spanish origin?
  - Yes
  - No
  - Refuse to answer
4. What do you identify as your race?
  - White
  - Black or African American
  - American Indian or Alaska Native
  - Asian or Pacific Islander
  - Native Hawaiian
  - Other
  - More than one race
  - Refuse to answer
5. What is the highest level of school you completed?
  - Less than high school
  - High school graduate or GED
  - Some college (vocational, associate's degree, or other)
  - Four-year college degree (for instance a bachelor's degree)
  - Graduate or professional degree (for instance a MA, MPH, MD, PhD, or JD)
  - Refuse to answer
6. What was the total family income (before taxes) from all sources within your household in the last year? Check one.
  - Less than \$10,000
  - \$10,000 - \$19,999
  - \$20,000 - \$ 29,999
  - \$30,000 - \$39,999
  - \$40,000 - \$49,999
  - \$50,000 - \$74,999
  - \$75,000 - \$99,999
  - \$100,000 to \$124,999
  - \$125,000 to \$149,000
  - \$150,000 or more
  - Refuse to answer

## Privacy Questions

1. How concerned are you about the privacy of your information?
  - Likert scale response from 1-7 with 1 being “not at all” and 7 being “very concerned”
2. How concerned are you about the privacy of your financial information?
  - Likert scale response from 1-7 with 1 being “not at all” and 7 being “very concerned”
3. How concerned are you about the privacy of your medical information?
  - Likert scale response from 1-7 with 1 being “not at all” and 7 being “very concerned”
4. How concerned are you about the privacy of your genetic information?
  - Likert scale response from 1-7 with 1 being “not at all” and 7 being “very concerned”
5. How concerned are you about the privacy of your family medical history?
  - Likert scale response from 1-7 with 1 being “not at all” and 7 being “very concerned”
6. How important do you think it is to have laws that prevent genetic test results from being used by employers, schools, or other parties outside of the medical field?
  - Likert scale response from 1-7 with 1 being “not at all important” and 7 being “extremely important”
7. Are you aware of any laws that protect against the use of genetic test results?
  - Yes
  - No
  - I don't know
  - Refuse to answer

## Employment and Insurance Questions

1. What aspect of "coverage" is more important to you?
  - Whether I am able to get insurance (eligibility)
  - How much I pay each month for my insurance (premiums)
  - They are of equal importance to me
  - Other
  - I don't know
  - Refuse to answer
2. If you were to have genetic testing done, how likely do you think it is that your genetic information would be used to determine the following? Likert scale response from 1-7 with 1 being “not at all likely” and 7 being “very likely”
  - (A) Health insurance coverage?
  - (B) Employment status?
  - (C) Life insurance coverage?
  - (D) Long-term care insurance coverage (coverage for nursing home care, adult day care or home health care)?

- (E) Disability income insurance coverage (income protection for persons unable to work for a certain period of time)?
3. How likely would you be to decline genetic testing based on concerns about genetic test results impacting the following? Likert scale response from 1-7 with 1 being “not at all likely” and 7 being “very likely”.
    - (A) Health insurance coverage
    - (B) Employment
    - (C) Life insurance coverage
    - (D) Long-term care insurance coverage
    - (E) Disability income insurance coverage

### Laws Questions

1. The laws that protect against misuse of genetic test results are likely to be effective.
  - Likert scale response from 1-7 with 1 being “strongly disagree” and 7 being “strongly agree”
2. How familiar are you with the US Health Insurance Portability and Accountability Act (HIPAA)?
  - Likert scale response from 1-7 with 1 being “not at all familiar” and 7 being “extremely familiar”
3. How familiar are you with the Affordable Care Act (ACA), sometimes referred to as Obamacare?
  - Likert scale response from 1-7 with 1 being “not at all familiar” and 7 being “extremely familiar”
4. How familiar are you with the US Genetic Information Nondiscrimination Act (GINA)?
  - Likert scale response from 1-7 with 1 being “not at all familiar” and 7 being “extremely familiar”
5. To your knowledge, does the US Genetic Information Nondiscrimination Act (GINA) protect against genetic discrimination in the following areas:
  - (A) Health Insurance?
    - Yes
    - No
    - I don't know
    - Refuse to answer
  - (B) Employment?
    - Yes
    - No
    - I don't know
    - Refuse to answer
  - (C) Life insurance?
    - Yes
    - No
    - I don't know
    - Refuse to answer
  - (D) Long-term care insurance?
    - Yes

