

Consumer Interest in Health & Genomic Information

prepared for:

Personalized Health
Care Initiative Workshop

July 7, 2008

Yankelovich Syndicated Sources

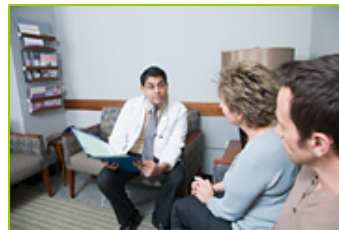
- 2007 Multinational Health and Wellness Study
 - 22,000 respondents (6000 US), 17 countries
 - Short form and database linkage
- 2006 Food For Life
 - 3,000 U.S. adults 18+
- 2007 Yankelovich MONITOR
 - 4,500 respondents, 38 years of consumer trends/values tracking
- 2007 & 2008 Health Security Index (CHW)
 - 2,000 U.S. adults
- 2008 Motivating Health Behavior Change
 - In process

- In addition, Yankelovich conducted a series of one-on-one in-depth interviews on the topic of consumer genomics (June 2008). Participants represented a diverse sample of individuals of different ages, educational and economic backgrounds.

Genetic Testing and Today's Health Consumers

- Many different voices
- Key consumer health trends
- Overall, familiarity with concept is limited
- Consumers are interested, but skeptical
- What does my doctor say?

Make it Relevant: Different People, Different Voices



LIVING Well Segments

Leading the Way
10%

"Health and wellness are important to me and I am doing everything I can to be healthy now and in the future."

In It For Fun
21%

"I am healthy because I lead a very active lifestyle. But for me it's not about being healthy. I just enjoy exercise and love physical competition."

Value Independence
15%

"I would like to be healthier, but I think doctors and modern medicine are overrated. I can figure out the best diet and exercise plan for me. The doctor is important but is not my first line of attack in the battle for wellness."

I Need a Plan
17%

"I know what I should do to be healthy, but I just don't have the will power to follow through. I need someone to give me a plan, and I rely heavily on my doctor."

Not Right Now
23%

"I drink too much and exercise too little -and so far I don't have any serious health problems. Disease is what happens to other people. Why worry or change?"

Get Through The Day
15%

"I'm in poor health, which makes it tough to exercise. I don't see the point, anyway - my health is out of my hands. I have tried and failed in the past."

A Few Key Health Trends to Watch

- **Evolving Health Mindset**
 - The wellness revolution: The masking of physical reality
 - It's not about the disease...
- **Home as Health Center**
 - The rise and needs of the multigenerational caregiver
- **Diagnose Me**
 - From information to tools
 - Web-based/In-home diagnostics
- **Self Invention**
 - Personalized Medicine/Health

Key Health Trends

- Consumers use the Internet as a source of health information to:
 - Self-diagnose
 - Prompt or supplement HCP info
 - Purchase medical products and devices

Reasons for Using the Internet as a Source for Health Information	
<i>Weighted Base: Use Internet as a source for health information</i>	Total US
To research a specific disease/illness	71%
To try to diagnose symptoms I am having	48%
To stay current on new developments in healthcare	42%
Curiosity	40%
To get a better understanding of something my health care professional told me	38%
To find information to help a friend or family member	36%
To find alternative medicines/ remedies	30%
To compare information across several sources	27%
I saw a health story in a magazine or newspaper and wanted to get more information	22%
To get information to take to my health care professional	22%
To find health care providers	12%
To find a medical device	12%
To find new drugs	11%

*2007 Multinational Health & Wellness Study

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Table of Contents/Qualitative Research

	<u>Page</u>
I. Background, Objectives & Methodology	9
II. Key Takeaways	13
III. Detailed Findings	16
1. Awareness & Understanding of Genetic Testing	16
2. Personal Interest in Genetic Testing	28
3. Concerns about Genetic Testing	32
IV. Future Research Directions	34

Background, Objectives & Methodology

Background

- The Department of Health and Human Services (HHS), Office of the Assistant Secretary for Planning and Evaluation (ASPE) is holding a workshop called “Understanding the Interest and Needs of Consumers in the Use of Genome-based Health Information Services” to discuss consumer demand for an interest in services that provide genetic testing/screening.
- This workshop will include major stakeholders in the field of genomics, including clinicians, genetic counselors, and consumer advocates. In order to provide specific consumer response to this issue, TSC a division of Yankelovich conducted qualitative primary research on the topic.

