

**Web-Based Survey to Understand Public Perceptions of Genetic Testing
May 28, 2008**

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Now we would like to ask your thoughts and feelings about genetic testing. Your participation in this survey is completely voluntary. Please be assured that your responses will be kept confidential and will not be disclosed except as otherwise required by law. You may skip any questions that you prefer not to answer.

Q1. Which of the following statements best describes how much you know about “genetic testing”? (1 question unit)

- I have not heard of genetic testing.....1
- I have heard of genetic testing, but I do not know much about it.....2
- I know basic information about genetic testing.....3
- I know quite a bit about genetic testing.....4
- I consider myself an expert on genetic testing.....5

Q2. When we talk about “genetic testing”, what we mean is looking at a person’s genetic makeup by examining a sample of their blood, saliva, or tissue to help determine whether they are more likely to get a certain disease.

Even before genetic testing is done, people may suspect that they are at risk for a health condition. For the health conditions listed below, please select which of the following statements best describes your risk, or likelihood, of developing these conditions compared to other people your age. If you’ve already been diagnosed with any of these conditions, please indicate that as well. The first condition is ...

- a. Cancer
- b. Heart disease
- c. Alzheimer’s disease
- d. Diabetes
- e. Obesity
- f. A mental health condition (e.g., depression)

g. Other health conditions

Would you say you are at: (ACCEPT ONE)

- 1 Below average risk?
- 2 Average risk?
- 3 Above average risk?
- 4 Previously diagnosed with this condition
- D Don't know

Q3. Which of the following health conditions would you consider getting genetic testing for (or have you been tested for) in order to determine if you are at increased risk? (Select as many as apply)

- Cancer.....1
- Heart disease.....2
- Alzheimer's disease.....3
- Diabetes.....4
- Obesity.....5
- A mental health condition (e.g., depression)6
- Other health conditions.....7
- Don't Know.....8

Q4. Now we'd like to know how much you agree or disagree with each of the following statements. (2 question units)

Strongly Disagree

Strongly Agree

1

2

3

4

5

6

- a. I would want to know if I had a higher-than-normal risk for a health condition that I **COULD NOT** take preventive action against (i.e. there is nothing I could do to improve my chances for avoiding the disease).
- b. I would want to know if I had a higher-than-normal risk for a health condition that I **COULD** take preventive action against (i.e. there are things I could do to improve my chances for avoiding the disease.)
- c. There are risks to finding out one's genetic makeup.
- d. I know where to find clear information about genetic testing.
- e. The benefits of genetic testing outweigh the risks.
- f. If I took a genetic test and discovered I had a higher-than-normal genetic risk for a disease, I would tell my family because they might have the same risk.
- g. If a family member discovered that they had a higher-than-normal genetic risk, I would want them to tell me.
- h. I would be interested in having genetic testing performed if there was no cost associated.

Q5. In your opinion, how valuable is each of the following benefits of genetic testing? (1 question unit)

Not At All
Valuable

Extremely
Valuable

1
○

2
○

3
○

4
○

5
○

6
○

- a. Results can provide relief from uncertainty about risk of getting a disease (“now you know”)
- b. A negative result can eliminate the need for unnecessary checkups and screening tests
- c. A positive result can direct a person toward available prevention, monitoring, and treatment options

Q6. How concerned are you about the each of the following aspects of genetic testing? (3 question units)

Not At All
Concerned

Extremely
Concerned

1
○

2
○

3
○

4
○

5
○

6
○

- a. Privacy and confidentiality issues related to finding out my personal genetic information
- b. The potential for discrimination for those who have higher-than-average risk for particular health conditions (e.g., by insurers, employers, courts, schools, adoption agencies, and the military, among others)
- c. The impact it would have on how a person feels about him/herself (by knowing their risk levels)
- d. The impact it would have on how others in society may feel about a person (by knowing their risk levels)
- e. Having standards and quality control measures available when interpreting genetic test results
- f. Effects of genetic testing on people’s reproductive choices (i.e., they may choose not to have children if they are predisposed to certain health conditions)
- g. The ability for people to understand the results of their genetic tests
- h. The ability for healthcare providers (e.g., doctors, nurses, etc.) to understand the results of genetic tests
- i. The usefulness of genetic information (e.g., the ability to use the information to improve medical care)
- j. Fairness in access to genetic services (e.g., if cost is high then services may not be affordable to all)
- k. The impact it would have on a person who learns they have a higher-than-average risk for a health condition that cannot be medically treated

Q7. There are many private companies that have recently begun providing genetic testing services directly to people for a fee. Please indicate on the scale below how involved, if at all, you think the government should be in regulating these types of services.

Not At All
Involved

Extremely
Involved

1
○

2
○

3
○

4
○

5
○

6
○

