Value of Knowing Risk of Developing Neurodegenerative Disease: A Discrete Choice Experiment

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Supplemental Material for ISPOR Poster Presentation

Contents

1. Text of Survey

Red = text for instructions, not included on survey

Text Section 1: Text explanations of genetic testing and neurodegenerative diseases

The topics of this survey are "neurodegenerative diseases" and "genetic tests". Please review the descriptions below to familiarize yourself with these topics before continuing with the survey.

Neurodegenerative Disease

A neurodegenerative disease is a type of disease in which cells from the brain or nervous system lose function over time.[1,2] They affect many of your body's activities, such as balance, movement, talking, breathing, and heart function.[2] They can often be serious or life-threatening and often a cure does not exist. Some examples of neurodegenerative diseases include:[3]

- Alzheimer's disease
- Huntington's disease
- Lewy body disease
- Parkinson's disease
- Spinal muscular atrophy

Many neurodegenerative diseases are genetic, meaning there is a risk of getting a disease that is passed from parents to their biological children.[1]

Genetic Testing

Genetic testing is a type of medical test that can help determine a person's chance of developing or passing on a disorder because someone in that person's family has it or is carrying the gene that causes it (a "genetic disorder"), whether they are feeling symptoms or not.[4]

[1]*National Cancer Institute, National Institutes of Health, https://www.cancer.gov/publications/dictionaries/cancer-terms/def/neurodegenerative-disorder*

[2]*National Institute of Environmental Health Sciences, National Institutes of Health, https://www.niehs.nih.gov/research/supported/health/neurodegenerative/index.cfm*

[3]*MedlinePlus, National Institutes of Health, https://medlineplus.gov/degenerativenervediseases.html*

[4]*National Cancer Institute, National Institutes of Health, https://www.cancer.gov/publications/dictionaries/cancer-terms/def/genetic-testing*

Question Section 1: Previous experience with genetic testing

Question 1: Have you ever had a genetic test (including tests prescribed by a doctor and those that you purchased on your own, such as 23andme)?

- ☐ Yes
- ☐ No

Display question 2 only if respondent answers 'yes' to question 1, otherwise skip to question 3

Question 2: Why did you have the genetic test? (Select all that apply)

- ☐ To find out if I am at risk for a disease
- ☐ To decide on a medical treatment
- ☐ To learn about my family history
- ☐ Other (please specify) _____

Question 3: Has one of your family members ever had a genetic test (including tests prescribed by a doctor and those that they purchased on their own, such as 23andme)?

- ☐ Yes
- ☐ No
- ☐ Don't know

Question 4: Do you have a blood relative (a person related to you by birth rather than by marriage or adoption) who has a neurodegenerative disease?

- ☐ Yes
- ☐ No
- ☐ Don't know

Question 5: Have you ever taken care of someone with a neurodegenerative disease? (Select all that apply)

- ☐ Yes, as part of an employed position (e.g., nurse, home health aide)
- ☐ Yes, for a loved one or family member
- ☐ No

Question 6: Has a doctor ever told you that you have a neurodegenerative disease?

- ☐ Yes
- ☐ No

☐ Don't know

Question 7: Do you have any children?

☐ Yes

☐ No

Text Section 2: Explanations of hypothetical test

In the next section of the survey, we will ask you to choose a hypothetical genetic test for a neurodegenerative disease for yourself or a loved one to take. When considering what genetic test to choose, you should consider the following questions:

How will the genetic test be done?

Genetic tests can be done in many ways. We will use two terms to describe how the test will be done:

Invasive (e.g., blood draw): If a genetic test is invasive, that there is some risk of being injured when receiving the test. An example is a procedure done by a doctor or nurse that uses a needle to collect blood or other bodily fluids.

Non-Invasive (e.g., cheek swab): If a genetic test is non-invasive, that means there is no risk of being injured when receiving the test. An example of this is a cheek swab, where a doctor or nurse takes a sample of saliva from the inside of a person's cheek.

You should assume that any genetic test is done in a doctor's office by a medical professional.

How much will the test cost?

There is a cost to have a genetic test done. Insurance may cover some genetic tests, but there may still be costs that you are responsible for. We will show you tests with costs to you that range from $50 to $1,000.

What is the chance of inaccurate results from the genetic test? What would happen if I receive an inaccurate result from the genetic test?

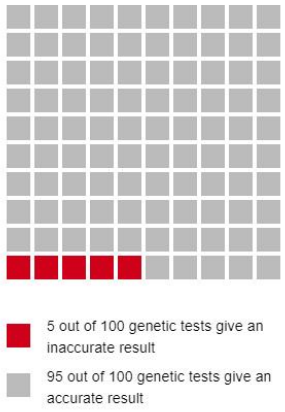
With all genetic tests, there is chance the results you receive are wrong. There are two ways the test can be wrong, and each way would have a different impact on your life.

1. A test may say you *are not* at risk of developing the disease but in reality, you *are* at risk of developing the disease. If you receive this test result, you may not receive timely diagnosis and, if there is any treatment available, you may not get in in time to delay or prevent symptoms, making your experience with the disease worse. This is sometimes called a false negative. For our hypothetical tests, we will describe this as **the chance of an inaccurate result that would prevent receiving timely treatment.**

2. A test may say you *are* at risk of developing the disease but in reality, you are *not* at risk of developing the disease. If you receive this test result, it may cause you to worry and plan for the future in unnecessary ways and you may receive more medical tests and costs that are unnecessary. This is sometimes called a false positive. For our hypothetical

tests, we will describe this as **the chance of an inaccurate result that would lead to worry and unnecessary medical tests.**

We will show you tests that have a 0%, 5%, or 20% chance of each type of inaccurate test result. This indicates the number of people out of 100 that receive an inaccurate result. For example, if there is a 5% chance of receiving an inaccurate result that prevents timely treatment, 5 out of every 100 people who get a genetic test will have an inaccurate result that prevents timely treatment (see illustration below).