Objectives

In a qualitative fashion, the research answers the following key questions related to attitudes toward genetic testing among consumers:

- **Awareness & Understanding of Genetic Testing**
 - What do consumers know about genetic testing?
 - How do they define genetic testing?
 - What words/concepts do they associate with the concept?
 - Is their overall evaluation of genetic testing positive or negative?
 - In what circumstances do they see genetic testing being used?
 - Who wants/needs testing? Why? Where?
 - How knowledgeable are they about online genetic testing sites?
- **Personal Interest in Genetic Testing**
 - What is the level of personal interest in testing?
 - And why?
 - How would they react to positive/negative results?
- **Concerns about Genetic Testing**
 - What are the biggest concerns consumers have about genetic testing?

Methodology

- **Interview Format:** 90-minute in-depth interviews with consumers
- **Sample:** Total of 9 consumers interviewed
 - Interviews were conducted in Raleigh, NC on June 25, 2008.
 - A diverse group of consumers (age, gender, education, HH income) were interviewed
- **Qualitative Research Caveat**
 - As with all qualitative research, these findings are based on a limited number of consumers. No assurances can be made that their attitudes and behaviors are projectable to the US population of consumers.
 - Accordingly, the use of the terms "many," "majority," "some," etc. in this report should be interpreted directionally, with the understanding that they are descriptive of the study sample.

Key Takeaways

Key Takeaways

- Familiarity with the concept of genetic testing is limited.
 - The majority of consumers say they have heard of genetic testing, but do not know much about it.
 - Most can provide a definition for genetic testing, but aren't sure what it involves, how the information is used, what the results would look like, or how much it would cost.
 - For many, they have neutral opinions about the genetic testing because they feel they don't know enough to fully evaluate it.
 - Consumers are largely unaware genetic testing information companies exist that provide services via the Internet.
- The healthcare professional is desired - and assumed to be - involved in the information gathering, testing and analysis processes.
- Most consumers say they would consider genetic testing, especially for conditions where they could affect their future risk by taking action.

Key Takeaways

- Though most are able to define *what* genetic testing is, consumer knowledge drops off around *how* genetic testing information is used.

- Most are open to genetic tests being performed, but have concerns about “what happens next?”

Hopes

Understanding disease risk

Taking preventive steps

Planning for the future

Concerns

Ability to understand results

-Delivery of information

-Interpretation/explanation of results

Actions taken after testing

-Risk of discrimination

-Religious/Ethical decisions (e.g., abortion)

