

Moderator's Guide

Genetic Testing Consumer Focus Groups National Cancer Institute 11/7/08

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OVERARCHING RESEARCH QUESTIONS [For Moderator Use Only]

1. What are consumers' levels of knowledge and awareness of genetic testing (in general and direct-to-consumer) that provides a person with their risk of developing various diseases?
2. What additional information do consumers want to know about genetic testing for diseases (in general and direct-to-consumer)?
3. Through what channels and from what sources would consumers look for additional information about genetic testing for diseases (in general and direct-to-consumer)?
4. What are the greatest benefits to consumers of genetic testing for diseases (in general and direct-to-consumer)?
5. What are the greatest barriers/concerns of consumers about genetic testing for diseases (in general and direct-to-consumer)?
6. What are consumers' expectations and/or experiences with the direct-to-consumer genetic testing for diseases process and results?
7. What kind of information on genetic testing for 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 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.

II. KNOWLEDGE AND AWARENESS OF GENETIC TESTING [5 min]

- A. What do you think of when you read or hear the term “genetic testing”?
- B. What have you heard others say about genetic testing that can tell a person what their risk is of getting certain diseases, like different types of cancers, diabetes, or heart disease (not including pregnancy-related tests)?
PROBE: media, doctor, family, friends
- C. What kinds of genetic testing have you heard about that can tell a person what their risk is of getting certain diseases, like different types of cancers, diabetes, or heart disease (not including pregnancy-related tests)?
- o Have you heard about the kind of test (single gene test) that tests a person’s risk for getting one, specific disease, such as breast cancer? What have you heard about it?
 - o Have you heard about the kind of test that scans a person’s entire genetic make-up (genome scan) to determine a person’s risk for getting any number of diseases? What have you heard about it?
 - o Have you heard of what is sometimes called direct-to-consumer testing, where people can have genetic tests done on their own, through a company, without going through their doctor first? What have you heard about it?
- D. What questions do you have about genetic testing?
- o Are there words or phrases that you don’t understand? What are they? PROBE: genome, DNA, phenotype, gene scan, etc.

III. BENEFITS AND BARRIERS OF GENETIC TESTING [15 min]

[DOERS ONLY]

- A. What made you consider genetic testing?
- o What did you want to learn from this testing?
 - o What disease or diseases were you most interested in learning your level of risk?
 - o Were there some diseases that you did not want to know what your risk is of getting them? Which ones?
- B. Before doing it, what concerns or worries did you have about genetic testing?

PROBE:

- o Fear
- o Privacy of results/information
- o Cost
- o Effect on health insurance, future employment
- o Ability to handle results
- o Knowing what to do with results

- o Impact on/reactions from family members
 - o No required doctor involvement (in cases of direct-to-consumer testing)
- C. In general, how much do you think people understand the results of their genetic tests?
- o How much do you think people understand the likelihood of getting a specific disease?
 - o Do you think a doctor should be involved in the interpretation of test results? How?
- D. How did your test results affect your health decisions or life planning?

[CONTEMPLATORS ONLY]

- E. What made you consider genetic testing?
- o What would you want to learn from this testing?
 - o What disease or diseases would you most be interested in learning your level of risk?
 - o Are there some diseases that you do not want to know what your risk is of getting them? Which ones?
- F. What concerns or worries do you have about genetic testing?
PROBE:
- o Fear
 - o Privacy of results/information
 - o Cost
 - o Effect on health insurance, future employment
 - o Ability to handle results
 - o Knowing what to do with results
 - o Impact on/reactions from family members
 - o No required doctor involvement (in cases of direct-to-consumer testing)
- G. What has kept you from participating in genetic testing so far?
- o What would make you change your mind?
- H. How much would you be willing to pay for a genetic test? (out-of-pocket costs not covered by insurance)
- I. In general, how much do you think people understand the results of their genetic tests?
- o How much would someone understand the likelihood of getting a specific disease?
 - o Do you think a doctor should be involved in the interpretation of test results? How?

- J. How do you think the test results you might get from a genetic test would affect your health decisions or life planning?

[PRE-CONTEMPLATORS ONLY]

- K. What, if anything interests you personally about genetic testing?
- o What would you want to learn from this testing?
 - o What disease or diseases would you most be interested in learning your level of risk?
 - o Are there some diseases that you do not want to know what your risk is of getting them? Which ones?

- L. What concerns or worries would you have about genetic testing?
PROBE:

- o Fear
- o Privacy of results/information
- o Cost
- o Effect on health insurance, future employment
- o Ability to handle results
- o Knowing what to do with results
- o Impact on/reactions from family members
- o No required doctor involvement (in cases of direct-to-consumer testing)

- M. What might keep you from participating in genetic testing so far?

- o What might make you change your mind?

