National Cancer Institute

# Perceptions of Genetic Testing Today: Findings from Focus Groups with the Public and Interviews with Physicians

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## Purpose

- Understand knowledge, attitudes, perceptions, opinions, and interest in genetic testing among:
  - Consumers
  - Primary care physicians
- Inform the development of a government Web site that would provide information about genetic testing for common disease

## Methods & Audiences

- Focus Groups with Consumers
  - Perceived risk of inheriting a genetic disease
    - Normal
    - Heightened
  - Stage of change
    - Precontemplators
    - Contemplators
    - “Doers”
- In-depth Interviews with Physicians

## Findings

### Public

- Wide range of knowledge and understanding about genetic testing
- Many do not want to know risk of getting certain diseases if no treatment or cure
- Some said they would want to know their risk for certain diseases, particularly those with a specific family history of disease
- Most concerned about privacy and confidentiality of test results, particularly with insurance companies and employers
- Most think trained health professional needs to be involved in interpretation of test results
- Nearly all “doers” got tested to find out their risk for specific disease, based on family history
- Expect to find a lot of information on a government Web site

## Findings (continued)

### Physicians

- Most reported the topic of genetic testing does not come up frequently in their practices
- A few had patients come to them for help interpreting genetic test results, including results from a “direct-to-consumer” company
- Agree that patients do not understand the probability aspect of developing a genetically-based condition
- Recommend that patient information about genetic testing be practical rather than technical
- Many feel they do not know enough about the kinds of genetic tests that are available to the public
- Most are skeptical about the value of genetic testing to their practice
- Agree that NIH has an important role in providing information on genetic testing, but opinions varied about how to provide it

## Recommendations

- Web site, and any other planned informational materials, should include basic and practical introduction to genetic testing
- Clearly acknowledge site’s expected audiences and consider organizing content around their corresponding information needs
- Conduct usability testing on the Web site to determine whether users can find information they want
- Explain “direct-to-consumer” testing in clear, unbiased terms that consumers can understand
- Include information about genetic counseling on site, and why it may be helpful both before and after making a decision to get genetic testing
- Include Web content specifically for physicians