*2008 HHS One-on-One Interviews/Raleigh, NC

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Detailed Findings

Awareness & Understanding of Genetic Testing

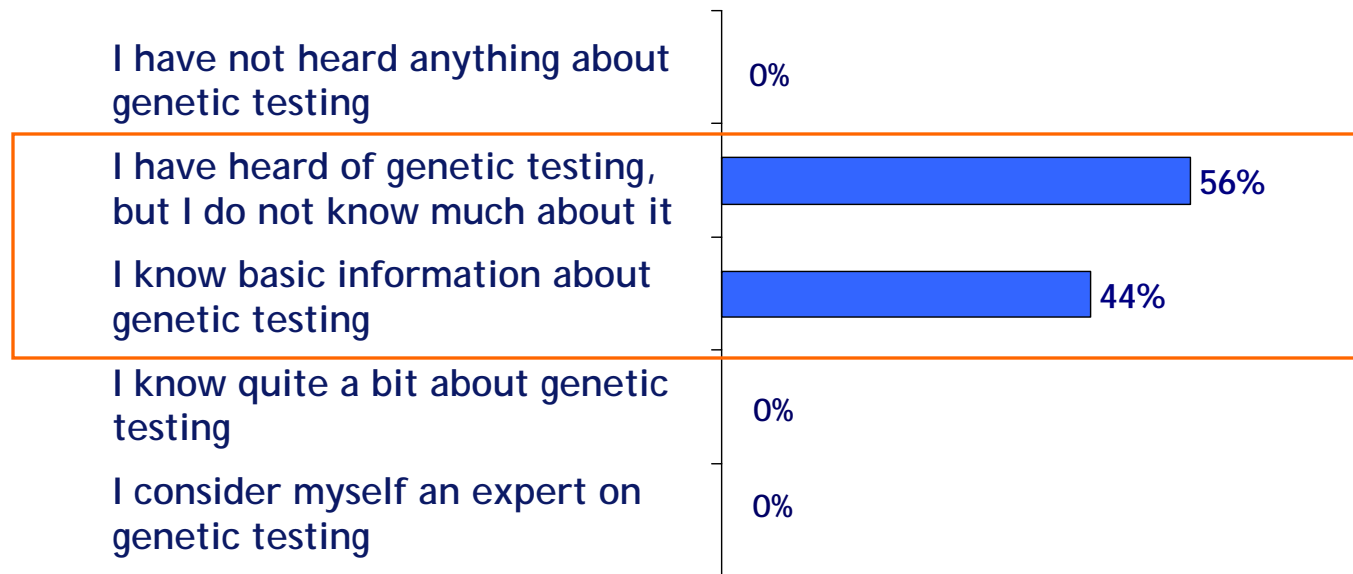
Personal Interest in Genetic Testing

Concerns about Genetic Testing

Familiarity with Genetic Testing

- Consumers have heard of genetic testing, but feel their knowledge is limited.

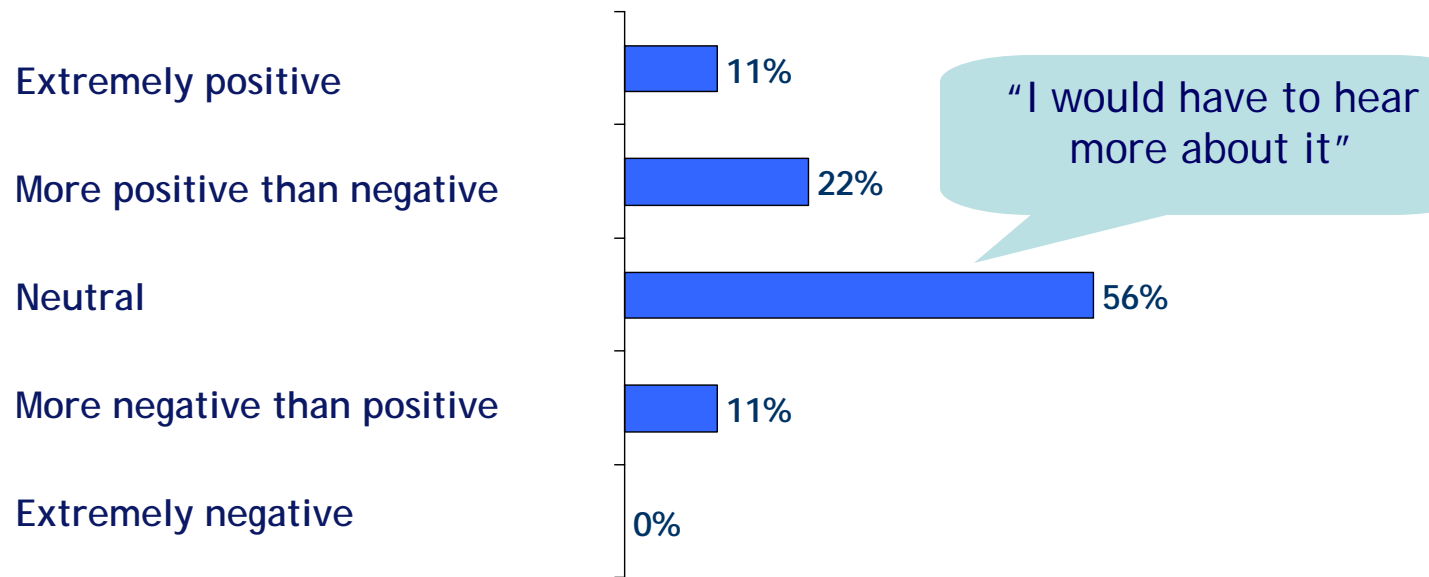
Which of the following statements best describes how much you know about genetic testing?