- N. How much might you be willing to pay for a genetic test? (out-of-pocket costs not covered by insurance)

- O. In general, how much do you think people understand the results of their genetic tests?

- o How much would someone understand the likelihood of getting a specific disease?
- o Do you think a doctor should be involved in the interpretation of test results? How?

- P. How do you think the test results you might get from a genetic test would affect your health decisions or life planning?

IV. GENETIC TESTING INFORMATION SOURCES AND NEEDS [20 min]

- A. Where would you go for information on genetic testing?

PROBE: doctor, Internet, family, friends

- o What kinds of thoughts [would run/went] through your mind as you searched for information?

- o What kind of information [would you be/were you] looking for?
PROBE: risks, benefits, process, how to interpret results, where to go to get tested, companies that provide it
- B. Has your doctor ever mentioned 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. Have you ever explored genetic testing services that are available online?
 - o Have you ever considered this kind of testing?
- D. What makes you feel that the information you found or got about genetic testing is accurate?
 - o If you don't think it's accurate, where would you look or go to get information you can trust about genetic testing?
PROBE: doctor, government Web site, medical orgs, patient advocacy groups
- E. What information does a person need about genetic testing to make an informed decision about whether to do it or not?
PROBE:
 - o What testing can and cannot tell you
 - o How it works
 - o Costs
 - o Risks
 - o Benefits
 - o How to interpret results
 - o Security/confidentiality

[CONTEMPLATORS ONLY]

- F. Of the information you found or received about genetic testing, what types have been most helpful to you?
PROBE: statistics/facts, testimonials, visual/graphic depiction of information
- G. What types of information are you still looking for or interested in seeing?

[CONTEMPLATORS AND PRE-CONTEMPLATORS ONLY]

- H. Where would you go to get genetic testing if you decided to do it?
PROBE: doctor's office, online company

[DOERS ONLY]

- I. Of the information you found or received about genetic testing, what types of were most helpful to you in making the decision to get genetic testing?
PROBE: statistics/facts, testimonials, visual/graphic depiction of information
- J. What types of information do you think are still needed?

K. Where did you go to get genetic testing?

V. TESTING EXPERIENCE [10 min]

[DOERS ONLY]

A. As someone who has participated in genetic testing, what would you tell others about your experience?

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

- 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 were told before doing a genetic test?
- o Would you recommend it to others? What would you tell them?

B. Tell me about any positive or negative outcomes that resulted from you participating in genetic testing?

- o Positives
- o Negatives
- o Unexpected/unanticipated

C. How did you feel when you got your results?

- o Did you understand them?
- o Did you get your questions answered?
- o Who did you share your results with?
PROBE: doctor, family, friends, children
- o How did you use, or do you plan to use, your results?
PROBE: share with doctor, family, change lifestyle, seek healthcare, reproductive decisions

VI. DIRECT-TO-CONSUMER GENETIC TESTING [10 min]

We've talked a little bit already about genetic testing services that are offered by companies, usually through company Web sites, which people (consumers) can purchase and have tests done on their own, without going through their doctor first. For the purposes of the next few questions, we're going to refer to this kind of genetic testing as "direct-to-consumer" testing, because the testing happens directly between the company and the person.

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

A. What have you heard about DTC genetic testing?

- o Are you familiar with any companies that offer DTC genetic testing?
Which ones?
- B. What would cause you to consider DTC genetic testing as opposed to genetic testing that is done through your doctor?
- C. What are the downsides of DTC genetic testing?
PROBE: privacy of information, no required doctor involvement, lack of ability to interpret results, etc.
- D. What are the benefits of this kind of genetic testing?
- E. What do you think people would do with the information they received from DTC genetic testing?
 - o How likely do you think it is that people would share their test results with their doctor?
 - o If you found out that you were very likely to get a disease based on DTC testing, what would you do with that information?
PROBE: consult doctor
- G. What questions do you have about DTC genetic testing?

VII. WEB SITE REACTIONS [10 min]

Now, I'd like to show you some information and features for a Web site that is being considered about genetic testing, to get your reactions and feedback.

- A. What do you think about the topics of information included on the Web site?
 - o Could this Web site answer peoples' questions about genetic testing?
Why or why not?
 - o What is missing?
- B. What features would be helpful to have on a Web site about genetic testing?
PROBE: expert interviews, video blog, chat room, etc.
- C. What would you improve or do differently?
- D. If you knew this Web site existed, would you go to it for information on genetic testing? Why/why not?

VIII. ROLE OF GOVERNMENT [5 min]

- A. What kinds of information about genetic testing would you expect the government to provide?
- B. What information would you want to find on a government Web site about genetic testing? What about for DTC genetic testing, specifically?

- C. How can government agencies help people make informed decisions about whether to participate in 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!