Text Section 3: Explanation of scenario

To choose a genetic test, you will also need some additional information about the disease and about yourself or your loved one. The following bullet points will give hypothetical explanations of some of these things. Imagine that all these things are true as you choose a genetic test for your or your loved one to take.

Suppose that:

- [INSERT 1]
- [INSERT 2]
- [INSERT 3]
- [INSERT 4]

In this hypothetical scenario, you will choose a genetic test [INSERT 5]. We will show you two options for genetic tests. You may choose either test, or a 'no test' option where [INSERT 6] will not be tested.

Question Section 2: DCE first half (each question should be on a new page)

Remember that:

- [INSERT 1]
- [INSERT 2]
- [INSERT 3]
- [INSERT 4]

Question 1: Please choose between Test 1, Test 2, or No Test, if these are the only options available.

	Test 1	Test 2
How the test is done	[DCE]	[DCE]
Cost of the test	[DCE]	[DCE]
Risk of an inaccurate result that would prevent receiving timely treatment	[DCE]	[DCE]
Risk of an inaccurate result that leads to worry and unnecessary medical tests	[DCE]	[DCE]

- ☐ Test 1
- ☐ Test 2
- ☐ No Test

Remember that:

- [INSERT 1]
- [INSERT 2]
- [INSERT 3]
- [INSERT 4]

Question 2: Please choose between Test 1, Test 2, or no test, if these are the only options available.

	Test 1	Test 2
How the test is done	[DCE]	[DCE]
Cost of the test	[DCE]	[DCE]
Risk of an inaccurate result that would prevent receiving timely treatment	[DCE]	[DCE]
Risk of an inaccurate result that leads to worry and unnecessary medical tests	[DCE]	[DCE]

- ☐ Test 1
- ☐ Test 2
- ☐ No Test

Remember that:

- [INSERT 1]
- [INSERT 2]
- [INSERT 3]
- [INSERT 4]

Question 3: Please choose between Test 1, Test 2, or no test, if these are the only options available.

	Test 1	Test 2
How the test is done	[DCE]	[DCE]
Cost of the test	[DCE]	[DCE]
Risk of an inaccurate result that would prevent receiving timely treatment	[DCE]	[DCE]
Risk of an inaccurate result that leads to worry and unnecessary medical tests	[DCE]	[DCE]

- ☐ Test 1
- ☐ Test 2
- ☐ No Test

Remember that:

- [INSERT 1]
- [INSERT 2]
- [INSERT 3]
- [INSERT 4]

Question 4: Please choose between Test 1, Test 2, or no test, if these are the only options available.

	Test 1	Test 2
How the test is done	[DCE]	[DCE]
Cost of the test	[DCE]	[DCE]
Risk of an inaccurate result that would prevent receiving timely treatment	[DCE]	[DCE]
Risk of an inaccurate result that leads to worry and unnecessary medical tests	[DCE]	[DCE]

- ☐ Test 1
- ☐ Test 2
- ☐ No Test

Text Section 4: Changing one attribute of scenario

For the next four questions, now suppose that [INSERT 7]. Everything else you know is the same. So, suppose that:

- [INSERT 8]
- [INSERT 9]
- [INSERT 10]
- [INSERT 11]

In this hypothetical scenario, you will choose a genetic test [INSERT 12]. We will show you two options for genetic tests. You may choose either test, or a 'no test' option where [INSERT 13] will not be tested.

Question Section 3: DCE second half (each question should be on a new page)

Remember that:

- [INSERT 8]
- [INSERT 9]
- [INSERT 10]
- [INSERT 11]

Question 5: Please choose between Test 1, Test 2, or No Test, if these are the only options available.

	Test 1	**Test 2**
How the test is done	[DCE]	[DCE]
Cost of the test	[DCE]	[DCE]
Risk of an inaccurate result that would prevent receiving timely treatment	[DCE]	[DCE]
Risk of an inaccurate result that leads to worry and unnecessary medical tests	[DCE]	[DCE]

☐ Test 1

☐ Test 2

☐ No Test

Remember that:

- [INSERT 8]
- [INSERT 9]
- [INSERT 10]
- [INSERT 11]

Question 6: Please choose between Test 1, Test 2, or no test, if these are the only options available.

	Test 1	**Test 2**
How the test is done	[DCE]	[DCE]
Cost of the test	[DCE]	[DCE]
Risk of an inaccurate result that would prevent receiving timely treatment	[DCE]	[DCE]
Risk of an inaccurate result that leads to worry and unnecessary medical tests	[DCE]	[DCE]

☐ Test 1

☐ Test 2

☐ No Test

Remember that:

- [INSERT 8]
- [INSERT 9]
- [INSERT 10]
- [INSERT 11]

Question 7: Please choose between Test 1, Test 2, or no test, if these are the only options available.

	Test 1	**Test 2**
How the test is done	[DCE]	[DCE]
Cost of the test	[DCE]	[DCE]
Risk of an inaccurate result that causes treatment to be given too late	[DCE]	[DCE]
Risk of an inaccurate result that leads to worry and unnecessary medical tests	[DCE]	[DCE]

☐ Test 1

☐ Test 2

☐ No Test

Remember that:

- [INSERT 8]
- [INSERT 9]
- [INSERT 10]
- [INSERT 11]

Question 8: Please choose between Test 1, Test 2, or no test, if these are the only options available.

	Test 1	**Test 2**
How the test is done	[DCE]	[DCE]
Cost of the test	[DCE]	[DCE]
Risk of an inaccurate result that causes treatment to be given too late	[DCE]	[DCE]
Risk of an inaccurate result that leads to worry and unnecessary medical tests	[DCE]	[DCE]

☐ Test 1

☐ Test 2

☐ No Test

Question section 4: Open text question

Question 9: What factors were most important to you when making your decision?

