

Screeners and Moderator's Guides for NCI Personal Genomics and Genetic Testing

Revised October 5, 2010

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**Attachment B2:
Focus Groups with Consumers
NCI Personal Genomics and Genetic Testing**

Moderator's Guide

August 2010

Public reporting burden for this collection of information is estimated to average 100 minutes per response, 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). Do not return the completed form to this address.

I. WELCOME (5 minutes)

Welcome everyone. My name is [MODERATOR NAME], and I work for AED, a nonprofit organization working across the U.S. and globally to improve health, education, civil society and economic development. We are currently working on a research project for the National Institutes of Health, or NIH, to help them develop communication materials for the public about genomics and genetic testing. We are gathering feedback from people about some ideas for health topics that NIH is planning to develop content around. Thank you for coming to this discussion.

Before we begin, I'd like to explain a few things about this room and how the discussion will work.

1. We are not trying to sell or promote any product or service to you.
2. There are **no right or wrong answers** -- We want to know your honest opinions.
3. Don't feel like you need to answer every question. But if I haven't heard from you in a while I may call on you occasionally.

4. There are microphones in this room that we are using to **audiotape** the discussion. We are not videotaping these discussions. Afterwards, I have to write a report and by having the tapes it will help me to do this.
5. Your feedback will be kept **secure to the extent permitted by law**. The findings will be reported to the NIH in a summary form and no names or other identifying information will be used.
6. Because we are taping, it is important that you try to **speak one at a time**. I may occasionally interrupt you when two or more people are talking at once in order to be sure everyone gets a chance to talk and that responses are accurately recorded.
7. Behind me is a **one-way mirror**. Some of the people working on this project are observing this discussion so that they can hear your opinions directly from you. However, your identity and anything you personally say here will remain **secure to the extent permitted by law**. When I write my report, I will not refer to anyone by name.
8. The group will last for **one hour and thirty minutes**. I want to be sure not to keep you here any longer, so I may occasionally interrupt the discussion to move us along.
9. Please turn off or silence your **cell phones**. Should you need to go to the restroom during the discussion, please feel free to leave, but we'd appreciate it if you would go one at a time.
10. I was not personally involved in the development of any of the ideas and items that I am going to share with you today. If you have something negative to say, it is all right. Remember, there are no right or wrong answers. We just want to hear your opinions.
11. Do you have any questions before we get started?

II. INTRODUCTIONS (5 minutes)

1. Let's go around the table and introduce ourselves to each other including:
 - your first name;
 - where you're from; and
 - something you like to do in your free time.

III. PERCEPTIONS AND EXPERIENCES RELATED TO GENOMICS (15 minutes)

To begin the discussion, I would like to hear about your interest in and experiences related to genomics and genetic testing. But first let's briefly go over the definitions of these key terms:

Personal Genomics – The study of an individual's entire genome, in which all of their genes are typed, sequenced, and analyzed. *Genomics* refers to the study of the entire

genome, essentially all the genes that can be found in a person. It's in contrast to *genetics* which can study individual genes one at a time.

Genetic Testing – Genetic testing is the use of a laboratory test to look for genetic variations associated with a disease. There are many different kinds of genetic tests. The results of a genetic test can be used to confirm or rule out a suspected genetic disease or to determine the likelihood of a person passing on a mutation to their offspring. Genetic testing is offered by some healthcare providers and is available directly to the public.

1. What interests you about personal genomics and learning about your genes?
 - a. Has the topic of genetics come up in the context of receiving healthcare?
 - b. How does your family's health history impact your interest in personal genomics?
 - c. What have you seen lately in the media about these topics?
2. What is your experience with personal genomics and/or genetic testing?
 - a. Have you gotten a genomic or genetic test? [IF YES, ASK:] Which test(s)? For what reasons?
 - b. [IF NO, ASK:] Have you looked into getting a genomic or genetic test? What did you learn?
 - c. What are some reasons you have considered getting tested? What are some reasons you have not gotten tested yet?
3. What personal genomics or genetic testing related information have you sought out?
 - a. When you have sought information about these topics, where did you go? [Probe: asking doctor, searching online, talking to friends and family]
 - b. How satisfied were you with the information that you found?
 - c. What additional information would you like to have?

