

## ***Moderator's Guide***

### **Genetic Testing Consumer Focus Groups National Cancer Institute 10/1/08**

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- additional information about genetic testing for common diseases (in general and direct-to-consumer)?
4. What are the greatest benefits to consumers of genetic testing for common diseases (in general and direct-to-consumer)?
  5. What are the greatest barriers/concerns of consumers about genetic testing for common diseases (in general and direct-to-consumer)?
  6. What are consumers' expectations and/or experiences with the direct-to-consumer genetic testing for common diseases process and results?
  7. What kind of information on genetic testing for common diseases would consumers like the government (NIH) to provide to the American public (in general and direct-to-consumer)?
  8. What are consumer reactions to draft Web content on genetic testing for common diseases (in general and direct-to-consumer)?

#### **I. OPENING REMARKS AND INTRODUCTIONS [10 min]**

##### **A. Introduction and Purpose**

1. Hello and welcome. My name is \_\_\_\_\_ and I work for the Academy for Educational Development, or AED.
2. We're working with the National Cancer Institute, or NCI, on a project, and talking to people in several cities to find out what you think about genetic testing. We really want to hear about your thoughts and experiences so we can create some useful materials.

3. We appreciate you taking the time to talk with us today and share your opinions. Thank you for being here.

**B. Confidentiality and Process**

1. Before we get started, I'd like to tell you how groups like this usually work. First, you'll notice that we're taking notes as well as tape recording our conversation. The audio recording is to help us remember what you said, and the note-taking is a back up in case the recorders break.
2. None of the information that is written down and recorded will be connected to you in any way.
3. After we have written a report about all the opinions we have heard here and in other cities, the tapes and notes will be destroyed.
4. When we have groups like this, we usually set ground rules that we can all agree on. I'm going to show you some that may be important to you. Let me know if you have others to add.  
[POST LIST]
5. Can we agree on these ground rules? Are there any others you would like to add?

**GROUND RULES**

1. There are no right or wrong answers.
2. It's okay to disagree.
3. Each person's comments are important and valued.
4. One person speaks at a time.
5. Speak loudly and clearly.
6. Don't have to answer every question.
7. Please be honest and tell us how you really feel.

**C. Self-introductions**

1. First name, one of your favorite Web sites.

**I. KNOWLEDGE AND AWARENESS - OVERALL [20 min]**

- A. What do you think of when you read or hear the term “genetic testing”?
- B. What questions come to mind when you think about genetic testing?
- C. What do you think of when you read or hear about genetic testing that can tell a person what their risk is of getting certain common diseases, like different types of cancers, diabetes, or Alzheimer's Disease?
- D. What have you heard others saying (such as Web sites, newspapers, magazines, doctors, etc.) about genetic testing?
- E. What would make/what has made you want to get a genetic test to learn what your risk is of getting certain common diseases like these?
  - o What do/did you want to learn from this kind of test?
  - o What do/did you not want to learn?
  - o What disease or diseases are you most interested in learning your level of risk?
  - o Are there some diseases that you don't want to know what your risk is of getting them? Which ones?
- F. What would make you not want to get this kind of genetic test to learn what your risk is of getting certain diseases?
- G. How would/did you go about making the decision to either get a genetic test to learn your risk of getting certain diseases or not?
  - o What thoughts would be/were running through your mind?
  - o Would/did you talk to anyone about it? If so, why?
  - o Who would/did you talk to?
  - o What would/did you say to them?
- H. If you did get a genetic test to learn your risk of getting certain diseases, what would you be/were you worried or concerned about afterwards?
- I. Do you ever hear any words or phrases with regard to genetic testing that you don't understand? What are they?  
PROBE: genome, DNA, phenotype, gene scan, etc.
- J. If a person gets a genetic test to find out their risk for a disease, such as cancer, diabetes or Alzheimer's Disease, how should a physician be involved once that person gets their test results?

## II. KNOWLEDGE AND AWARENESS – DIRECT-TO-CONSUMER [5 min]

Throughout the rest of our discussion, we're going to talk about genetic testing services that are being offered by companies, usually through company Web sites, which people can purchase and have tests done without going through their physician. For the purposes of our discussion, we're going to refer to these kinds of genetic tests as "direct-to-consumer" tests, because the testing happens directly between the company and the person. The person's physician is not involved.

**[Note: Read "DTC" as "direct-to-consumer"]**

- A. What have you heard about DTC genetic testing services?
  - o Has the topic of this kind of genetic testing ever come up in conversations with your family, friends or coworkers? If so, what do you talk about?  
PROBE: reasons for doing it, benefits, risks, process, companies providing it
- B. As someone who has looked into/participated in this kind of genetic testing service, what is it that you most want(ed) to learn?
  - o For what reasons?
- C. What would cause/caused you to look into getting DTC genetic testing and not go through your doctor?