[Open text response]

2. Survey Text Inserts for Scenarios

Scenarios

Participants will see 4 questions from 2 scenarios, totaling 8 questions. Each scenario is introduced as a series of 4 bullet points defining the 4 attributes of the scenario.

The level of each attribute for scenario 1 should be randomly assigned.

Attributes and all possible levels for scenarios

Attribute	Levels
Attribute 1: Perspective	Perspective 1 (self)
	Perspective 2 (family)
	Perspective 3 (child)
Attribute 2: Risk	Risk 1 (high)
	Risk 2 (low)
	Risk 3 (uncertain)
Attribute 3: Severity	Severity 1 (fatal)
	Severity 2 (high)
	Severity 3 (moderate)
	Severity 4 (low)
Attribute 4: Treatment	Treatment 1 (none)
	Treatment 2 (temporary)
	Treatment 3 (permanent)
	Treatment 4 (life expectancy)
	Treatment 5 (cure)

To reduce cognitive burden, each participant should only have one attribute level randomly changed for scenario 2. For the 1 attribute that will change, the participant should be randomly assigned to a level of that attribute different than the level they saw in scenario 1.

Example: A participant is randomly assigned to Perspective 1, Risk 2, Severity 2, and Treatment 5 for scenario 1. That participant is randomly assigned to have the level of Risk change for scenario 2. In this case, the change is from Risk 2 to Risk 3. The participant is therefore assigned to Perspective 1, Risk 3, Severity 2, and Treatment 5 for scenario 2.

Text for inserts

[INSERT 1] Perspective

Text in insert 1 depends on randomization to perspective

If randomized to perspective 1 (self)	You are choosing a genetic test for yourself to find out if you have a neurodegenerative disease.
If randomized to perspective 2 (family)	You are choosing a genetic test for an adult family member or loved one. You would serve as the primary caregiver for your adult family

	member or loved one if they develop the disease.
If randomized to perspective 3 (child)	You are choosing a genetic test for your child. You would serve as the primary caregiver for your child if they develop the disease.

[INSERT 2] Risk of getting the disease

The text in insert 2 depends on randomization to perspective and to risk

If randomized to risk 1 (high) and perspective 1 (self)	You consider yourself more likely to get the disease because you have a known relative with this disease (family history) or you consider the disease to be common.
If randomized to risk 2 (low) and perspective 1 (self)	You consider yourself less likely to get the disease because you know you don't have a relative with this disease (no family history) or you consider the disease to be rare.
If randomized to risk 3 (uncertain) and perspective 1 (self)	You are unsure how likely you are to get the disease because you are unsure if any of your relatives have had this disease (unknown family history) or you have little knowledge of how common the disease is.

If randomized to risk 1 (high) and perspective 2 (family)	Your loved one considers themself more likely to get the disease because they have a known relative with this disease (family history) or they consider the disease to be common.
If randomized to risk 2 (low) and perspective 2 (family)	Your loved one considers themself less likely to get the disease because they know they don't have a relative with this disease (no family history) or they consider the disease to be rare.
If randomized to risk 3 (uncertain) and perspective 2 (family)	Your loved one is unsure how likely they are to get the disease because they are unsure if any of their relatives have had this disease (unknown family history) or they have little knowledge of how common the disease is.

If randomized to risk 1 (high) and perspective 3 (child)	You consider your child more likely to get the disease because they have a known relative with this disease (family history) or you consider the disease to be common.
If randomized to risk 2 (low) and perspective 3 (child)	You consider your child less likely to get the disease because you know they don't have a relative with this disease (no family history) or you consider the disease to be rare.
If randomized to risk 3 (uncertain) and perspective 3 (child)	You are unsure how likely your child is to get the disease because you are unsure if any of

	their relatives have had this disease (unknown family history) or you have little knowledge of how common the disease is.

[INSERT 3] Severity

The text in insert 3 depends on randomization to severity

If randomized to severity 1 (fatal)	The disease is fatal, meaning the disease causes rapid death within a few months or a year. During that time, symptoms make daily activities (e.g., walk, bathe, go to the bathroom) extremely difficult to do alone and may impact the ability to communicate.
If randomized to severity 2 (high)	The disease has high severity, meaning symptoms will interfere with the ability to accomplish daily activities (e.g., walk, bathe, go to the bathroom). Without treatment, anyone diagnosed with this disease can expect to die within 10 years after the disease is diagnosed.
If randomized to severity 3 (moderate)	The disease has moderate severity, meaning symptoms will affect the ability to accomplish daily activities (e.g., walk, bathe, go to the bathroom) but symptoms can be managed with any available treatment. Without treatment, there may be some impact on how long someone will live, but anyone diagnosed with this disease can expect to live for 10 or more years after the disease is diagnosed.
If randomized to severity 4 (low)	The disease has low severity, meaning it causes minor symptoms that will not affect the ability to accomplish daily activities (e.g., walk, bathe, go to the bathroom). Anyone diagnosed with this disease can expect to live the same amount of time as they would without the disease.

[INSERT 4] Treatment

The text in insert 4 depends on randomization to treatment

If randomized to treatment 1 (none)	There is no treatment available for this disease.
If randomized to treatment 2 (temporary)	Available treatment will temporarily improve symptoms but symptoms will eventually return. Treatment will not change how long a person survives with the disease.

If randomized to treatment 3 (permanent)	Available treatment can improve someone's symptoms but will not affect how long a person survives with the disease
If randomized to treatment 4 (life expectancy)	Available treatment can improve someone's symptoms and allow them to survive as long as they would without the disease
If randomized to treatment 5 (cure)	There is a cure available for this disease. The treatment will prevent the disease from worsening and will stop symptoms. Anyone who uses this treatment can expect to live as long as they had if they didn't have the disease.