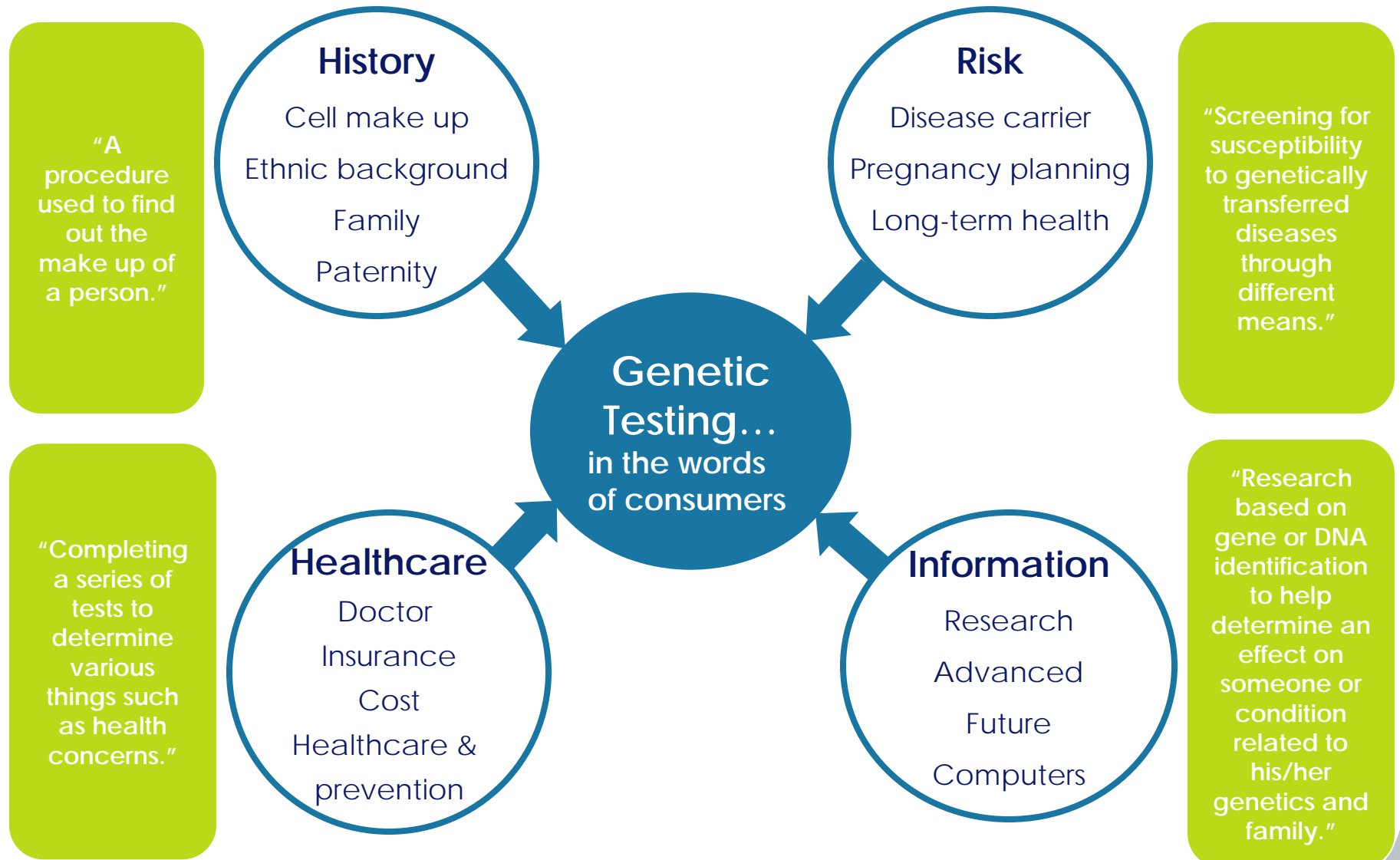
Feelings Toward Genetic Testing

- Many consumers say their overall feelings about genetic testing are neutral, largely because they don't know enough about it to have an informed opinion.

How would you rate your feelings about genetic testing overall?



Familiarity: What is Genetic Testing?



Familiarity: Who....Why....Where?

Who is likely to get genetic testing?

- Everyone (if possible)
- Everybody
- Children, parents, and grandchildren
- Anyone interested in finding or helping cure diseases
- People who suspect they have susceptibility of disease
- People with a bad medical history
- People with conditions that can't be diagnosed
- Overweight man or woman
- Babies and children
- Children
- Couples
- Prospective parents
- Pregnant women
- People who can't get pregnant

Why do they need genetic testing?

- To prevent future disease or lessen negative outcome of disease
- To know if and what chance of having a baby with a disease
- To plan a pregnancy
- Suspicion of likelihood of disease
- Better health for you and your family
- Know how much time you have
- Prevention
- If predisposed to disease with family history
- Future research to help others
- Advances in medicine

Where do they go to have it done, and by whom?

- Doctor's office
- Hospital
- University hospital
- Specialist
- DNA lab
- Overseas
- Approved facility

Familiarity: Direct-to-Consumer Services

- None of the participants in this study were aware that they could currently purchase genetic testing from an online company.
 - One respondent, though, was not surprised because “you can buy everything else online”.