- No
- I don't know
- Refuse to answer
- (E) Disability income insurance?
  - Yes
  - No
  - I don't know
  - Refuse to answer
- (F) Auto insurance?
  - Yes
  - No
  - I don't know
  - Refuse to answer
- (G) Property insurance (like a homeowner's policy)?
  - Yes
  - No
  - I don't know
  - Refuse to answer

## Genetic Testing Questions

1. Has a medical care provider ever offered you any of the following types of genetic testing? Please check all that apply.
  - Genetic diagnostic test (this is where you may have some symptoms and you are offered testing to help figure out the diagnosis or treatment options)
  - Genetic predictive/presymptomatic test (this is where you do not have symptoms and you are offered testing to see if you may be at risk of developing a disease in the future)
  - Carrier test (Generally done to determine risk to future children, "carrier testing is used to identify people who carry one copy of a gene mutation that, when present in two copies, causes a genetic disorder.")
  - Prenatal test ("Prenatal testing is used to detect changes in a fetus' genes or chromosomes before birth.")
  - I'm not sure if I have ever been offered any of these tests
  - I have not been offered any of these tests
  - Refuse to answer
2. (This question appears if respondent selected in the previous question that they were offered a genetic diagnostic test) Have you ever completed a genetic diagnostic test?
  - Yes
  - No
  - I don't know
  - Refuse to answer
3. (This question appears if respondent selected in the previous question that they were offered a genetic predictive/presymptomatic test) Have you ever completed a genetic predictive/presymptomatic test?

- Yes
  - No
  - I don't know
  - Refuse to answer
4. (This question appears if respondent selected in the previous question that they were offered a carrier test) Have you ever completed a carrier test?
- Yes
  - No
  - I don't know
  - Refuse to answer
5. (This question appears if respondent selected in the previous question that they were offered a prenatal test) Have you ever completed a prenatal test?
- Yes
  - No
  - I don't know
  - Refuse to answer
6. (This question appears if respondent selected in the previous question that they were offered another type of genetic test) Have you ever completed another type of genetic test?
- Yes (blank for test name)
  - No
  - I don't know
  - Refuse to answer
7. (This question appears if respondent indicated that they have completed a genetic diagnostic test). What were the results of your genetic diagnostic test?
- I received a positive result. (A gene change was identified that was associated with disease.)
  - I received a negative result. (No gene change was identified that is associated with disease.)
  - I received a result of uncertain significance. (A gene change was identified, but it is not yet known if it is associated with disease.)
  - I do not recall my results.
  - I do not want to share my results.
  - Refuse to answer
8. (This question appears if respondent indicated that they have completed a predictive/presymptomatic test). What were the results of your predictive/presymptomatic test?
- I received a positive result. (A gene change was identified that was associated with disease.)
  - I received a negative result. (No gene change was identified that is associated with disease.)
  - I received a result of uncertain significance. (A gene change was identified, but it is not yet known if it is associated with disease.)
  - I do not recall my results.
  - I do not want to share my results.

- Refuse to answer
9. (This question appears if respondent indicated that they have completed a carrier genetic test). What were the results of your carrier genetic test?
- I received a positive result. (A gene change was identified that was associated with disease.)
  - I received a negative result. (No gene change was identified that is associated with disease.)
  - I received a result of uncertain significance. (A gene change was identified, but it is not yet known if it is associated with disease.)
  - I do not recall my results.
  - I do not want to share my results.
  - Refuse to answer
10. (This question appears if respondent indicated that they have completed a prenatal genetic test). What were the results of your prenatal genetic test?
- I received a positive result. (A gene change was identified that was associated with disease.)
  - I received a negative result. (No gene change was identified that is associated with disease.)
  - I received a result of uncertain significance. (A gene change was identified, but it is not yet known if it is associated with disease.)
  - I do not recall my results.
  - I do not want to share my results.
  - Refuse to answer
11. (This question appears if respondent indicated that they have completed another genetic test). What were the results of your other genetic test?
- I received a positive result. (A gene change was identified that was associated with disease.)
  - I received a negative result. (No gene change was identified that is associated with disease.)
  - I received a result of uncertain significance. (A gene change was identified, but it is not yet known if it is associated with disease.)
  - I do not recall my results.
  - I do not want to share my results.
  - Refuse to answer
12. (This question appears if respondent indicated that they did not complete a genetic diagnostic test). Why did you not go through with the genetic diagnostic testing that was offered? Was it concerns about (check all that apply):
- Cost of genetic testing
  - Health insurance eligibility
  - Health insurance premiums
  - Life insurance eligibility
  - Life insurance premiums
  - Long-term care eligibility
  - Long-term care premiums
  - Disability income insurance eligibility