[INSERT 5]

The text in insert 5 depends on randomization to perspective

If randomized to perspective 1 (self)	for yourself
If randomized to perspective 2 (loved)	for your loved one
If randomized to perspective 3 (child)	for your child

[INSERT 6]

The text in insert 6 depends on randomization to perspective

If randomized to perspective 1 (self)	you
If randomized to perspective 2 (loved)	your loved one
If randomized to perspective 3 (child)	your child

[INSERT 7]

The text in insert 7 depends on randomization to what attribute is changed. If possible, the bolding in the following text options should be included.

If randomized to have perspective changed to perspective 1 (self)	you are choosing a genetic test for **yourself.**
If randomized to have perspective changed to perspective 2 (family)	you are choosing a genetic test for **an adult family member or loved one.**
If randomized to have perspective changed to perspective 3 (child)	you are choosing a genetic test for **your child.**

If randomized to perspective 1 (self) in scenario 1 and randomized to have risk changed to risk 1 (high)	you consider yourself **more likely** to get the disease.
If randomized to perspective 1 (self) in scenario 1 and randomized to have risk changed to risk 2 (low)	you consider yourself **less likely** to get the disease.

If randomized to perspective 1 (self) and in scenario 1 randomized to have risk changed to risk 3 (uncertain)	you are **unsure** how likely you are to get the disease.

If randomized to perspective 2 (family) in scenario 1 and randomized to have risk changed to risk 1 (high)	your family member or loved one considers themself **more likely** to get the disease.
If randomized to perspective 2 (family) in scenario 1 and randomized to have risk changed to risk 2 (low)	your family member or loved one considers themself **less likely** to get the disease.
If randomized to perspective 2 (family) in scenario 1 and randomized to have risk changed to risk 3 (uncertain)	your family member or loved is **unsure** how likely they are to the get the disease.

If randomized to perspective 3 (child) in scenario 1 and randomized to have risk changed to risk 1 (high)	you consider your child **more likely** to get the disease.
If randomized to perspective 3 (child) in scenario 1 and randomized to have risk changed to risk 2 (low)	you consider your child **less likely** to get the disease.
If randomized to perspective 3 (child) in scenario 1 and randomized to have risk changed to risk 3 (uncertain)	you are **unsure** how likely your child is to get the disease.

If randomized to have severity changed to severity 1 (fatal)	the disease is **fatal**.
If randomized to have severity changed to severity 2 (high)	the disease has **high severity**.
If randomized to have severity changed to severity 3 (moderate)	the disease has **moderate severity**.
If randomized to have severity changed to severity 4 (low)	the disease has **low severity**.

If randomized to have treatment changed to treatment 1 (none)	there **is no treatment available**.
If randomized to have treatment changed to treatment 2 (temporary)	there **is a treatment available that will temporarily reduce symptoms**.
If randomized to have treatment changed to treatment 3 (permanent)	there **is a treatment available that will permanently reduce symptoms but not change life expectancy.**
If randomized to have treatment changed to treatment 4 (life expectancy)	there **is a treatment available that will permanently reduce symptoms and improve life expectancy.**
If randomized to have treatment changed to treatment 5 (cure)	there **is a cure available**.

[INSERT 8]

The text in insert 8 depends on randomization to what attribute is changed.

If the participant is randomized to have risk, severity, or treatment changed, the text in insert 8 should be identical to the text in [INSERT 1].

If the participant is randomized to have perspective changed, the text in insert 8 depends on randomization to a different level of perspective.

If randomized to have perspective changed to perspective 1 (self)	You are choosing a genetic test for yourself to find out if you have a neurodegenerative disease.
If randomized to have perspective changed to perspective 2 (family)	You are choosing a genetic test for an adult family member or loved one. You would serve as the primary caregiver for your adult family member or loved one if they develop the disease.
If randomized to have perspective changed to perspective 3 (child)	You are choosing a genetic test for your child. You would serve as the primary caregiver for your child if they develop the disease.

[INSERT 9]

The text in insert 9 depends on randomization to what attribute is changed.

If the participant is randomized to have severity or treatment changed, the text in insert 9 should be identical to the text in [INSERT 2].

If the participant is randomized to have perspective changed, the text in insert 9 depends on randomization to a different level of perspective.

If randomized to risk 1 (high) in scenario 1 and randomized to have perspective changed to perspective 1 (self)	You consider yourself more likely to get the disease because you have a known relative with this disease (family history) or you consider the disease to be common.
If randomized to risk 1 (high) in scenario 1 and randomized to have perspective changed to perspective 2 (family)	Your loved one considers themself more likely to get the disease because they have a known relative with this disease (family history) or they consider the disease to be common.
If randomized to risk 1 (high) in scenario 1 and randomized to have perspective changed to perspective 3 (child)	You consider your child more likely to get the disease because they have a known relative with this disease (family history) or you consider the disease to be common.

If randomized to risk 2 (low) in scenario 1 and randomized to have perspective changed to perspective 1 (self)	You consider yourself less likely to get the disease because you know you don't have a relative with this disease (no family history) or you consider the disease to be rare.

If randomized to risk 2 (low) in scenario 1 and randomized to have perspective changed to perspective 2 (family)	Your loved one considers themself less likely to get the disease because they know they don't have a relative with this disease (no family history) or they consider the disease to be rare.
If randomized to risk 2 (low) in scenario 1 and randomized to have perspective changed to perspective 3 (child)	You consider your child less likely to get the disease because you know they don't have a relative with this disease (no family history) or you consider the disease to be rare.

If randomized to risk 3 (uncertain) in scenario 1 and randomized to have perspective changed to perspective 1 (self)	You are unsure how likely you are to get the disease because you are unsure if any of your relatives have had this disease (unknown family history) or you have little knowledge of how common the disease is.
If randomized to risk 3 (uncertain) in scenario 1 and randomized to have perspective changed to perspective 2 (family)	Your loved one is unsure how likely they are to get the disease because they are unsure if any of their relatives have had this disease (unknown family history) or they have little knowledge of how common the disease is.
If randomized to risk 3 (uncertain) in scenario 1 and randomized to have perspective changed to perspective 3 (child)	You are unsure how likely your child is to get the disease because you are unsure if any of their relatives have had this disease (unknown family history) or you have little knowledge of how common the disease is.