 - They also had no idea about cost for the test, with estimates ranging from \$20 to \$2500 for testing for one disease.
- Most were skeptical of the accuracy of the test
 - Worrying that their test would get mixed up with someone else’s
- While most consumers said they would consider having the test done online, they remained skeptical
 - And all said that if the online test came back positive they would go to the doctor to take another test
- All consumers also said that they would take their results to their doctor for interpretation

Perceived Benefits of Genetic Testing

- Consumers say that genetic testing is valuable because it provides information about their health, and gives them the opportunity to seek treatment.
- In contrast, a negative test result is not the end of the story. Many said that just because a test is negative does not mean that you shouldn't continue to have screenings and check-ups because "the tests are not a guarantee - you could still get the disease"

"Genetic testing is valuable because..."

Mean, with scale: 1 (Strongly Disagree) to 6 (Strongly Agree)

It can provide relief from uncertainty about the risk of getting a disease (you know your risk)

4.9

A negative test result can eliminate the need for unnecessary checkups and screening tests

2.8

A positive result can direct a person toward available prevention, monitoring and treatment options.

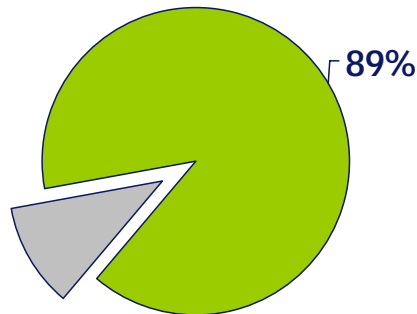
5.4

Knowledge about Test Meaning

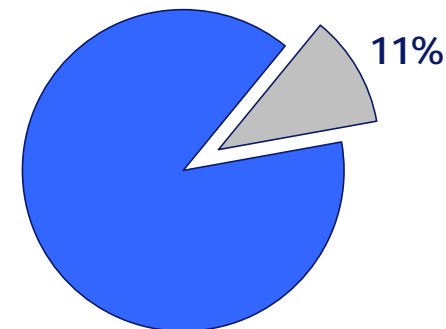
- Most consumers understand that genetic testing will tell them their risk level of developing a disease rather than a certainty of developing that disease.

