



Views on Genetic Testing: An AARP Bulletin Survey

Conducted for the AARP Bulletin

September 2010



Views on Genetic Testing: An AARP Bulletin Survey

Report written by

Helen W. Brown
Strategic Issues Research
Research and Strategic Analysis

Survey conducted by
GfK Roper Custom Research North America

© Copyright AARP
Reprinting with permission
601 E St. NW
Washington, D.C 20049
www.aarp.org

September 2010

AARP is a nonprofit, nonpartisan membership organization that helps people 50+ have independence, choice and control in ways that are beneficial and affordable to them and society as a whole. AARP does not endorse candidates for public office or make contributions to either political campaigns or candidates. We produce AARP The Magazine, the definitive voice for 50+ Americans and the world's largest-circulation magazine with over 35.7 million readers; AARP Bulletin, the go-to news source for AARP's millions of members and Americans 50+; AARP VIVA, the only bilingual U.S. publication dedicated exclusively to the 50+ Hispanic community; and our website, AARP.org. AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. We have staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

Acknowledgements

The author would like to thank GfK Roper Custom Research North America for conducting the survey, and Jennifer Leslie and Mary Ann Nguyn for reviewing the report. For additional information contact the author, Helen Brown at 202-434-6172.

INTRODUCTION

In June 2000, scientists joined then U.S. President Clinton at the White House to unveil the Human Genome Project's "working draft" of the full set of DNA that makes us human. The complete set of some 30,000 to 40,000 genes is called the human genome. In this tenth year anniversary of the project, experts are hailing its accomplishments to date and predicting that future advances will revolutionize the diagnosis, prevention, and treatment of most, if not all, human disease. For example, already, genome profiles have begun to enable individuals to know diseases and conditions that they are at risk of developing and to be able to individualize their preventative medicine plans.

While the scientific community is enthusiastic about the prospect that as a result of the Human Genome Project, everyone will be able to have access to vast amounts of information about his or her own genetic makeup, the extent to which the general public shares this interest and enthusiasm is not clear. Thus, the *AARP Bulletin* commissioned GfK Roper North America to conduct a survey of Americans that focused on genetic testing. The survey included questions to gain insight on perspectives and views regarding learning about one's own genetic structure, and on attitudes about the use of one's genetic information. This paper reports the results of interviews conducted from July 23 – 25, 2010 with a total 1,000 interviews completed with approximately 500 female and 500 male respondents ages 18 years and older. The margin of error for the weighted data is +/- 3 percentage points for the full sample.

OVERALL RESULTS

The findings, overall, for this *AARP Bulletin* survey are as follows:

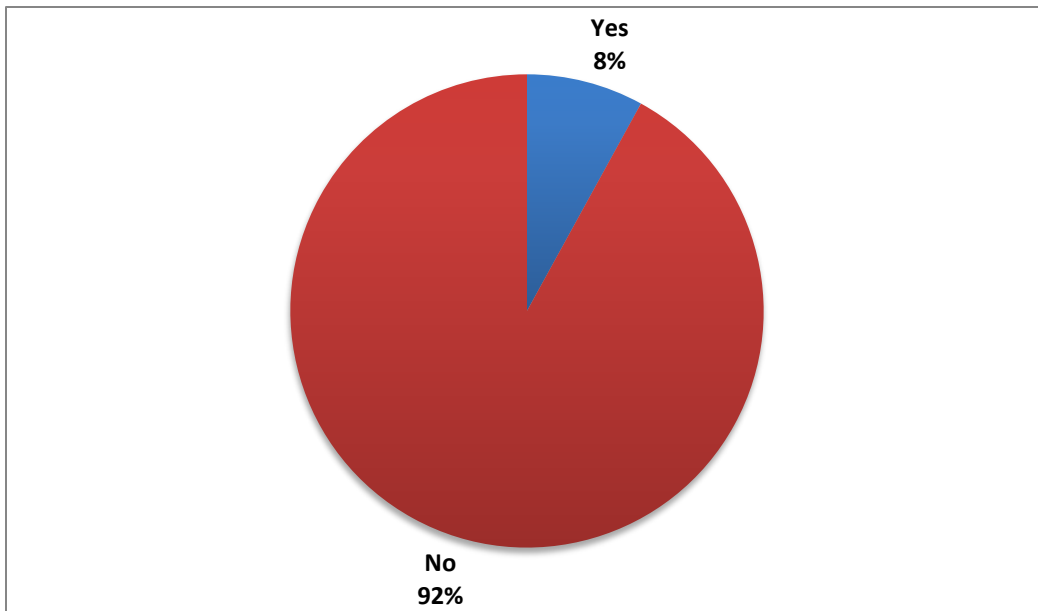
- Most adults have never undergone any type of genetic testing
- Most have never given any thought to undergoing genetic testing
- Most would not consider undergoing genetic testing to find if they are susceptible to a disease
- About two thirds of the respondents would make one or more change if a genetic test showed they could live to be 100 years old; most often the changes are they would take better care of themselves and save more money