If the participant is randomized to have risk changed, the text in insert 9 depends on randomization to a different level of risk and depends on level of perspective.

If randomized to perspective 1 (self) in scenario 1 and randomized to have risk changed to risk 1 (high)	You consider yourself more likely to get the disease because you have a known relative with this disease (family history) or you consider the disease to be common.
If randomized to perspective 1 (self) in scenario 1 and randomized to have risk changed to risk 2 (low)	You consider yourself less likely to get the disease because you know you don't have a relative with this disease (no family history) or you consider the disease to be rare.
If randomized to perspective 1 (self) and in scenario 1 randomized to have risk changed to risk 3 (uncertain)	You are unsure how likely you are to get the disease because you are unsure if any of your relatives have had this disease (unknown family history) or you have little knowledge of how common the disease is.

If randomized to perspective 2 (family) in scenario 1 and randomized to have risk changed to risk 1 (high)	Your loved one considers themself more likely to get the disease because they have a known relative with this disease (family history) or they consider the disease to be common.

If randomized to perspective 2 (family) in scenario 1 and randomized to have risk changed to risk 2 (low)	Your loved one considers themself less likely to get the disease because they know they don't have a relative with this disease (no family history) or they consider the disease to be rare.
If randomized to perspective 2 (family) in scenario 1 and randomized to have risk changed to risk 3 (uncertain)	Your loved one is unsure how likely they are to get the disease because they are unsure if any of their relatives have had this disease (unknown family history) or they have little knowledge of how common the disease is.

If randomized to perspective 3 (child) in scenario 1 and randomized to have risk changed to risk 1 (high)	You consider your child more likely to get the disease because they have a known relative with this disease (family history) or you consider the disease to be common.
If randomized to perspective 3 (child) in scenario 1 and randomized to have risk changed to risk 2 (low)	You consider your child less likely to get the disease because you know they don't have a relative with this disease (no family history) or you consider the disease to be rare.
If randomized to perspective 3 (child) in scenario 1 and randomized to have risk changed to risk 3 (uncertain)	You are unsure how likely your child is to get the disease because you are unsure if any of their relatives have had this disease (unknown family history) or you have little knowledge of how common the disease is.

[INSERT 10]

The text in insert 10 depends on randomization to what attribute is changed.

If the participant is randomized to have perspective, risk, or treatment changed, the text in insert 10 should be identical to the text in [INSERT 3].

If the participant is randomized to have severity changed, the text in insert 10 depends on randomization to a different level of severity.

If randomized to have severity changed to severity 1 (fatal)	The disease is fatal, meaning the disease causes rapid death within a few months or a year. During that time, symptoms make daily activities (e.g., walk, bathe, go to the bathroom) extremely difficult to do alone and may impact the ability to communicate.
If randomized to have severity changed to severity 2 (high)	The disease has high severity, meaning symptoms will interfere with the ability to accomplish daily activities (e.g., walk, bathe, go to the bathroom). Without treatment, anyone diagnosed with this disease can expect to die within 10 years after the disease is diagnosed.
If randomized to have severity changed to severity 3 (moderate)	The disease has moderate severity, meaning symptoms will affect the ability to accomplish

	daily activities (e.g., walk, bathe, go to the bathroom) but symptoms can be managed with any available treatment. Without treatment, there may be some impact on how long someone will live, but anyone diagnosed with this disease can expect to live for 10 or more years after the disease is diagnosed.
If randomized to have severity changed to severity 4 (low)	The disease has low severity, meaning it causes minor symptoms that will not affect the ability to accomplish daily activities (e.g., walk, bathe, go to the bathroom). Anyone diagnosed with this disease can expect to live the same amount of time as they would without the disease.

[INSERT 11]

The text in insert 11 depends on randomization to what attribute is changed.

If the participant is randomized to have perspective, risk, or severity changed, the text in insert 11 should be identical to the text in [INSERT 4]

If the participant is randomized to have treatment changed, the text in insert 11 depends on randomization to a different level of treatment.

If randomized to have treatment changed to treatment 1 (none)	There is no treatment available for this disease.
If randomized to have treatment changed to treatment 2 (temporary)	Available treatment will temporarily improve symptoms but symptoms will eventually return. Treatment will not change how long a person survives with the disease.
If randomized to have treatment changed to treatment 3 (permanent)	Available treatment can improve someone's symptoms but will not affect how long a person survives with the disease
If randomized to have treatment changed to treatment 4 (life expectancy)	Available treatment can improve someone's symptoms and allow them to survive as long as they would without the disease
If randomized to have treatment changed to treatment 5 (cure)	There is a cure available for this disease. The treatment will prevent the disease from worsening and will stop symptoms. Anyone who uses this treatment can expect to live as long as they had if they didn't have the disease.

[INSERT 12]

The text in insert 12 depends on randomization to what attribute is changed.

If the participant is randomized to have risk, severity, or treatment changed, the text in insert 12 should be identical to the text in [INSERT 5].

If the participant is randomized to have perspective changed, the text in insert 12 depends on randomization to a different level of perspective.

If randomized to have perspective changed to perspective 1 (self)	for yourself
If randomized to have perspective changed to perspective 2 (loved)	for your loved one
If randomized to have perspective changed to perspective 3 (child)	for your child

[INSERT 13]

The text in insert 13 depends on randomization to what attribute is changed.

If the participant is randomized to have risk, severity, or treatment changed, the text in insert 13 should be identical to the text in [INSERT 6].

If randomized to have perspective changed to perspective 1 (self)	you
If randomized to have perspective changed to perspective 2 (loved)	your loved one
If randomized to have perspective changed to perspective 3 (child)	your child

3. Survey Text Inserts for Discrete Choice Experiment

Discrete Choice Experiment

Each participant will see a total of 8 questions from the discrete choice experiment, in 2 sections of 4 questions each. The 2 sections differ in the scenario (defined above).