If you have genetic testing for cancer - which of the following describes what the test will tell you?

Whether I will have a higher than average risk of developing cancer in the future



Whether I will definitely get cancer in the future

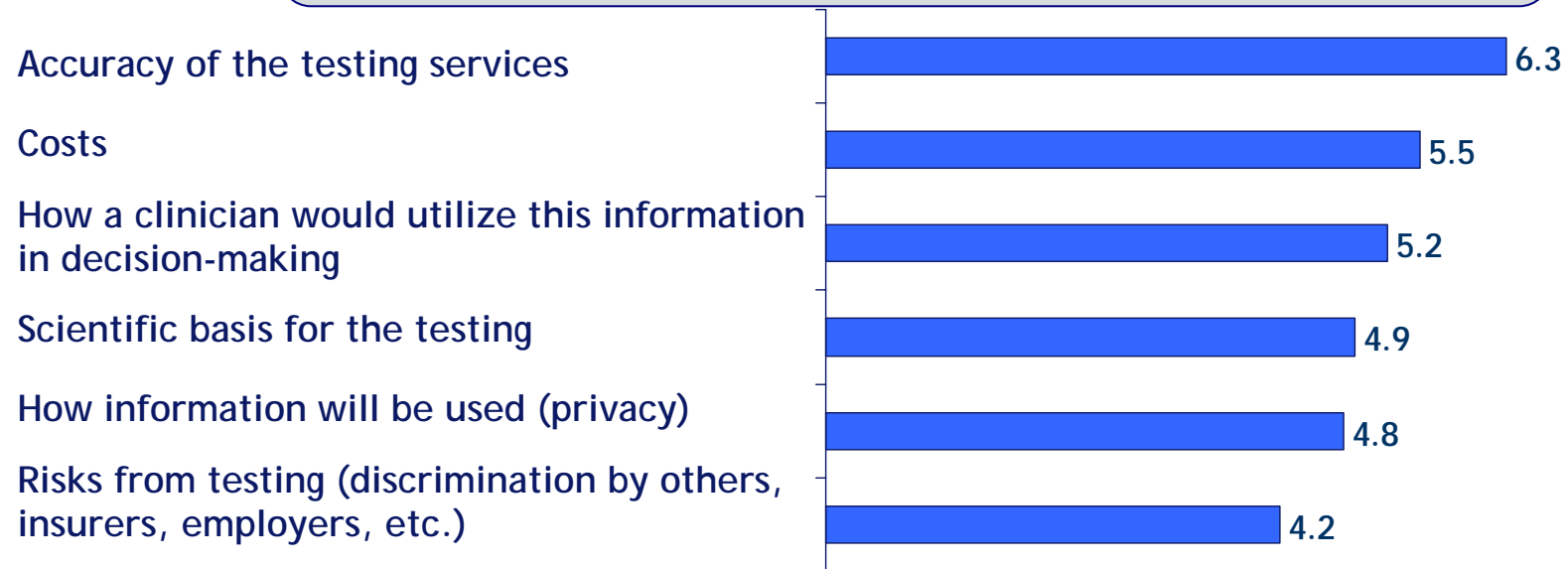


Desired Information Before Testing

- Above all, the accuracy of the test was the most important information for consumers.
- Consumers also wanted to know about basic logistics of the test - what is the process? Where would I go for the test? How much time would it take? What would it involve?

If you were looking for information on genetic testing, how important is each of the following types of information to you?

