

Individual ID: \_\_\_\_\_

Family ID: \_\_\_\_\_

Date Completed: \_\_\_\_\_

**Genome Sequencing Attitudes Survey**

**Demographics**

- A. Date of birth: \_\_\_\_\_
- B. Gender: (Please Circle)      M(1)    F(2)
- C. Ethnicity/Race \_\_\_\_\_ USE SAME 2-QUESTION SYSTEM AS DIGS FACE
- D. Level of education in years \_\_\_\_\_
- E. Profession \_\_\_\_\_ USE SAME SCALE AS DIGS
- F. Marital Status
  - 1. Single/Never Married
  - 2. Married
  - 3. Separated
  - 4. Divorced
  - 5. Widowed
  - 6. Domestic Partner
- G. Number of children \_\_\_\_\_
- H. Religion \_\_\_\_\_  
Are you current observant/practicing? Y (1) / N (0)

**Beliefs/Behaviors**

**If we could develop a test that would look at all of your genes and compare them to those of others, in order to better understand how genes might play a role in health and disease...**

I. Would you be interested in participating?

1	2	3	4	5
Not at all	Probably not	Somewhat	Probably Yes	Very

- J. If yes, what would be your reasons for participating? (Free response)
  - 1. Curiosity
  - 2. Contributing to science
  - 3. Gaining self-knowledge
  - 4. Prevention/treatment
  - 5. Concern for family members
  - 6. Other – specify \_\_\_\_\_

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K. If no, what would be your reasons for not participating?

1. Lack of interest
  2. Worried how information might be used by others
  3. Worried how the information might affect me
  4. Worried what the information might mean for my relatives
  5. Other - Specify
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L. Do you have any knowledge about genome sequencing technology?

**Yes (1)**

**No (0)**

If yes, from where?

1. Media/News
  2. Class/School
  3. Movie
  4. Television
  5. Book
  6. Other People
  7. Other – specify
- 

**If you did decide to participate and we had all of this information about your genes...**

M. Would you want to know if we find anything that could have health implications? Y(1) / N (0)

N. What would you want to know about it?

1. Things I could prevent or treat
2. Things that are very likely to happen.
3. Things that might affect my children or grandchildren
4. Anything that might have implications for my health (all of the above)

5. Other - Specify.

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O. How would you like to be told (multiple answers possible)?

1. Phone
2. Letter
3. Email
4. Sending information through your primary care physician
5. Through a genetic counselor
6. Other – specify

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P. What would be the most important things to know?

Examples of information that could potentially be learned: risks for inherited neurological diseases like Huntington’s disease, cancer risk, heart disease, diabetes, Alzheimer’s, to list a few.

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Q. What would you do with that information (multiple answers possible)?

1. Nothing
2. Talk to doctor
3. Talk to family members
4. Talk to a scientist/geneticist

R. Would you change your behavior based on this information?

1. Yes
2. Maybe
3. No
4. Don’t know

Specify: Why?

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S. Would your decision about wanting to know this information be influenced by whether or not you can do something about it? For example, a disease that will affect you no matter what, versus a disease that is medically treatable or preventable?

Y(1) / N(0)

Specify \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

T. Would having this information influence your decision to have children, or, if you already do have children, would it have influenced your decision?

Y(1) / N (0)

Specify \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### Privacy Protection and Research Ethics

U. What do you feel is the researcher's responsibility with regard to this genetic information?

Specify:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

V. Do you feel that someone should be responsible for informing your relatives?

Y (1) / N (0)

1. If yes, who? \_\_\_\_\_

2. If no, why not? \_\_\_\_\_

W. Would you consent to other researchers accessing your genetic information for different studies, if it was anonymous?

Y (1) / N (0)

X. Do you have any concerns about who could access this information?

Y (1) /N (0) – who?

Specify:

\_\_\_\_\_  
\_\_\_\_\_

Y. Do you have any concerns about “genetic discrimination,” especially when it comes to things like health insurance and employment?

1	2	3	4	5
Not at all	A little concerned	Somewhat Concerned	Concerned	Very Concerned

Probably need to give examples here: If you were found to have a genetic predisposition for early-onset Alzheimer’s, genetic discrimination could include not being hired for a job or being denied life insurance coverage.

Specify:

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Z. Would you agree to your genetic information being made publicly available, for example, on the internet, if it was anonymous? Why/why not?

Y (1) / (N)

Specify:

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AA. Are you worried that your personal genetic information could be used against you somehow?

Y (1) / N (0)

1	2	3	4	5
Not at all	A little concerned	Somewhat Concerned	Concerned	Very Concerned

Specify:

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