DETAILED FINDINGS

Prevalence of Genetic Testing

Figure 1 shows that the vast majority of the respondents (92%) have never undergone any type of genetic testing. Of those who have had a genetic test (8%), the largest share is age 65 and older (11%) compared to individuals age 50 to 64 years (5%).

Figure 1
Percentage Who Have Ever Undergone any Type of Genetic Testing
Base: All respondents (Weighted N=1,000)



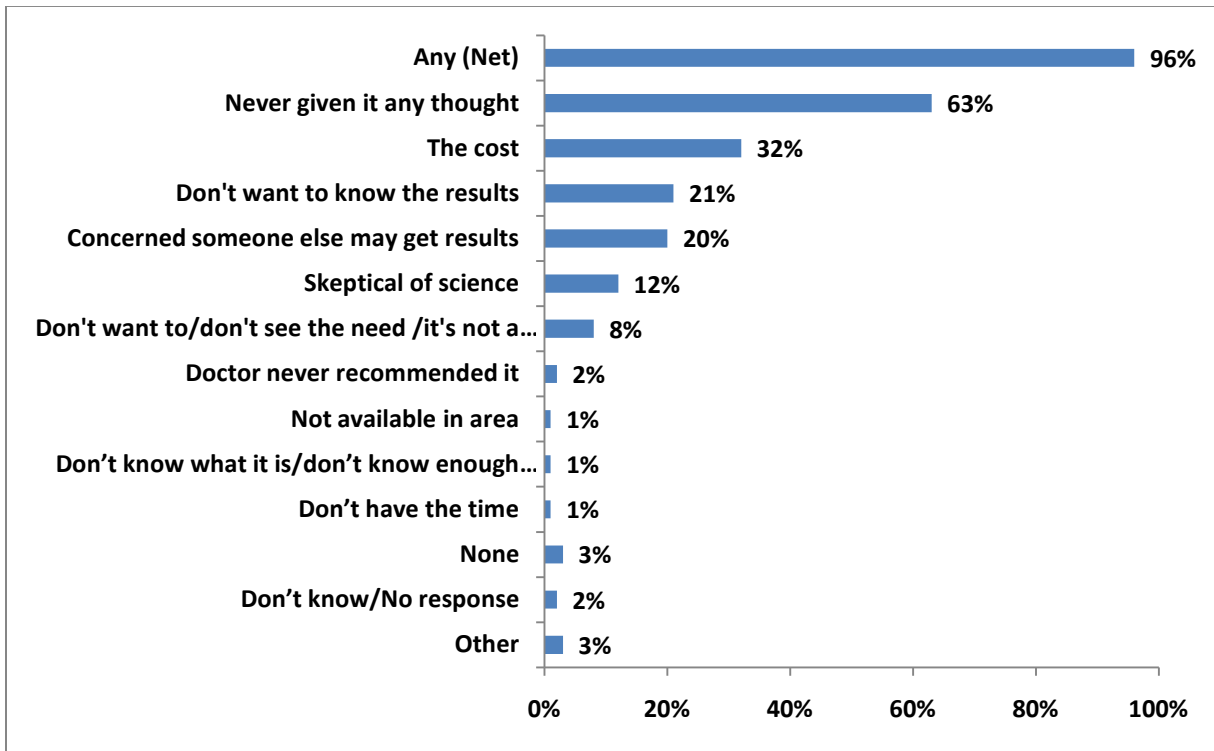
Source: Views on Genetic Testing: An AARP Bulletin Survey, September 2010.