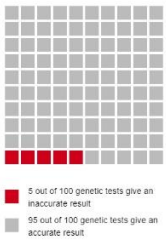
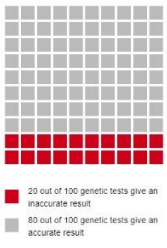
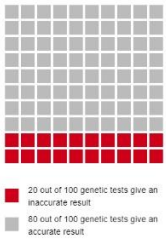
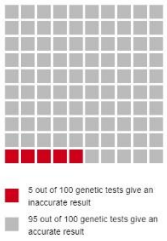
There are 18 possible choice sets to define a question. Each participant should be randomized to 1 of the 18 choice sets for each of the 8 questions, thus each participant will see 8 out of 18 of the choice sets.

Attribute	Level	Text to input in choice set
How the test is done	1	Invasive
	2	Non-invasive
Cost of the test	1	$50
	2	$250
	3	$1000
Risk of an inaccurate result that would prevent receiving timely treatment	1	0%
	2	5%
	3	20%
Risk of an inaccurate result that leads to worry and unnecessary medical treatment	1	0%
	2	5%
	3	20%

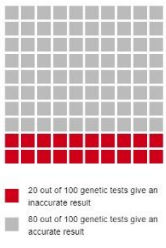
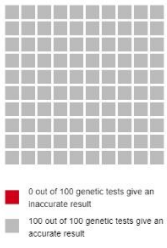
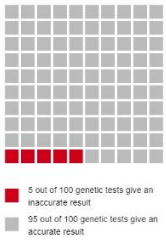
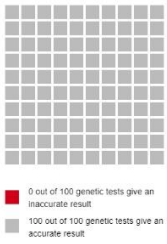
		Choice Set																	
Attribute	**Test**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**
How the test is done	1	1	2	2	2	2	1	2	1	1	2	1	2	1	2	2	2	2	1
	2	2	1	1	1	1	2	1	2	2	1	2	1	2	1	1	1	1	2
Cost of the test	1	1	2	2	3	2	2	3	1	3	3	1	3	3	1	1	1	1	3
	2	3	1	1	2	3	1	1	3	2	2	2	2	1	2	2	3	3	2
Risk of an inaccurate result that would prevent receiving timely treatment	1	2	3	2	2	3	1	3	3	3	1	3	1	2	2	3	2	3	3
	2	3	1	1	1	1	2	2	2	1	2	1	3	1	3	2	1	2	1
Risk of an inaccurate result that leads to worry and unnecessary medical tests	1	3	2	3	3	1	3	1	2	3	2	2	3	2	1	1	2	3	3
	2	2	1	1	2	2	2	3	1	2	1	3	1	3	3	2	1	1	1

Full text of all possible choice sets

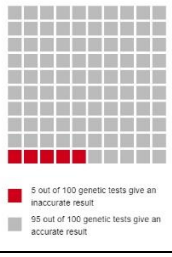
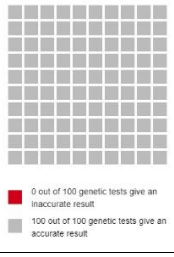
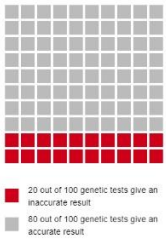
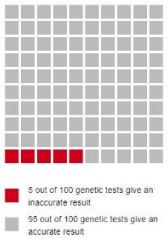
Choice set 1

	Test 1	**Test 2**
How the test is done	Invasive	Non-invasive
Cost of the test	$50	$1000
Risk of an inaccurate result that would prevent receiving timely treatment	5% 	20% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	20% 	5% 

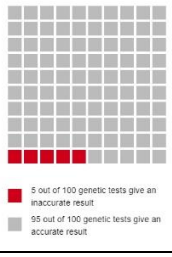
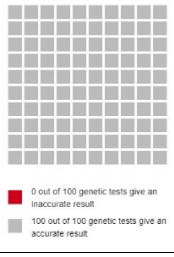
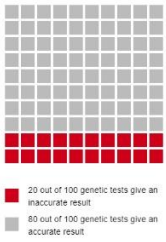
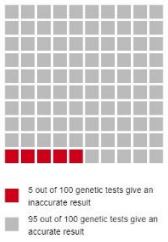
Choice set 2

	Test 1	**Test 2**
How the test is done	Non-invasive	Invasive
Cost of the test	$250	$50
Risk of an inaccurate result that would prevent receiving timely treatment	20% 	0% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	5% 	0% 

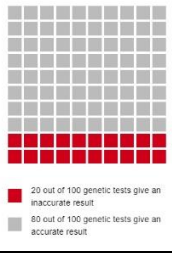
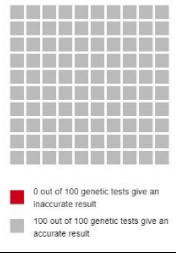
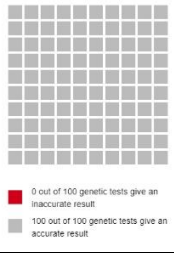
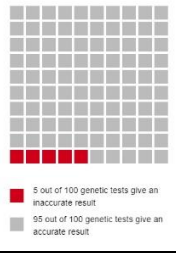
Choice set 3

	Test 1	**Test 2**
How the test is done	Non-invasive	Invasive
Cost of the test	$250	$50
Risk of an inaccurate result that would prevent receiving timely treatment	5% 	0% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	20% 	5% 

