



Academy for Educational Development

## Focus Group Recruitment Screener

**Project:** Consumer Views on Genetic Testing  
**Client:** National Cancer Institute and National Institutes of Health  
**Dates/Locations:** December 3-4, 2008 in Chicago, IL  
The week of December 8<sup>th</sup>, 2008 in the Washington, DC area  
December 18, 2008 in New York City

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### Recruit 10 for 8 participants

Hello, I'm \_\_\_\_\_. I work for \_\_\_\_\_, an independent research firm. We are doing a research study about peoples thoughts and opinions about genetic testing. We are not selling any product or service.

We are looking for people to take part in discussion groups also known as focus groups. Everyone who joins will be paid \$ 75 I would like to ask you some questions to see if there is a discussion group that you could join. These questions will only take a few moments to answer. The groups will be held in [TBD] on [Date] at [Location] and will last about two hours. Do you have time now to answer a few questions?

I'm going to ask you a series of questions about genetic testing. Before we begin I am going to give you some basic information about genetic testing. I want to make sure we have a common understanding of the topic when discussing it.

People have many different reasons for being interested in genetic testing. Sometimes, they are just curious to find out their genetic make up. In other cases, a family history of a particular condition or disease increases people's interest in having a test done.

Genetic tests are sometimes used to predict a person's risk of developing common diseases such as certain types cancer and diabetes. They are also used to for diagnoses of genetic diseases and disorders in individuals, families, or populations.

One widespread type of genetic testing involves prenatal screenings to find possible genetic diseases in unborn babies. Other types of genetic testing can be used to determine a person's ancestry or to establish paternity.

Some genetic tests are focused on a single condition, while others involve a scan of all of a person's genetic material, sometimes referred to as a genome-wide scan.

Traditionally, genetic tests have been available only through healthcare providers such as physicians, nurse practitioners, and genetic counselors. Healthcare providers order the appropriate test from a laboratory, collect and send the samples, and interpret the test results. One example is a genetic test that a person might have done through their physician that identifies mutations in the BRCA1 gene. If a person has a mutation in this gene, they are at increased risk for developing breast cancer, as well as several other kinds of cancer.

Some genetic tests are now available directly to consumers by businesses. This testing, which is also known as at-home genetic testing, provides people with their genetic information without involving a doctor or insurance company in the process.

Genetic tests that provide genome-wide scan of a person's DNA can also be used to determine genetic contributions to the risk of some common diseases, such as breast cancer, ovarian cancer, and colon cancer, in order to guide preventive care. These are available for purchase to many Americans directly, without working through a physician.

1. How familiar are you with ANY of the kinds of genetic testing I've just described? In general, would you say your are...? [Read response options a – d.]
  - ( ) a. Not at all familiar..... Terminate
  - ( ) b. A little familiar..... Continue
  - ( ) c. Somewhat familiar..... Continue
  - ( ) d. Very familiar..... Continue
  - ( ) e. Refused, or any other answer..... Terminate
  
2. Have you ever participated in genetic testing either through your doctor or on your own that was NOT related to prenatal testing?
  - ( ) a. Yes.....(Eligible for Group E) Continue to Q3
  - ( ) b. No..... Continue to Q4
  - ( ) c. Refused, or any other answer..... Terminate
  
3. Was this genetic testing done through your doctor or on your own? (Mark all that apply.)
  - ( ) a. Through doctor..... Continue to Q 5
  - ( ) b. On his/her own..... Continue to Q 5
  - ( ) c. Refused, or any other answer..... Terminate
  
4. Do you plan to have any kind of genetic testing done in the next three years that is NOT related to prenatal testing?
  - ( ) a. Yes.....(Eligible for Groups B or D) Continue
  - ( ) b. No.....(Eligible for Groups A or C) Continue
  - ( ) c. Refused, or any other answer..... Terminate

I'm going to ask you a few questions about your thoughts on genetically-based diseases. These questions refer to diseases that can be passed down through generations in a family. Examples of these diseases include breast cancer, Alzheimer's disease, and diabetes.

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**NOTE:** Use the following language to "TERMINATE" call throughout screening process: "Thank you for taking the time to answer our questions. Unfortunately, the category you fall into is currently full. If it should open back up, may we call you back?"

5. In your opinion, how useful is it for a person to use genetic testing to determine their risk of developing a genetically-based disease? [Read response options a – d.]
- a. Not at all useful..... Terminate
  - b. A little useful..... Continue
  - c. Somewhat useful..... Continue
  - d. Very useful..... Continue
  - e. Refused, or any other answer..... Terminate

6. Do you have any genetically-based diseases in your family history?
- a. Yes..... Continue to Q7
  - b. No..... Continue to Q8
  - c. I don't know..... Continue to Q8
  - d. Refused, or any other answer..... Terminate

