



Academy for Educational Development

Focus Group Recruitment Screener

Project: Direct-to-Consumer Genome-wide Genetic Testing
Client: National Cancer Institute and National Institutes of Health
Locations: Washington, DC; Chicago IL; and possibly TBD
Dates: TBD

Public reporting burden for this collection of information is estimated to average 30 minutes total, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0046-11). Do not return the completed form to this address.

| | | | |
|------------------|----------|----------------------|------------|
| Day 1: | Group 3 | Contemplating DTC GT | Normal |
| Day 2: | Group 4 | Rejected DTC GT | Heightened |
| Day 2: | Group 5 | Accepted DTC GT | Normal |
| Day 2: | Group 6 | Contemplating DTC GT | Heightened |
| Market #2 | | | |
| Day 1: | Group 7 | Rejected DTC GT | Normal |
| Day 1: | Group 8 | Accepted DTC GT | Heightened |
| Day 1: | Group 9 | Contemplating DTC GT | Normal |
| Day 2: | Group 10 | Rejected DTC GT | Heightened |
| Day 2: | Group 11 | Accepted DTC GT | Normal |
| Day 2: | Group 12 | Contemplating DTC GT | Heightened |

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 various genetic testing services. 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 **\$[amount]**. 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?

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

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.

More recently, some genetic tests are being made available directly to consumers by commercial businesses. This form of testing, which is also known as at-home genetic testing, provides a people with their genetic information without necessarily 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 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 *commercially-available genome-wide genetic testing services*? By "commercially-available genome-wide genetic testing services" I'm referring to services that are available direct to a consumer, and that provide a person with a genetic scan of all of his or her DNA and information of their risk of common diseases. While some of tests include information about a person's ancestry, I'm referring to those that also offer information about a person's risk of common diseases such as various types of cancer. 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..... Terminate

1. Which of the following statements best describes you? [Read response options a – c.]

- a. I have heard of genome-wide genetic testing services but I have not explored them any further..... Terminate
- b. I have heard of genome-wide genetic testing services and explored them further because I'm generally curious about my health..... Continue

[Eligible for Normal Personal Interest Groups]

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?"

() c. I have heard of genome-wide genetic testing services, and explored them further because I feel there might be an increased risk for a specific disease in my family Continue
.....
[Eligible for Heightened Personal Interest Groups]

2. Which of the following best describes you?

() a. I considered purchasing or using genome-wide genetic testing services, but have decided not to purchase these services..... Continue
[Eligible for Rejecter Groups]

() b. I am considering purchasing or using genome-wide genetic testing services, but am undecided as to whether or not I am going to purchase these services..... Continue
[Eligible for Contemplator Groups]

() c. I have already purchased or used genome-wide genetic testing services..... Continue
.....
[Eligible for Adopter Groups]

3. Which specific companies, if any, are you aware of that are offering direct-to-consumer genome-wide genetic testing services? [Do not read list.]

- () No specific companies named..... Continue
- () 23andMe..... Continue
- () Navigenics..... Continue
- () deCODEme..... Continue
- () other (please specify _____)..... Continue

4. Are you comfortable talking in a small group setting about your thoughts, opinions, and experiences related to these genome-wide genetic testing services?

- () Yes..... Continue
- () No..... Terminate
- () Refused, or any other answer..... Terminate

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

5. What is your age?

____|____| **[RECORD AGE]**

- () Under 21..... Terminate
- () 21 to 74..... Continue
- () 75 or older..... Terminate
- () Refuse..... Terminate

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(Recruit adults ages 21 to 74)

6. What is your occupation?

7. Do you currently or have you ever worked.... ?

(Read each response listed below. Terminate, if any apply.)

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

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

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

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

Yes..... Terminate

No..... Continue

(Continue if not employed by the Federal Government)

9. Which of the following best describes the highest level of education you have completed?

(Read and record response)

some high school..... Terminate

High school diploma/GED..... Continue

Some college or trade school..... Continue

Bachelor's degree..... Continue

Graduate degree..... Continue

Refuse, or any other answer..... Terminate

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

10. Are you Hispanic/Latino?

Yes..... Continue

No..... Continue

Refuse, or any other answer..... Continue

11. Which of the following best describes your race?

African American/Black..... Continue

White/Caucasian..... Continue

- () Native American/American Indian..... Continue
- () Asian/Pacific Islander..... Continue
- () Other..... Continue

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

|__| |__| **RECORD NUMBER OF CHILDREN**

13. 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?

- () 0 Invite to appropriate group
- () 1 or 2..... Continue to Q14a
- () 3 or more..... Terminate

14a. What topics were discussed?

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

15. 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?

- () Female..... Continue
- () 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 _____

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HOME PHONE _____

ADDRESS _____

WORK PHONE _____ CELL PHONE _____ E-MAIL _____

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