- Disability income insurance premiums
  - Employment eligibility
  - Other reasons (please explain)
13. (This question appears if respondent indicated that they did not complete a predictive/presymptomatic test). Why did you not go through with the genetic predictive/presymptomatic testing that was offered? Was it concerns about (check all that apply):
- Cost of genetic testing
  - Health insurance eligibility
  - Health insurance premiums
  - Life insurance eligibility
  - Life insurance premiums
  - Long-term care eligibility
  - Long-term care premiums
  - Disability income insurance eligibility
  - Disability income insurance premiums
  - Employment eligibility
  - Other reasons (please explain)
14. (This question appears if respondent indicated that they did not complete a carrier genetic test). Why did you not go through with the carrier testing that was offered? Was it concerns about (check all that apply):
- Cost of genetic testing
  - Health insurance eligibility
  - Health insurance premiums
  - Life insurance eligibility
  - Life insurance premiums
  - Long-term care eligibility
  - Long-term care premiums
  - Disability income insurance eligibility
  - Disability income insurance premiums
  - Employment eligibility
  - Other reasons (please explain)
15. (This question appears if respondent indicated that they did not complete a prenatal genetic test). Why did you not go through with the prenatal testing that was offered? Was it concerns about (check all that apply):
- Cost of genetic testing
  - Health insurance eligibility
  - Health insurance premiums
  - Life insurance eligibility
  - Life insurance premiums
  - Long-term care eligibility
  - Long-term care premiums
  - Disability income insurance eligibility
  - Disability income insurance premiums

- Employment eligibility
  - Other reasons (please explain)
16. (This question appears if respondent indicated that they did not the other genetic testing). Why did you not go through with the other genetic testing that was offered? Was it concerns about (check all that apply):
- Cost of genetic testing
  - Health insurance eligibility
  - Health insurance premiums
  - Life insurance eligibility
  - Life insurance premiums
  - Long-term care eligibility
  - Long-term care premiums
  - Disability income insurance eligibility
  - Disability income insurance premiums
  - Employment eligibility
  - Other reasons (please explain)
17. Has a medical care provider ever offered you genetic counseling? Genetic counseling is "a health service that provides information and support to people who have, or may be at risk for, genetic disorders."
- Yes, I have been offered genetic counseling
  - No, I have never been offered genetic counseling
  - I'm not sure if I have ever been offered genetic counseling
  - Refuse to answer
18. Have you ever had genetic testing that wasn't offered by a medical provider (for example through an internet company like Ancestry.com or 23andme.com)?
- Yes
  - No
  - I don't know
  - Refuse to answer
19. (This question appears if respondent indicated that they have completed genetic testing that was not offered by a medical provider (for example through an internet company like Ancestry.com or 23andme.com) For your genetic testing not offered by a medical provider, did the test provide medical information in addition to ancestry information?
- Yes
  - No
  - I don't know
  - Refuse to answer
20. (This question appears if respondent indicated that they have completed genetic testing that was not offered by a medical provider (for example through an internet company like Ancestry.com or 23andme.com) Why did you complete genetic testing not offered by a medical provider? Please check all that apply.
- Cost considerations
  - Interest in family history or ancestry results
  - Concerns about who might have access to genetic test results
  - Other



- Refuse to answer
21. Have you ever participated in a research study?
- Yes
  - No
  - I don't know
  - Refuse to answer
22. (This question appears if respondent indicated that they have participated in a research study before) Have you ever had genetic testing as part of a research study?
- Yes
  - No
  - I don't know
  - Refuse to answer

## Genetics Knowledge Questions

1. How confident are you in your ability to understand information about genetics?
  - Likert scale response from 1-7 with 1 being “not confident at all” and 7 being “extremely confident”
2. Your DNA can uniquely identify you.
  - False
  - True
3. Most DNA changes do not lead to disease.
  - False
  - True
4. If a healthy person has their genome sequenced they will almost certainly find out they have a disease causing DNA change.
  - False
  - True
5. Genes determine everything about you, your current health, and your future health.
  - False
  - True
6. Scientists understand what most of the genes in our body do.
  - False
  - True
7. Once a DNA change for a disorder is identified in a person, the disorder can always be prevented.
  - False
  - True
8. Genes can influence how well certain medications will work for you.
  - False
  - True
9. A person who is a carrier of a DNA change may be completely healthy.
  - False
  - True
10. Some of the inherited disorders express themselves later in adult life.