IV. FEEDBACK ON DRAFT MESSAGES (55 minutes)

Now I am going to show you eight messages that NIH has drafted about personal genomics, genetic testing and related topics. With your input, they plan to revise and refine these messages and then develop Web site content and perhaps a brochure to communicate them to the general public. We are going to look at each message one-by-one as a group.

[ROTATE THE ORDER THE EIGHT MESSAGES ARE PRESENTED IN BETWEEN GROUPS]

1. [SHOW BOARD WITH MESSAGE 1 TO PARTICIPANTS. DISTRIBUTE HANDOUT WITH MESSAGE 1 TO EACH PERSON.] Take a minute to review this message. What is the main idea that this message is trying to get across, in your own words?

- a. Was this a new idea or something that you've heard before?
 - b. What action is this message prompting you to take?
2. How would you describe your impressions of this message?
 - a. How does this message make you feel? Anything positive? Anything negative?
 - b. What makes the message appealing or unappealing? What do you like about it? What do you not like?
3. Overall, how important is this message to you? How interested are you in the information conveyed?
 - a. What is the most important part of this message in your opinion?
 - b. How relevant are the ideas presented in this message for your life? How useful are they to you?
 - c. How motivated are you to learn more about the topics discussed in this message?
 - d. If you did (on a Web site) click for more information related to this message, what would you expect to find?
4. How could this message be improved?
 - a. Is there anything confusing, unclear, or hard to understand? What other words can be used in their place?
 - b. How could it be said differently to make you more likely to notice and think about the message?[Probe: words or phrases within the message]
 - c. What additional information would you need to better understand this message?

[REPEAT QIV.1-4 FOR ALL EIGHT MESSAGES BEING TESTED, SEE ATTACHED. SPEND ABOUT 5-6 MINUTES ON EACH MESSAGE.]

5. Now that you've seen all of the messages about personal genomics and genetic testing, I am interested in hearing about the messages you are most interested in hearing more about. NIH may not develop content for each of these messages, so they need your advice.

Think about which of these messages NIH should definitely include in future materials on this subject and which should be dropped. I am going to give you three green sticky notes and three red ones. Everyone please get up and place the green notes on the three messages you are most interested in learning more about and put the red sticky notes on the three messages you are least interested in.

[DISTRIBUTE GREEN AND RED STICKY NOTES AND ALLOW TIME FOR PARTICIPANTS TO MAKE THEIR SELECTIONS. ONCE THE GROUP IS SEATED, DISCUSS THEIR TOP AND BOTTOM THREE MESSAGES.]

- a. [TOP THREE, ASK:] Why do you think this message is among the most interesting? What about it interests you?
 - b. [BOTTOM THREE, ASK:] Why is this message among the least interesting? What would make it more of interest to you?
6. Thinking about all of the messages that you have reviewed, was there something missing? What, if any, information or ideas about personal genomics or genetic testing are important for the general public to know, but that you do not see in any of these?
- a. Why do you think NIH should include this content?

V. PREFERENCES FOR SOURCES, CHANNELS, AND FORMATS (5 minutes)

1. How would you prefer to receive personal genomics and genetic testing information like the messages we just discussed?
 - a. Through what people, places, or information sources? [Probe: mass media, doctors, Internet, other channels and intermediaries]
2. When it comes to these health topics, are there any people or organizations that you would really trust as a reliable source of information? [Probe: government agencies, companies, advocacy groups]
 - a. What makes them a trusted source of information?
 - b. Are there any people or organizations that you would not trust?
3. How do you prefer to see personal genomics and genetic testing information presented? In what format?
 - a. What kind of printed materials do you prefer? [Probe: posters, brochures, fliers]
 - b. What about electronic formats? [Probe: Web sites, PDFs, emails]

VI. CONCLUSION (5 minutes)

1. Before we conclude, is there anything else you would like to share, or do you have any questions for me?
2. Thank you for sharing your opinions and feedback on the personal genomics and genetic testing messages we have shared with you today. NIH will be using your input to develop communication materials for the public on these topics.
3. Each of you will receive your gift for participating in today's discussion as you leave the facility. Don't forget to stop by the reception desk on your way out.

THANK YOU!

