**Interview Guide for Decision Aid**

**Instructions for interviewer:**
This section is a semi structured, open-ended interview. Use the questions here to guide the conversation. Probes are provided to help you explore the questions with the participant and to provide some bearing on what is important to explore in the conversation. Your questions may branch into other topics not covered in the interview questions. This information is important as well and it is ok to depart from the interview questions in order to explore these elements.

Before ending the interview review the questions provided here to be sure you discussed all of the topics outlined.

*Hello [participant]. Thank you very much for your participation in this study. We are going to ask you some questions about making a decision about the types of incidental findings you would like to have returned to you from whole genome sequencing. The information you provide us with will help us better understand the decision making process regarding WGS and incidental findings. Please remember that our questions about incidental findings are hypothetical, you will not be receiving whole genome sequencing and you will not be receiving any incidental findings. Your participation is completely voluntary, you can stop at any time and you can opt out of any questions you do not wish to answer or discuss. Your answers are confidential. Once this interview is completed we will have it transcribed, at which time we will remove any references to names or places that could identify you. Once the transcription is verified we will erase the audio recording. Please note that if for any reason in this interview you inform us of your intent to harm yourself or other we will have to report this information.*

**Introduction:** We are interested in learning about how you chose the different categories of incidental findings while you [used the DA/spoke with our GS], and what you thought about while making your choices.

**Topic: Genome sequencing impressions, experiences**

**Goal:** To gauge their impressions of GS.

1. **To start off, what are your impressions of genome sequencing and incidental findings?**
   [PROBES: What do you see as benefits? What do you see as concerns? Is it something you would consider?]

2. **What has been your experience with genetic testing up to this point?**
   [PROBES: What was the context of having testing? What were your motivations for considering testing? What factors did you take into consideration when deciding whether to get tested?]
**Topic:** Decision Drivers

**Goal:** To understand what drove their category choices, and specifically how perceived actionability, impact, uncertainty and magnitude of risk influenced their category choices.

3. **When thinking about the 5 categories of incidental results that you were hypothetically offered** [Review categories if necessary] - You chose [state the participant’s choice(s)]. What did you think about when choosing those categories? (alternatively: Take me through your thinking around the different categories)
   [PROBES: Probe each category. What was important for you? What wasn’t important for you? Why? What would you hope to do with those results? *If they say “Information is important” or similar, probe, why is that information important for you?*

4. **What factors did you think about or take into consideration when deciding to receive (or not receive) results from category one?**
   [PROBES: Probe and define each decision driver.]
   **ACTIONABILITY:** When we say “medically actionable,” we mean there are known medical preventions and treatments available for the disease. What does “actionable” mean to you? What role did “actionability” play in your decision to receive these results?
   **IMPACT:** Perceived Impact is subjective in nature, but refers to ones’ interpretation of the disease (or category) on health care decision-making, quality of life, family life, future planning etc. What did you see as the (potential) impact of results from this category? Impacts on healthcare? Emotional impacts? Impacts on family members? How did these impacts influence your decision to receive this category or not? How did the disease example provided in this category inform your interpretation of impact?
   **UNCERTAINTY:** Often, genetic results are probabilities; mostly they indicate that you may have a higher or lower chance of developing a disease, rather than being a definitive yes or no. How does this influence your category choices? The interpretation of genetic information may change over time, how does this influence your category choices?
   **RISK:** The genetic risk associated with each category is different. Did the magnitude of risk factor in to your decision to receive these results (for example, the knowledge that genetic risk for this category is quite high compared to others)?

5. **What factors did you think about or take into consideration when deciding to receive (or not receive) results from category two?**
   [PROBES: Probe each decision driver and define again if necessary.]
   **ACTIONABILITY:** What does actionable mean to you in terms of this category? What role did “actionability” play in your decision to receive results from this category?
   **IMPACT:** What did you see as the (potential) impact of results from this category? Impacts on healthcare? Emotional impacts? Impacts on family members? How did these impacts influence your decision to receive this category or not? How did the disease example provided in this category inform your interpretation of impact?
UNCERTAINTY: How does potential uncertainty influence your category choices? The interpretation of genetic information may change over time, how does this influence your category choices?

RISK: The genetic risk associated with each category is different. Did the magnitude of risk factor in to your decision to receive these results (for example, the knowledge that genetic risk for this category is quite low compared to others)?

6. What factors did you think about or take into consideration when deciding to receive (or not receive) results from category three?

[PROBES: Probe each decision driver and define again if necessary.

ACTIONABILITY: What does “actionable” mean to you in terms of this category? What role did “actionability” play in your decision to receive these results?

IMPACT: What did you see as the (potential) impact of results from this category? Impacts on healthcare? Emotional impacts? Impacts on family members? How did these impacts influence your decision to receive this category or not? How did the disease example provided in this category inform your interpretation of impact?

UNCERTAINTY: How does potential uncertainty influence your category choices? The interpretation of genetic information may change over time, how does this influence your category choices?

RISK: The genetic risk associated with each category is different. Did the magnitude of risk factor in to your decision to receive these results (for example, the knowledge that genetic risk for this category is moderate compared to others)?

7. What factors did you think about or take into consideration when deciding to receive (or not receive) results from category four?

[PROBES: Probe each decision driver and define again if necessary.

ACTIONABILITY: What does “actionable” mean to you in terms of this category? What role did “actionability” play in your decision to receive these results?

IMPACT: What did you see as the (potential) impact of results from this category? Impacts on healthcare? Emotional impacts? Impacts on family members? How did these impacts influence your decision to receive this category or not? How did the disease example provided in this category inform your interpretation of impact?