Why Respondents Have Not Undergone Genetic Testing

The respondents who have never been tested were read eight reasons why one may not have been tested and asked to indicate which ones were their reasons for not being tested. As Figure 2 shows, more than 10 percent identified the following reasons:

- 63% they had never given it any thought
- 32% the cost
- 21% they did not want to know the results
- 20% concerned that someone else may get the results
- 12% skeptical of science

Figure 2
Reason for Having Never Been Tested
 Base: Respondents who have never had a genetic test (N=921)



Source: Views on Genetic Testing: An *AARP Bulletin* Survey, September 2010.

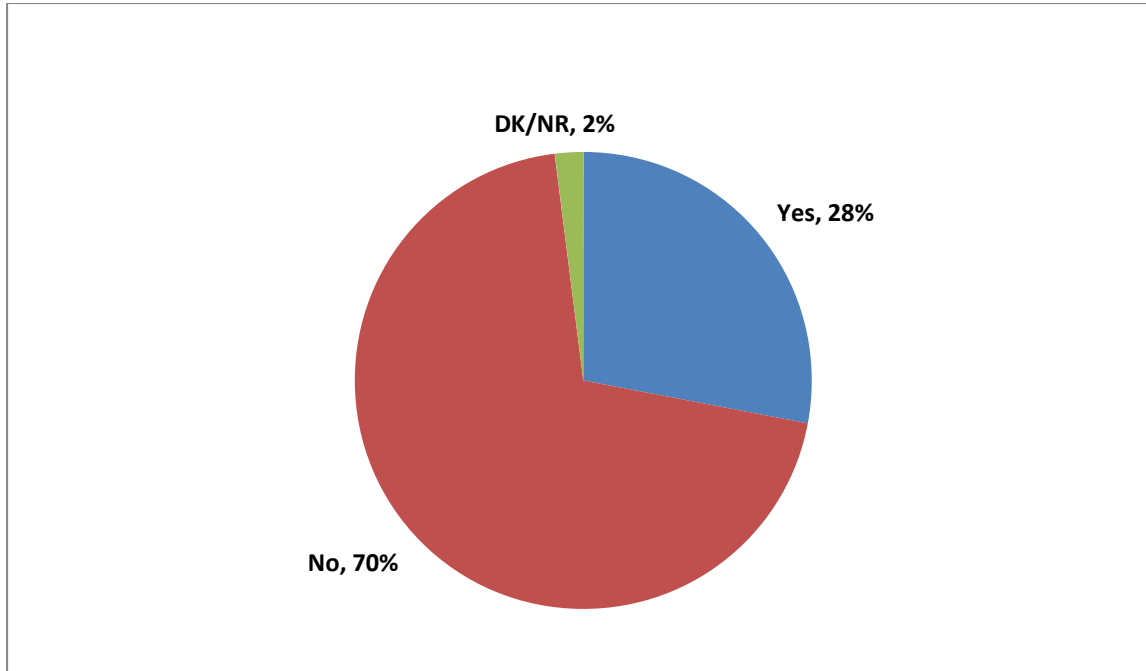
Genetic Profile to Learn Susceptible to Disease

While a large majority had not had any type of genetic testing, about a third (29%) of the respondents would consider having their genetic profile analyzed to learn if they are susceptible to diseases such as Alzheimer's, cancer, or diabetes.