**Attachment B3:
Triad Discussions with Advocates
NCI Personal Genomics and Genetic Testing**

August 2010

Public reporting burden for this collection of information is estimated to average 65 minutes per response, 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). Do not return the completed form to this address.

I. WELCOME (5 minutes)

Welcome everyone. My name is [MODERATOR NAME], and I work for AED, a nonprofit organization working across the U.S. and globally to improve health, education, civil society and economic development. We are currently working on a research project for the National Institutes of Health, or NIH, to help them develop communication materials for the public about genomics and genetic testing. We are gathering feedback from advocates of various constituent groups about some ideas for health topics that NIH is planning to develop content around personal genomics. Thank you being part of this discussion.

Before we begin, I'd like to explain a few things about how the discussion will work.

1. First, we are connected via teleconference and AED is recording our conversation. The recording is to help us remember what you said when we are writing the report.
2. None of the information that is written down and recorded during this session will be connected to you in any way. Your security will be maintained to the extent permitted by law.
3. After we have written a report about all the opinions we have heard here and in other small group discussions, the tapes and notes will be destroyed. Neither your name nor any other personal identifying information will appear in the report.

4. When we have groups like this, we usually set ground rules that we can all agree on. The following is a list of ground rules we have used:
 - o There are no right or wrong answers. We want to know your honest opinions.
 - o It's okay to disagree
 - o Each person's comments are important and valued
 - o No judging or criticizing others or what they say
 - o One person speaks at a time
 - o Speak loudly and clearly
 - o Don't have to answer every question
5. Since we are not all in the same room, from time to time I may call on one of you to answer a question first. I am, however, very interested in hearing from all of you throughout this discussion.
6. The group will last for **one hour**. I want to be sure not to keep you longer than necessary, so I may occasionally interrupt the discussion to move us along.
7. I was not personally involved in the development of any of the ideas and items that I am going to share with you today. If you have something negative to say, it is all right. We just want to hear your opinions.
8. Do you have any questions before we get started?

II. INTRODUCTIONS (5 minutes)

1. Let's go around the table and introduce ourselves to each other including:
 - your first name;
 - where you're from; and
 - how are personal genomics part of your current work? Who are your constituents?

III. PERCEPTIONS AND EXPERIENCES RELATED TO GENOMICS (15 minutes)

To begin the discussion, I would like to hear about your work with and experiences related to genomics and genetic testing. First, let's make sure that we are on the same page about some of the key definitions on which we will base our discussion.

Personal Genomics – The study of an individual's entire genome, in which all of their genes are typed, sequenced, and analyzed. *Genomics* refers to the study of the entire genome, essentially all the genes that can be found in a person. It's in contrast to *genetics* which can study individual genes one at a time.

Genetic Testing – Genetic testing is the use of a laboratory test to look for genetic variations associated with a disease. There are many different kinds of genetic tests. The results of a genetic test can be used to confirm or rule out a suspected genetic disease or

to determine the likelihood of a person passing on a mutation to their offspring. Genetic testing is offered by some healthcare providers and is available directly to the public.

1. What is your professional experience with personal genomics and/or genetic testing?
 - a. In what ways does the topic of genetics come up in your work?
 - b. What have you seen lately in the media about these topics?
2. What interests your constituents about their personal genomics and learning about their genes?
 - a. How does family health history impact what interest your constituents in personal genomics?
 - b. What are some reasons that make your constituents consider getting tested? What are some reasons they decide to not get tested yet?
 - c. What pros and cons to genetic testing do you think are important for your constituents to know?
3. What personal genomics or genetic testing related information have you sought out for your constituents?
 - a. When you have sought information about these topics, what sources did you go to?
 - b. How satisfied were you with the information that you found?
 - c. What additional information would you like to have?

IV. FEEDBACK ON DRAFT MESSAGES (55 minutes)

Now I am going to show you eight messages that NIH has drafted about personal genomics, genetic testing and related topics. With your input, they plan to revise and refine these messages and then develop Web site content and perhaps a brochure to communicate them to the general public. We are going to look at each message one-by-one as a group.