- False True

## Demographic Questions

1. Do you have any children?
  - Yes
  - No
  - Refuse to answer
2. (This question appears if respondent indicates that they have a four-year degree or a graduate or professional degree). Do you have a degree in the field of science?
  - Yes
  - No
  - Refuse to answer
3. (This question appears if respondent indicates that they have a four-year degree or a graduate or professional degree). Do you have a degree in a health-related field?
  - Yes
  - No
  - Refuse to answer
4. (This question appears if respondent indicates that they have a four-year degree or a graduate or professional degree). Do you have a degree in the legal field?
  - Yes
  - No
  - Refuse to answer
5. Which state do you currently live in?
6. Which of the following best describes your employment situation?
  - I am employed and working 1-39 hours per week.
  - I am employed and working 40 or more hours per week.
  - I am a student.
  - I am retired.
  - I am disabled and not able to work.
  - Not employed, looking for work.
  - Not employed, not looking for work.
  - Refuse to answer
7. (This question appears if respondent indicates that they are employed and working 1-39 hours per week or 40 or more hours per week) Do you work in the field of science?
  - Yes
  - No
  - Refuse to answer
8. (This question appears if respondent indicates that they are employed and working 1-39 hours per week or 40 or more hours per week) Do you work in a health-related field?
  - Yes
  - No
  - Refuse to answer

9. (This question appears if respondent indicates that they are employed and working 1-39 hours per week or 40 or more hours per week) Do you work in the legal field?
- Yes
  - No
  - Refuse to answer
10. Do you serve in the U.S. military?
- Yes
  - No
  - I am a veteran
  - Refuse to answer
11. Overall, how would you rate your health?
- Poor
  - Fair
  - Good
  - Very good
  - Excellent
  - Refuse to answer
12. Do you have a diagnosed genetic condition?
- Yes
  - No
  - I don't know
  - Refuse to answer
13. Do you have a first degree relative (parent, child, or sibling) who has been diagnosed with a genetic condition?
- Yes
  - No
  - I don't know
  - Refuse to answer
14. Do you currently have health insurance?
- Yes, I am covered by private insurance through a current or former employer or union (of you or another family member)
  - Yes, I am covered by insurance purchased directly from an insurance company
  - Yes, I am covered by insurance purchased directly from HealthCare.gov or a state Health Insurance Marketplace
  - Yes, I am covered by Medicare (for people 65 and older, or people with certain disabilities)
  - Yes, I am covered by Medicaid, Medical Assistance, or any kind of government-assistance plan for people with low incomes or a disability
  - Yes, I am covered by TRICARE or other military health care
  - Yes, I am covered by VA
  - Yes, I am covered by Indian Health Service
  - Yes, I am covered by another type of health insurance or health coverage plan. Please specify: (12) \_\_\_\_\_
  - No, I am not currently covered by health insurance

- I don't know if I am currently covered by health insurance
  - Refuse to answer
15. Do you currently have Life insurance?
- Yes, I have private life insurance through a current or former employer or union
  - Yes, I have life insurance purchased directly from an insurance company
  - Yes, I currently have another type of life insurance. Please specify:
- 
- No, I do not currently have life insurance
  - I don't know if I currently have life insurance
  - Refuse to answer
16. Do you currently have Long-term care insurance?
- Yes, I have private long-term care insurance through a current or former employer or union
  - Yes, I have long-term care insurance purchased directly from an insurance company
  - Yes, I have long-term care coverage through Medicaid
  - Yes, I currently have another type of long-term insurance. Please specify:
- 
- No, I do not currently have long-term care insurance
  - I don't know if I currently have long-term care insurance
  - Refuse to answer
17. Do you currently have Disability income insurance?
- Yes, I have private disability income insurance through a current or former employer or union
  - Yes, I have disability income insurance purchased directly from an insurance company
  - Yes, I have disability income protection through a state government plan
  - Yes, I currently have another type of disability income insurance. Please specify:
- 
- No, I do not currently have disability income insurance
  - I don't know if I currently have disability income insurance
  - Refuse to answer
18. Have you ever been denied insurance because of a medical condition?
- Yes
  - No
  - I don't know
  - Refuse to answer
19. Where would you place yourself on this scale, or haven't you thought much about this?
- Extremely liberal
  - Liberal
  - Slightly liberal
  - Moderate, middle of the road
  - Slightly conservative
  - Conservative

- Extremely conservative
- Haven't thought much about it
- Refuse to answer

20. How religious are you?

- Likert scale response from 1-7 with 1 being “not at all religious” and 7 being “very religious”