UNCERTAINTY: How does potential uncertainty influence your category choices? The interpretation of genetic information may change over time, how does this influence your category choices?

RISK: The genetic risk associated with each category is different. Did the magnitude of risk factor in to your decision to receive these results (for example, the knowledge that genetic risk for this category is quite high compared to others)?

8. What factors did you think about or take into consideration when deciding to receive (or not receive) results from category five?

[PROBES: Probe each decision driver and define again if necessary.
ACTIONABILITY: What does “actionable” mean to you in terms of this category? What role did “actionability” play in your decision to receive these results?

IMPACT: What did you see as the (potential) impact of results from this category? Impacts on healthcare? Emotional impacts? Impacts on family members? How did these impacts influence your decision to receive this category or not? How did the disease example provided in this category inform your interpretation of impact?

UNCERTAINTY: How does potential uncertainty influence your category choices? The interpretation of genetic information may change over time, how does this influence your category choices?

RISK: The genetic risk associated with each category is different. Did the magnitude of risk factor in to your decision to receive these results (for example, the knowledge that there is no risk of you developing the disease, but a moderate genetic risk that your children or grandchildren could be affected)?

9. Of the four factors we talked about – risk, actionability, impact, uncertainty which do you think was most influential in your decision making process and category selection?

[PROBES: Which factor is the most important? Least important? What other factors played into your decisions?]

Topic: Scenarios and use of results

Goal: To learn how they anticipate using GS results, the impact GS results would have on their healthcare and other aspects of their life.

Category 1:

Imagine you choose to receive results from category 1, and you learn that you carry a genetic variant associated with a high-risk (80%) of developing a heart disease, which can lead to heart failure. Treatments can include taking medications and/or implanting a surgical device to correct irregular heart rhythms, or you could monitor for symptoms. What do you imagine you would do if you learned such a result?

[PROBES: What actions would you take for your own health? Medication, devices, lifestyle changes, consultations? What actions would you take for your family members? How would you feel about this result? How would this result change your day to day life? How would this result change your future plans? What is the value of learning this result for you?]

Category 2:

You choose to receive results from category two, and learn you have a low risk for developing a heart disease. There are no preventions or treatment, but exercising more, changing your diet or making or other lifestyle changes might lower your risk. How do you imagine you would respond to such a result?

[PROBES: What actions would you take for your own health? What actions would you take for your family members? How would you feel about this result? How would this result change your
day to day life? How would this result change your future plans? What is the value of learning this result for you?

**Category 3:**

Imagine you choose to receive results from category 3, and you learn that you carry a genetic variant associated with a moderate risk of developing a rare heart condition. The implications of this condition are serious. In this scenario, there are no proven medical treatments or disease prevention options available to you. What do you imagine you would do if you learned such a result?

[PROBES: What actions would you take for your own health? What actions would you take for your family members? How would you feel about this result? How would this result change your day to day life? How would this result change your future plans? What is the value of learning this result for you?]

**Category 4:**

Imagine that you choose to receive results from category 4, and you learn that you carry a genetic variant associated with a high-risk of developing a brain disease. This condition is associated with deterioration in one’s memory, thinking, and behavior. Ultimately this brain disease will impair your ability to function independently and care for yourself. There is no proven medical treatment or prevention options available for this condition. What do you imagine you would do if you learned such a result?

[PROBES: What actions would you take for your own health? What actions would you take for your family members? How would you feel about this result? How would this result change your day to day life? How would this result change your future plans? What is the value of learning this result for you?]

**Category 5:**

Imagine you choose to receive results from category 5, and you learn that you carry a genetic variant associated with a heart condition that you may pass along to your children (and possibly grandchildren). The implications of this heart condition could be serious. The available treatments will vary depending on the individual’s condition, but may include taking medications and/or implanting a surgical device to correct irregular heart rhythms, as well as making lifestyle modifications to reduce one’s risk. What do you imagine you would do if you learned such a result?

[PROBES: What actions would you take for your own health? Medication, devices, lifestyle changes, consultations? What actions would you take for your family members? How would you feel about this result? How would this result change your day to day life? How would this result change your future plans? What is the value of learning this result for you?]

**Topic: Genetic knowledge**
Goal: To learn their perspectives on genetic determinism and genetic exceptionalism.

10. How important do you see genetic factors in determining individuals’ future or current health?
   [PROBES: How do you use genetics when thinking about your health now and in the future? What role do you think genetics plays in your health? Do you see genetic results as the sole determinant of your health?]

11. How is personal genetic information different from other kinds of health information?
   [PROBES: How is having the result from a genetic test different from having the result from another type of test, such as a mammogram or blood test?]

12. What do you see as being the value of genetic information?
   [PROBES: What purpose does genetic information have for you? Describe how important genetic information about your health is to you. What role would this information play in your day-to-day life?]

Topic: Feedback on DA

Goal: To elicit feedback on the GC/DA and how it supported their decision making process.

1. You made your decision about which categories you would chose by [working through the decision aid/speaking with a genetic counselor]. How was that experience?
   [PROBES: What worked? What didn’t work? What would have helped you feel more confident in your decision? What other information would you have wanted? Were your category choices influenced by (the DA/genetic counselor)?]

Topic: Future use of GS

2. Where do you see genome sequencing going in the future?
   [PROBES: What do you see as potential benefits? Concerns? Societal impacts of the technology?]

Topic: Wrap up

3. Any final thoughts that you wish to share?