[ROTATE THE ORDER THE EIGHT MESSAGES ARE PRESENTED IN BETWEEN GROUPS]

1. [USING GOTOMEETING.COM, SHOW BOARD WITH MESSAGE 1 TO PARTICIPANTS. DISTRIBUTE HANDOUT WITH MESSAGE 1 TO EACH PERSON.] Take a minute to review this message.
What is the main idea that this message is trying to get across, in your own words?
 - a. Was this a new idea or something that you've heard before?
 - b. What action is this message prompting you to take?

2. How would you describe your impressions of this message?
 - a. How does this message make you feel? Anything positive? Anything negative?
 - b. What makes the message appealing or unappealing? What do you like about it? What do you not like?
3. Overall, how important is this message to your constituents?
 - a. What is the most important part of this message in your opinion?
 - b. How relevant are the ideas presented in this message for your constituents? How useful are these ideas?
 - c. If you did (on a Web site) click for more information related to this message, what would you expect to find?
 - d. How interested do you think your constituents would be in receiving the information conveyed in this message?
4. How could this message be improved?
 - a. Is there anything confusing, unclear, or hard to understand? What other words can be used in their place?
 - b. How could it be said differently to make you more likely to notice and think about the message?[Probe: words or phrases within the message]
 - c. What additional information would you need to better understand this message?

[REPEAT QIV.1-4 FOR ALL EIGHT MESSAGES BEING TESTED, SEE ATTACHED.
SPEND ABOUT 5-6 MINUTES ON EACH MESSAGE.]

5. Now that you've seen all of the messages about personal genomics and genetic testing, I am interested in hearing about the messages you are most interested in hearing more about. NIH may not develop content for each of these messages, so they need your advice on which ones to pursue.

Think about which of these messages NIH should definitely include in future materials on this subject and which should be dropped. I am going to show you all the messages now on the screen in front of you. Please note which three messages you think your constituents would be most interested in and which three they would be least interested in.

[USING GOTOMEETING.COM, SHOW THE EIGHT MESSAGES]

- a. [TOP THREE, ASK:] Which messages are the most interesting for your constituents? What about them is interesting?
- b. [BOTTOM THREE, ASK:] Which messages are the least interesting for your constituents? Why?

6. Thinking about all of the messages that you have reviewed, was there something missing? What, if any, information or ideas about personal genomics or genetic testing are important for your constituents to know, but that you do not see in any of these?
 - a. Why do you think NIH should include this content?

V. PREFERENCES FOR SOURCES, CHANNELS, AND FORMATS (5 minutes)

1. How would your constituents prefer to see personal genomics and genetic testing information presented? In what formats?
 - a. What kind of printed materials would they prefer? [Probe: posters, brochures, fliers]
 - b. What about electronic formats? [Probe: Web sites, PDFs, emails]
2. How would you prefer to receive personal genomics and genetic testing information like the messages we just discussed?
 - a. Through what sources and channels? [Probe: mass media, Internet, other channels and intermediaries]

VI. CONCLUSION (5 minutes)

1. Before we conclude, is there anything else you would like to share, or do you have any questions for me?
2. Thank you for sharing your opinions and feedback on the personal genomics and genetic testing messages we have shared with you today. NIH will be using your input to develop communication materials for the public on these topics.
3. Each of you will receive your gift for participating in today's discussion as you leave the facility. Don't forget to stop by the reception desk on your way out.

THANK YOU!

**Attachment B4:
Recruitment Screener
Personal Genomics and Genetic Testing Messages
Consumer Focus Groups
August 2010**

Public reporting burden for this collection of information is estimated to average 10 minutes per response, 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 (0925-0046-16). Do not return the completed form to this address.

Project: **Consumer Views on Genetic Testing**
Locations: **Washington, DC area and a second metropolitan area (e.g., Chicago, Atlanta, or New York City)**
Dates: **TBD**

Summary Table:

Group	Location	Date/Time	Audience
#1	<i>Washington, DC area</i>	TBD	Group A: Interested consumers
#2	<i>Washington, DC area</i>	TBD	Group B: Motivated consumers
#3	<i>Washington, DC area</i>	TBD	Group C: Experienced consumers
#4	<i>2nd metropolitan area</i>	TBD	Group B: Motivated consumers
#5	<i>2nd metropolitan area</i>	TBD	Group C: Experienced consumers
#6	<i>2nd metropolitan area</i>	TBD	Group A: Interested consumers

Recruitment: Recruit 9 participants for 8 to show to each focus group.