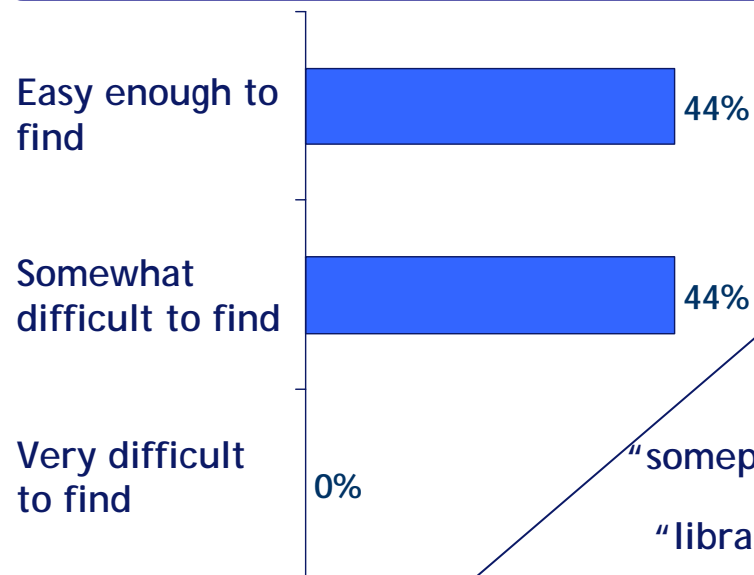
Mean, with scale: 1(Not at all important) to 7 (Extremely important)



Information about Genetic Testing

- Most consumers believe that information on genetic testing is out there, and their go-to sources for information would be the Internet or their doctor.

When it comes to finding information that would help consumers use genetic information to improve their health, do think such information is:



Where would you go to find information about genetic testing?*

“the Internet”

“a reliable approved website” “WebMD”

“NIH website” “Google search”

“someplace that is not trying to profit” **“my regular doctor”**

“library”

“a college, university, or other non-biased source”

*note: size of lettering reflects more mentions, such that the Internet, with largest font, was most often mentioned.

Information Sources

- Consumers believe that doctors, other medical professionals and genetic counselors should be involved in developing public information about genetic testing.
- In contrast, most consumers did not expect (or want) the government to be involved in developing information.
 - However, if asked whether the FDA should be involved they were somewhat more open to the possibility.
 - The concept of “government” did not elicit favorable reactions.

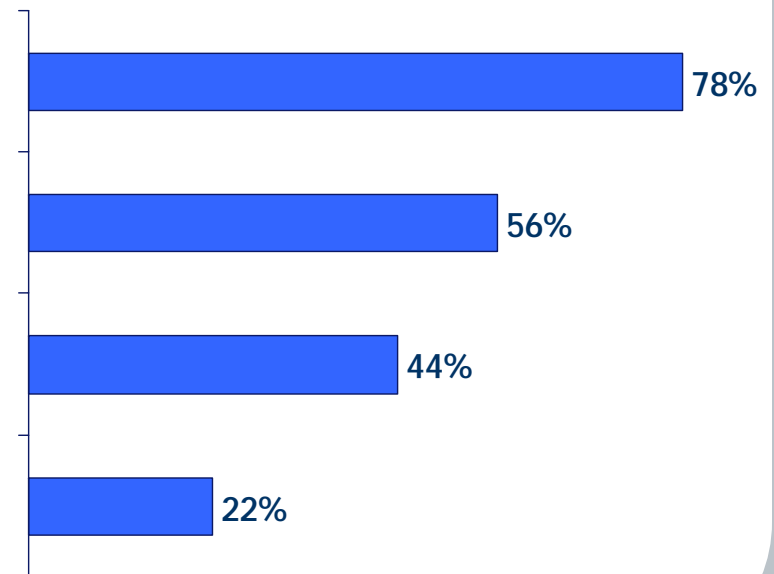
Which of the following sources should be responsible for helping consumers by developing public information about genetic testing?

Doctors & other medical professionals

Genetic counselors

Companies that provide genetic health information services

The government*



Regulation & Industry Standards for Testing

- Consumers wanted a “reputable organization” to create an industry standard to help consumers identify which companies were trustworthy for genetic testing
- The organizations mentioned included:
 - FDA
 - AMA
 - Independent group of doctors
 - Well-known medical journal
 - “I would trust medical professionals more than the government”

Detailed Findings

Awareness & Understanding of Genetic Testing

Personal Interest in Genetic Testing

Concerns about Genetic Testing

Personal Interest in Genetic Testing

- Consumers want to know about their disease risk, particularly if they could take steps to lower their risk.
 - While interest was lower for learning risk for diseases for which there was no action, the majority were still interested.
 - Interest was lowest in non-health related information.