7. What genetically based-disease or diseases do you have in your family history?

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8. How concerned are you about the possibility of having inherited genes that put you at risk for genetically based disease? [Read response options a – d.]
- a. Not at all concerned..... (Eligible for Groups A, B, or E) Continue
  - b. A little concerned .....(Eligible for Groups A, B, or E) Continue
  - c. Somewhat concerned.....(Eligible for Groups C, D, or E) Continue
  - d. Very concerned.....(Eligible for Groups C, D, or E) Continue
  - e. Refused, or any other answer ..... Terminate

9. Are you comfortable talking in a small group setting about your thoughts, opinions, and experiences related to these genetic testing?
- a. Yes..... Continue
  - b. No..... Terminate
  - c. Refused, or any other answer..... Terminate

**(Recruit only those who are comfortable talking about this topic)**

10. What is your age?

|\_|\_| [RECORD AGE]

- a. Under 21..... Terminate
- b. 21 to 74..... Continue
- c. 75 or older..... Terminate
- d. Refuse..... Terminate

**(Recruit adults ages 21 to 74)**

11. What is your occupation?

**NOTE:** Use the following language to “**TERMINATE**” call throughout screening process: “Thank you for taking the time to answer our questions. Unfortunately, the category you fall into is currently full. If it should open back up, may we call you back?”

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12. Do you currently or have you ever worked.... ? (Read each response listed below.  
Terminate, if any apply.)

( ) a. As an employee in advertising, marketing, market research, public relations  
or health promotion?..... Terminate

( ) b. As an employee in the medical or health science fields..... Terminate

**(Continue if not employed in the marketing or medical fields)**

13. Do you currently work as an employee of the Federal Government?

( ) a. Yes..... Terminate

( ) b. No..... Continue

**(Continue if not employed by the Federal Government)**

14. Which of the following best describes the highest level of education you have completed?  
(Read list and record response) RECRUIT MIX

( ) a. some high school..... Terminate

( ) b. High school diploma/GED..... Continue

( ) c. Some college or trade school..... Continue

( ) d. Bachelor's degree..... Continue

( ) e. Graduate degree..... Continue

( ) f. Refuse, or any other answer..... Terminate

**(Continue only if highest level of education is at least high school diploma/GED)**

15. Are you Hispanic/Latino?

( ) a. Yes..... Continue

( ) b. No..... Continue

( ) c. Refuse, or any other answer..... Continue

16. Which of the following best describes your race? RECRUIT MIX IF POSSIBLE

( ) a. American Indian or Alaska Native..... Continue

( ) b. Asian..... Continue

( ) c. Black or African American ..... Continue

( ) d. Native Hawaiian or Other Pacific Islander..... Continue

( ) e. White ..... Continue

17. How many children do you have, if any?

I \_\_\_ | \_\_\_ | RECORD NUMBER OF CHILDREN

18. How many focus group discussions have you attended in the past year? By "focus group" we mean a discussion led by a moderator, in which you were asked to share your opinions?

- ( ) a. 0 ..... Invite to appropriate group
- ( ) b. 1 or 2..... Continue to Q18a
- ( ) c. 3 or more..... Terminate

18a. What topics were discussed?

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(Terminate if any discussions were related to genetics or medical testing of any kind)

19. Because it can sometimes be hard to tell based on what a person's voice sounds like over the phone, could you please state your gender?

- ( ) a. Female..... Continue
- ( ) b. Male..... Continue

**(Recruit approximately half women and men)**

**INVITATION:**

Thank you for answering my questions. I would like to tell you a little more about the discussion group. The group will meet on **[Date]** at **[Time]** at our facility in **[Location]**. **[Give address]**. You will join up to 8 other men and women and a moderator. It will meet for about two hours. You will get **[\$amount]** for coming.

So that we can start and end on time, please come about 15 minutes early to pick up your nametag and to have some snacks. Please be sure to contact us as soon as possible if something comes up and you can't come. **(Give phone number)**.

Before we hang up, let me get the correct spelling of your name, and your address and phone numbers so we can send you a letter with directions and give you a reminder call the day of the group.

NAME \_\_\_\_\_

HOME PHONE \_\_\_\_\_

ADDRESS \_\_\_\_\_  
\_\_\_\_\_

WORK PHONE \_\_\_\_\_ CELL PHONE \_\_\_\_\_ E-MAIL \_\_\_\_\_

**Thanks again for your time and we'll see you at the group!**

## Revised Genetic Testing Study Design

		Stage of Change		
		<b>Precontemplation</b> <i>Generally aware of GT, but has no intention of taking action in the next year</i>	<b>Contemplation</b> <i>Generally aware of GT, and is considering/has an intention of taking action in the next year</i>	<b>Action/Doer</b> Has already participated in GT
<b>Perceived Risk of Inheriting a Genetic Disease</b>	<b>Normal</b> Has no perceived family history of a genetic disease, and is not concerned about inheriting a predisposition to a genetic disease	<b>A</b> 2 FGs	<b>B</b> 2 FGs	<b>E</b> 2 FGs
	<b>Heightened</b> Has a perceived family history of a genetic disease, and/or is concerned about inheriting a predisposition to a genetic disease	<b>C</b> 2 FGs	<b>D</b> 2 FGs	

(Total of 10 focus groups)