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?”

[INTRODUCTION]

Hello, I'm _____. I work for _____, an independent research firm. We are doing a research study about people's 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 provided \$75 as a thank you for your time. 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?

[BACKGROUND]

I'm going to ask you some 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.

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 health 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 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.

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?”

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 a gene that is associated with breast cancer. 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.

Genome-wide scans of a person's DNA type all of their genes. The information from these scans can also be used to determine genetic contributions to the risk of some common diseases, such as diabetes, heart disease, rheumatoid arthritis, and colon cancer — in order to guide preventive care and lifestyle changes.

Some of these genetic tests are available for purchase to many Americans directly by businesses, without working through a physician. 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.

1. How familiar are you with ANY of the kinds of genetic testing I've just described? In general, would you say you are...? [Read response options a – d.]
 - () a. Not at all familiar..... Terminate
 - () b. A little familiar..... Terminate
 - () 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 C) Continue to Q3
 - () b. No..... Continue to Q6
 - () c. Refused, or any other answer..... Terminate

[POTENTIAL EXPERIENCED CONSUMERS]

3. Was this genetic testing done through your doctor or on your own? (Mark all that apply.)

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?”*

- () a. Through doctor..... Continue
 - () b. On his/her own..... Continue
 - () c. Refused, or any other answer..... Terminate
4. Were there any health conditions, genetically based-diseases, or other diseases are in your family history that made you interested in these kinds of tests?
- () a. Yes..... Continue to Q5
 - () b. No..... Continue to Q9
5. What were these health conditions, genetically based-diseases, or other diseases?

_____ Continue to Q9

[POTENTIAL INTERESTED AND MOTIVATED CONSUMERS]

6. Are you thinking about having any kind of genetic testing done in the next three years that is NOT related to prenatal testing?
- () a. Yes..... Continue
 - () b. No..... Terminate
 - () c. Refused, or any other answer..... Terminate
7. Which one of the following two statements best describes your level of interest in genetic testing? [Read response options “a” and “b” verbatim.]
- () a. I am generally interested in these kinds of tests.....
(Eligible for Group A) Go to Q9
 - () b. I am specifically interested in these kinds of tests because of the possibility of a health condition or disease that is in my family history.....
(Eligible for Group B) Continue to Q8
 - () c. Refused..... Terminate

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?”

8. What health conditions, genetically based-diseases, or other diseases are in your family history that make you interested in these kinds of tests?

[ALL POTENTIAL CONSUMERS]

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

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?

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?

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?”*

- 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)

- a. some high school..... Terminate
- b. High school diploma/GED..... Continue
- c. Some college or trade school..... Continue
- d. Bachelor’s degree..... Continue
- e. Master’s level degree..... Continue
- f. Doctoral level degree (JD, MD, PhD)..... Terminate
- g. Refuse, or any other answer..... Terminate

(Recruit a mix. Continue only if highest level of education is at least high school diploma/GED and less than a doctoral degree.)

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

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?”

(Recruit at least three Hispanic or Non-White participants to each focus group.)

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

|__|__| **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?

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

19. [DO NOT ASK. RECORD WHETHER RESPONDENT IS MALE OR FEMALE.]

() a. Female..... Continue

() b. Male..... Continue

(Recruit approximately half women and men)

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?”*

[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 \$75 as a thank you 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 _____

CELL PHONE _____ E-MAIL _____

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

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?”*

**Attachment B5:
Recruitment Screener
Personal Genomics and Genetic Testing Messages
Advocate Triad Discussions
August 2010**

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Project: Consumer Views on Genetic Testing
Locations: Remote sessions
Dates: TBD

Summary Table:

Group	Location	Date/Time	Audience
#1	Nationwide	TBD	Advocates
#2	Nationwide	TBD	Advocates
#3	Nationwide	TBD	Advocates

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?”*

Recruitment: Recruit 3 participants for each triad discussion.

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INTRODUCTION

Good morning/afternoon/evening. My name is _____, and I'm working with **[NAME OF FACILITY]** in **[LOCATION]**. I'm calling today on behalf of the National Cancer Institute or NCI. NCI is conducting a study on advocates' reactions to some information being developed for the general public on topics related to personal genomics and genetic testing. We are looking for people to take part in small discussion groups through a telephone conference call. We are hoping you or someone from your organization who works in communications, education, or outreach will be willing to view information on in draft form, and share thoughts on how we can make the information more useful.