## III. INFORMATION SOURCES AND TRUSTED SOURCES [5 min]

- A. Where did you first hear about DTC genetic testing services?
- B. Has your physician ever mentioned DTC genetic testing? If so, what did he/she say?
  - o What was the conversation like?
  - o Did you or your doctor start the conversation?
- C. After you first heard about it, where did you get your information on DTC genetic testing?
- D. What makes you feel that the information you found or got about this kind of genetic testing is accurate?  
**[For Early Adopters, information learned before purchasing test]**
  - o If you don't think it's accurate, where would you look or go to get trusted information on this kind of genetic testing?  
PROBE: physician, government Web site, medical orgs

**IV. BARRIERS AND BENEFITS [10 min]**

A. As you were/are making the decision to either participate or not participate in DTC genetic testing, what concerns or worries did/do you have?

PROBE:

- Done by a company
- No physician input
- Effect on health insurance, future employment
- Fear
- Privacy
- Cost
- Ability to handle results
- Compared to getting it through your doctor
- Impact on/reactions from family members

B. How much would you be willing to pay for this kind of test?  
(out-of-pocket costs not covered by insurance)

C. What are the downsides of DTC genetic testing?

D. What are the benefits?

E. How would/did your test results affect your health decisions or life planning?

V. **[EARLY ADOPTERS ONLY] TESTING EXPERIENCE [10 min]**

- A. As someone who has done a DTC genetic test, what would you tell others about your experience?

PROBE: Process, test results, learning this information about yourself

- o If yes, would you recommend it others?
- o If you had the decision to make all over again, would you do it? Why, why not?
- o What, if anything, do you wish you had known before doing a DTC genetic test?

- B. Are you satisfied with your results?

- o What parts of your results were hard to understand?
- o Did you get your questions answered?
- o Who did you share your results with?

PROBE: doctor, family, friends, children

**[Need to add question about how they are interpreting their results]**

- C. Do you trust the results you received?

- o What is it about the company you used that makes you feel like you can trust your results?
- o What do you wish the company would have done so you could feel like you can trust your results?

- D. How did you use, or plan to use, your results?

PROBE: share with doctor, family, change lifestyle, seek healthcare, reproductive decisions

- E. Tell me about any positive or negative outcomes that resulted from you taking a DTC genetic test?

- o Positives
- o Negatives
- o Unexpected/unanticipated

## VI. INFORMATION NEEDS [5 min]

- A. What information does a person need about DTC genetic testing to make an informed decision to participate in the testing process?  
PROBE: what they can find out, how it works, cost, how to interpret results, security/confidentiality
- B. **[Rejectors only]**  
What information about DTC genetic testing did you get that made you decide not to participate in this kind of test?
- o Where did you get this information?
  - o What information might make you change your mind?
  - o What other factors might make you change your mind?  
PROBE: reduced cost, ADD OTHERS...
- C. **[Contemplators only]**  
What information about DTC genetic testing might help you make a decision to participate in this kind of test or not?
- o What other information might help you make a decision?
  - o What other factors might help you make a decision?  
PROBE: cost, confidentiality, security of information
- D. **[Early Adopters only]**  
What information about DTC genetic testing did you learn that made you decide to participate in this kind of test?
- o Where did you get this information?
  - o What other information helped you make your decision?
  - o What other factors helped you make your decision?  
PROBE: cost, what you wanted to learn (e.g., family history)
- E. What types of information are/were most helpful to you in making an informed decision about participating in DTC genetic testing?  
PROBE: statistics/facts, testimonials, visual/graphic depiction of information
- o What types of information do you think are still needed?
- F. What questions do you still have about DTC genetic testing?

## **VII. WEB CONTENT REACTIONS [10 min]**

Now, I'd like to show you an example of information that is being considered for a Web site about genetic testing services that are offered to people directly without having to go through their physician.

- A. What do you like about it?
  - o Layout/design
  - o Images
  - o Colors
  - o Types of information
- B. What don't you like about it?
- C. Of the information included, what is confusing or hard to understand?
- D. Which information would be most useful to someone thinking about getting DTC genetic testing?
- E. What would you improve or do differently?
- F. What is missing?
- G. If you knew this Web site existed, would you go to it for information on DTC genetic testing? Why/why not?

## **VIII. ROLE OF GOVERNMENT [5 min]**

- A. What kinds of information about genetic testing in general would you expect the government to provide?
- B. What information would you want to find on a government Web site about DTC genetic testing, specifically?
- C. How can government agencies help people make informed decisions about whether to participate in DTC genetic testing?

**IX. CLOSING REMARKS [5 min]**

- A. Thank you for helping us to learn more about what you think about genetic testing. We will be using your input to develop helpful information about this topic.
- B. Is there anything else you would like to tell us about anything we talked about today?
- C. Do you have any questions for me?
- D. Each of you will receive your gift for participating today as you leave the building.

**THANK YOU!**