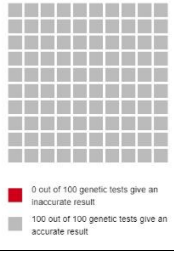
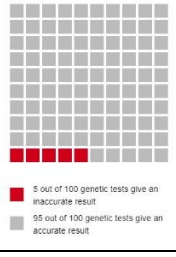
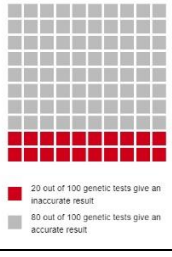
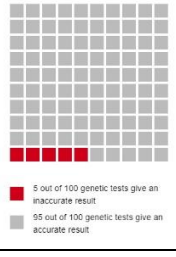
Choice set 4

	Test 1	**Test 2**
How the test is done	Non-invasive	Invasive
Cost of the test	$1000	$250
Risk of an inaccurate result that would prevent receiving timely treatment	5% 	0% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	20% 	5% 

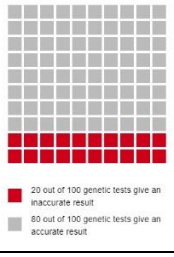
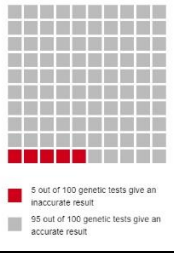
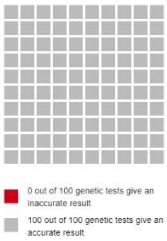
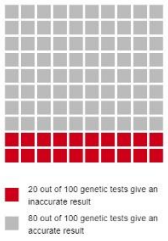
Choice set 5

	Test 1	**Test 2**
How the test is done	Non-invasive	Invasive
Cost of the test	$250	$1000
Risk of an inaccurate result that would prevent receiving timely treatment	20% 	0% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	0% 	5% 

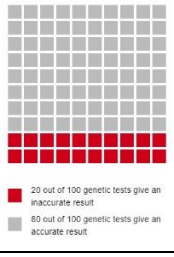
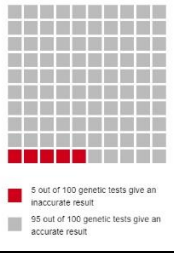
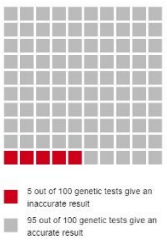
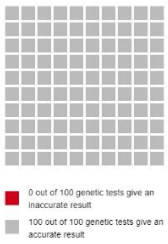
Choice set 6

	Test 1	**Test 2**
How the test is done	Invasive	Non-invasive
Cost of the test	$250	$50
Risk of an inaccurate result that would prevent receiving timely treatment	0% 	5% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	20% 	5% 

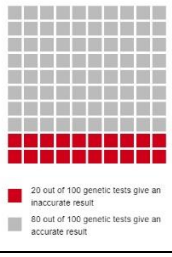
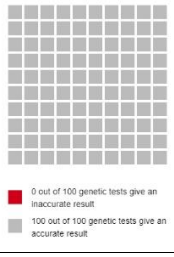
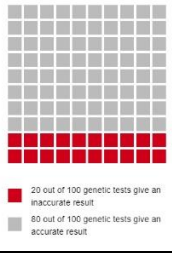
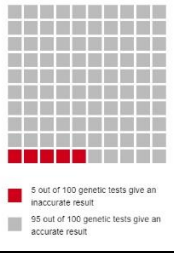
Choice set 7

	Test 1	**Test 2**
How the test is done	Non-invasive	Invasive
Cost of the test	$1000	$50
Risk of an inaccurate result that would prevent receiving timely treatment	20% 	5% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	0% 	20% 

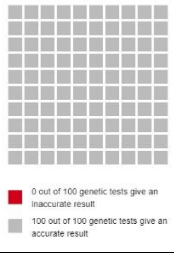
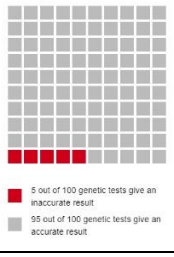
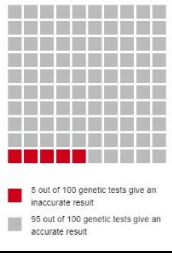
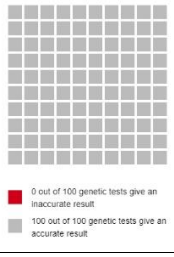
Choice set 8

	Test 1	**Test 2**
How the test is done	Invasive	Non-invasive
Cost of the test	$50	$1000
Risk of an inaccurate result that would prevent receiving timely treatment	20% 	5% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	5% 	0% 

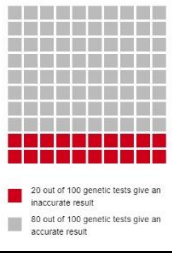
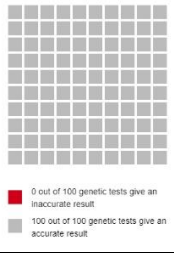
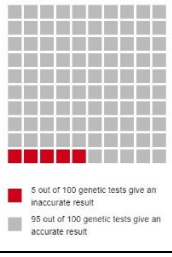
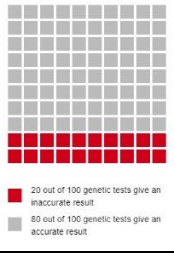
Choice set 9

	Test 1	**Test 2**
How the test is done	Invasive	Non-invasive
Cost of the test	$1000	$250
Risk of an inaccurate result that would prevent receiving timely treatment	20% 	0% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	20% 	5% 

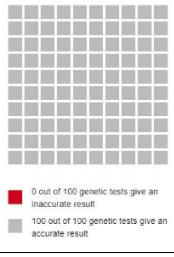
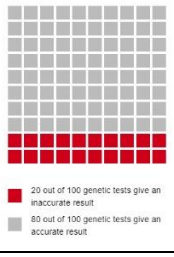
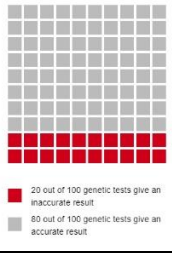
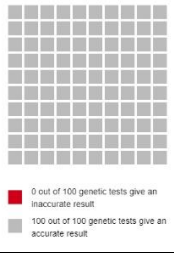
Choice set 10