We are not selling any products or services. Everyone who is eligible and participates will be **provided \$75** as a thank you for your time.

The discussion groups will be held on **[Dates]** and the conference call will last no more than one hour. 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. Do you have a few moments now to answer a few questions?

[If they do not have time now, ask if there is a time when they would be able to talk or a better phone number to use.]

When would be a better time for you? _____ **[Record and re-contact]**

- 1. Are you currently working as an advocate for a population who is likely to be interested in topics related to personal genomics and genetic testing?
 No **[Terminate]** _____
 Yes..... _____

(Recruit only advocates.)

- 2. And, can you confirm for me that you currently work at _____?
[Confirm the name of the organization where the participant works. We should know this in advance of contact.]
[Record confirmed organization] _____

- 3. What is your title or position at the organization where you work?
[Record position] _____

(Recruit only 1 participant from any given institution.)

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4. What special population, disease, or cause do you focus on in your advocacy work?

[Record advocacy focus] _____

5. How many years have you worked in advocacy for this special population, disease, or cause? **[Record years]** _____

6. Which of the following are a *regular* part of your job responsibilities? **[Read each response below and check all that apply.]**

- a. Communications (Internal or external)..... _____
- b. Patient education..... _____
- c. Outreach to patients..... _____

[Terminate if none of the above are checked.]

(Recruit participants whose job responsibilities *regularly* include communications, patient education, and/or outreach to patients)

7. How often over the past 6 months have you personally gone on the Internet to search for information related to your advocacy work? This includes any use of the Internet as a professional resource, for funding, or for product or treatment information.

Never / Not at all **[Terminate]** _____

Less than once a month **[Terminate]** _____

About once a month _____

Several times a month _____

Several times a week _____

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8. We are going to ask you to look at some material on your computer using GoToMeeting, a program that will let all of the people participating in the group discussion see the same thing. Will you have Internet access and be able to use this product while participating in the discussion?

Yes..... _____

Not Sure..... _____

No..... [Terminate] _____

(Recruit only those who will or may be able to use GoToMeeting)

9. Are you comfortable talking about issues related to personal genomics and genetic testing in a small group with other advocates?

Yes..... _____

No..... [Terminate] _____

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

10. Finally, in the past year have you participated in any market research or other projects where you discussed topics related to personal genomics and genetic testing?

No [Invite to group] _____

Yes [Terminate] _____

11. [DO NOT ASK. RECORD WHETHER RESPONDENT IS MALE OR FEMALE.]

Female..... _____

Male..... _____

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*****TERMINATE LANGUAGE:** “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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INVITE TO INTERVIEW

Thank you for answering my questions. As I mentioned, the National Cancer Institute is interested in learning more about advocates' reactions to some information being developed for the general public on topics related to personal genomics and genetic testing. We will also ask about the kinds of professional resources, web sites, collaborative tools, and patient education resources and materials you have found helpful in your work.

To compensate you for your time, you will be mailed a check for \$75 after participating in the discussion group. This is not a sales effort of any kind and no one will call on you as a result of your participation.

I would like to invite you to participate in a telephone discussion group with two or three other advocates and a moderator. The discussions will last about one hour. Groups are scheduled to take place on **[Date]** at **[Time]**, and you will need to be in front of a computer during the call. We will send you a meeting invitation using GoToMeeting. Can we schedule your participation?

Before we hang up, let me get the correct spelling of your name, your address so we can mail you your check, email address, and phone numbers so we can give you a reminder call the day of the group. You will receive an email today confirming your scheduled participation, along with the toll-free conference call-in information for the discussion. Prior to the discussion, we will send you an email with some information for you to refer to on the call. We will also send you a GoToMeeting test invitation. This will allow us to test out the connection before the actual discussion. When would be a good time for us to test the connection with you?

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CONTACT AND SCHEDULING INFORMATION

Name: _____

Address: _____

City: _____

State: _____

Zip Code: _____

Email: _____

Phone: (DAY) _____

(EVE) _____

(FAX) _____

(CELL) _____

Thanks again for your time and for agreeing to participate in a call.

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