Figure 3

**Percentage Who Would Consider Having Their Genetic Profile
to Learn If Susceptible to Disease**

Base: All respondents (N=1,000)



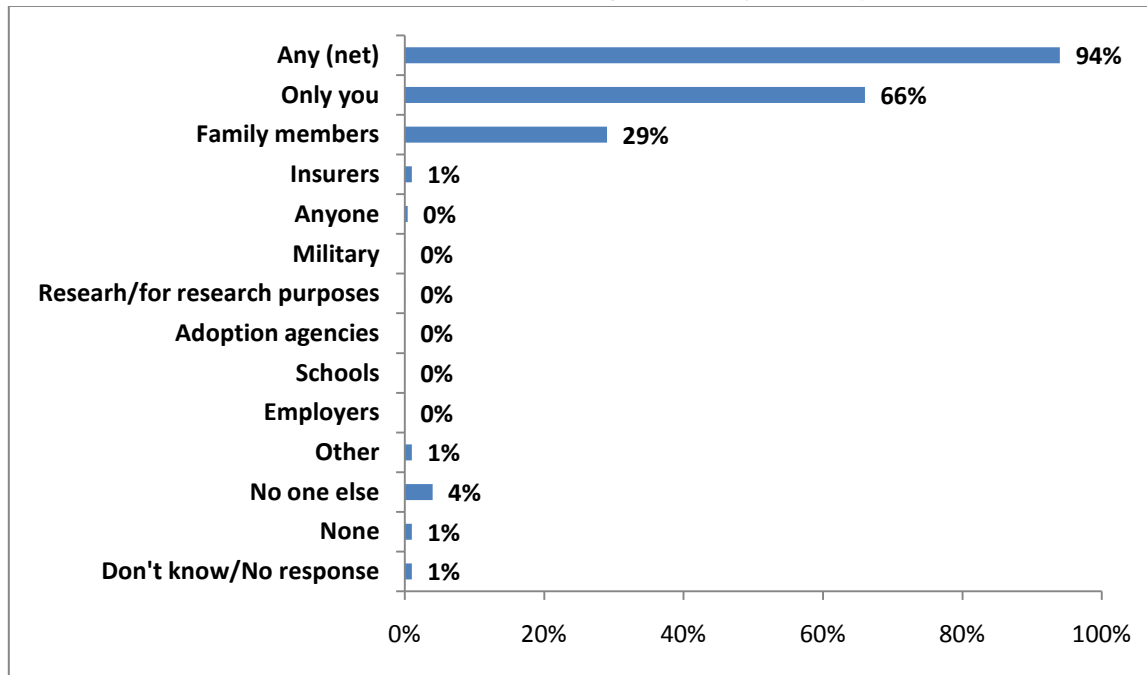
Source: Views on Genetic Testing: An *AARP Bulletin* Survey, September 2010.

Respondents age 50 to 64 years old (33%) are more likely to consider getting their profile than those 65 years and older (22%). Where one resides also is associated with willingness to consider having one's genetic profile analyzed. A larger share of residents in the South (34%) and West (33%) would consider having their genetic profile analyzed than those in the Midwest (19%).

Who Should Have Access to Genetic Information

When asked, "Who do you think should have access to your genetic information besides your doctor?" nine in ten (94%) identified one or more source. As Figure 4 shows, most often the response was themselves only (66%), and two in seven (29%) said other family members. Those age 65 years and older (44%) were more likely to think family members should have access to their information than their younger age 50 to 64 counterparts (26%).