	Test 1	**Test 2**
How the test is done	Non-invasive	Invasive
Cost of the test	$1000	$250
Risk of an inaccurate result that would prevent receiving timely treatment	0% 	5% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	5% 	0% 

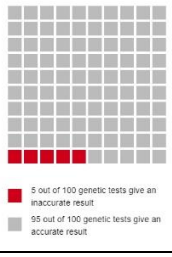
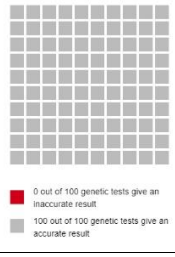
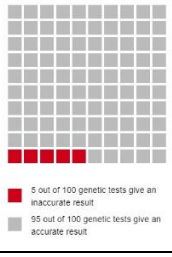
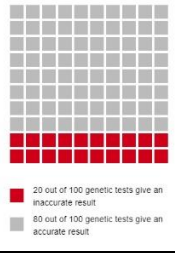
Choice set 11

	Test 1	**Test 2**
How the test is done	Invasive	Non-invasive
Cost of the test	$50	$250
Risk of an inaccurate result that would prevent receiving timely treatment	20% 	0% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	5% 	20% 

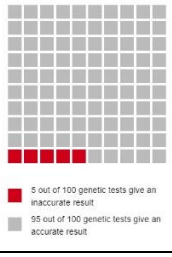
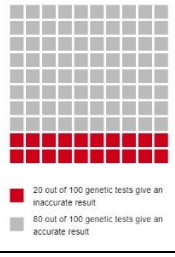
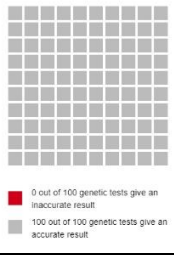
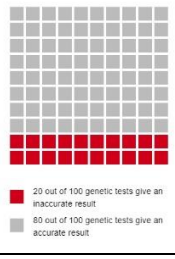
Choice set 12

	Test 1	**Test 2**
How the test is done	Non-invasive	Invasive
Cost of the test	$1000	$250
Risk of an inaccurate result that would prevent receiving timely treatment	0% 	20% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	20% 	0% 

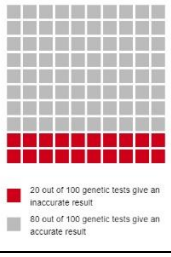
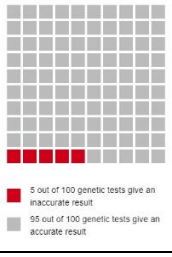
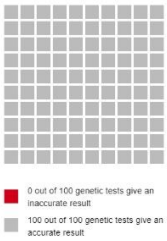
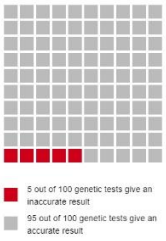
Choice set 13

	Test 1	**Test 2**
How the test is done	Invasive	Non-invasive
Cost of the test	$1000	$50
Risk of an inaccurate result that would prevent receiving timely treatment	5% 	0% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	5% 	20% 

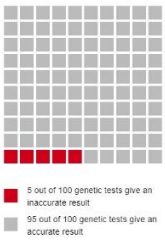
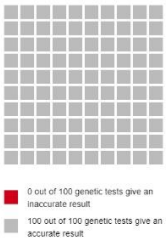
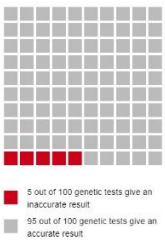
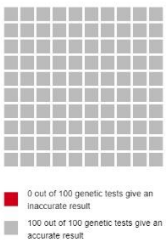
Choice set 14

	Test 1	**Test 2**
How the test is done	Non-invasive	Invasive
Cost of the test	$50	$250
Risk of an inaccurate result that would prevent receiving timely treatment	5% 	20% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	0% 	20% 

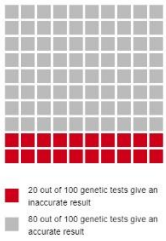
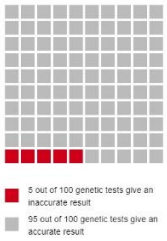
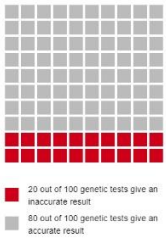
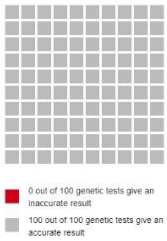
Choice set 15

	Test 1	**Test 2**
How the test is done	Non-invasive	Invasive
Cost of the test	$50	$250
Risk of an inaccurate result that would prevent receiving timely treatment	20% 	5% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	0% 	5% 

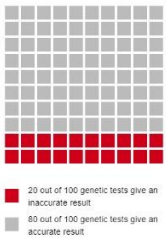
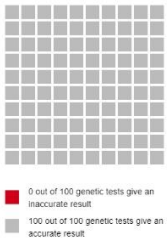
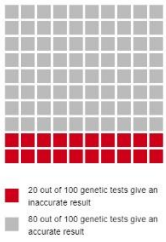
Choice set 16

	Test 1	**Test 2**
How the test is done	Non-invasive	Invasive
Cost of the test	$50	$1000
Risk of an inaccurate result that would prevent receiving timely treatment	5% 	0% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	5% 	0% 

Choice set 17

	Test 1	**Test 2**
How the test is done	Non-invasive	Invasive
Cost of the test	$50	$1000
Risk of an inaccurate result that would prevent receiving timely treatment	20% 	5% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	20% 	0% 

Choice set 18

	Test 1	**Test 2**
How the test is done	Invasive	Non-invasive
Cost of the test	$1000	$250
Risk of an inaccurate result that would prevent receiving timely treatment	20% 	0% 
Risk of an inaccurate result that leads to worry and unnecessary medical tests	20% 	0%