Which of the following types of personal genetic information would you be interested in?: Information that tells you...

Your risk for a specific disease (with or without your doctor knowing) 89%

Your risk for a disease that you could do something about - that is, by knowing that you are at risk you could alter the onset of the disease by using a medical intervention or making lifestyle changes 100%

Your risk for a disease you could not do something about - that is, even knowing your risk you could not do anything to change your risk level, but it might influence your life decisions (such as having children or retirement planning) 67%

Your ancient ancestors (which portion of your DNA that came from a particular region of the world) 44%

Your physical traits (such as eye and hair color, type of earwax, height, caffeine metabolism, baldness, or odor detection) 67%

Personal Interest in Genetic Testing

- Consumers were most interested in personal testing for cancer and heart disease.
 - The general sentiment was that they would want testing for more “serious” diseases.
 - In contrast, few saw need for testing for obesity because it was “about personal control” and “I can just look at myself to know”
- None of the participants in this study had undergone genetic testing for any reason, though several knew children who had been tested.

Which of the following health conditions would you consider getting genetic testing for (or have you been tested for) in order to determine if you are at increased risk?

Cancer	100%
Heart disease	78%
Diabetes	67%
Alzheimer's	44%
A mental health condition (e.g., depression)	22%
Obesity	22%

Genetic Testing & Family

- Consumers say they would want to share genetic testing information with family members if those individuals might be at risk
- Likewise, they would want family members to tell them if they discovered an above-average risk.

Mean, with scale: 1 (Strongly Disagree) to 6 (Strongly Agree)

If I took a genetic test and discovered I had a higher-than-normal genetic risk for a disease, I would tell my family because they might have the same risk.

5.3

If a family member discovered that they had a higher-than-normal genetic risk, I would want them to tell me.

5.7

Detailed Findings

Awareness & Understanding of Genetic Testing

Personal Interest in Genetic Testing

Concerns about Genetic Testing

Concerns about Genetic Testing

How concerned are you about each of the following aspects of genetic testing?

Mean on scale: 1 (Not at all concerned) to 6 (Extremely concerned)

Having standards and quality control measures available when interpreting genetic test results	5.3
The ability for people to understand the results of their genetic tests	5.1
The potential for discrimination for those who have higher-than-average risk for particular health conditions (e.g., by insurers, employers, courts, schools, adoption agencies, and the military, among others)	4.9
The ability for healthcare providers (e.g., doctors, nurses, etc.) to understand the results of genetic tests	4.9
Fairness in access to genetic services (e.g., if cost is high then services may not be affordable to all)	4.9
The usefulness of genetic information (e.g., the ability to use the information to improve medical care)	4.8
The impact it would have on a person who learns they have a higher-than-average risk for a health condition that cannot be medically treated	4.8
Privacy and confidentiality issues related to finding out my personal genetic information	4.7
The impact it would have on how a person feels about him/herself (by knowing their risk levels)	4.2
The impact it would have on how others in society may feel about a person (by knowing their risk levels)	4.1
Effects of genetic testing on people's reproductive choices (i.e., they may choose not to have children if they are predisposed to certain health conditions)	4.0

Future Directions for Research

Future Directions for Research

Consumer-oriented research

- Segmentation to identify high-targeted audiences for genetic testing
 - Including prime prospect analysis
 - And to identify what makes consumers more/less likely to undergo genetic testing
- Test around the information delivery
 - What information will be conveyed, language and/or numbers used, etc.
 - Follow-up based on results
- Price-elasticity
 - How much would consumers be willing to pay for the test?
 - When is it no longer “worth it”?

HCP-oriented research

- To determine characteristics of strongest proponents of genetic testing
- Concept positioning for HCPs/How to engage HCPs as the consumer sees them as integral to the process

Thank You

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