Figure 4
Percentage of Respondents That Indicate
Who Should See Their Genetic Profile Results
 Base: All Respondents (N=1,000)

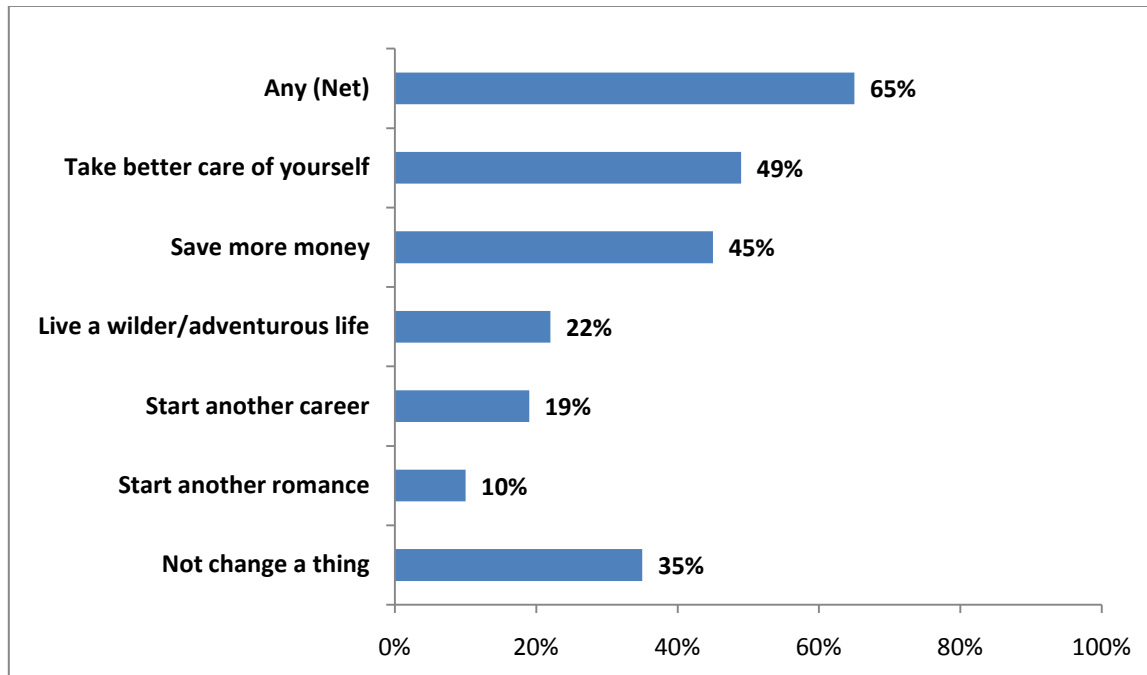


Source: Views on Genetic Testing: An AARP Bulletin Survey, September 2010.

Behavior Change If Test Showed You Could Live To Be 100

As Figure 5 shows, while a third of the respondents (35%) said they would not change a thing if a genetic test showed that they could live to be 100 years old, nearly half said they would take better care of themselves (49%) and save more money (45%). Almost a quarter would live a wilder, more adventurous life (22%). One in ten said they would start another romance (10%).

Figure 5
Percentage Who Indicated They Would Change Something
Base: All respondents (N=1,000)



Source: Views on Genetic Testing: An *AARP Bulletin* Survey, September 2010.

METHODOLOGY

GfK Roper, a division of GfK Custom Research North America included the AARP Bulletin's Genetic Testing questions to their OMNITEL, a weekly national telephone omnibus service. The interviews were conducted from July 23-25, 2010 with a total of 1,000 completed interviews, made up of male and female adults (in approximately equal number), all 18 years of age and over. The margin of error on weighted data is +/- 3 percentage points for the full sample.

All interviews are conducted by telephone from four GfK sites: Twin Falls & Rexburg, ID; San Jose, Costa Rica and Cebu, Philippines. Together, the four sites have a full-time capacity of 400 lines, and utilize an interviewing procedure known as CATI - Computer Assisted Telephone Interviewing. Interviewers have been professionally trained and are continuously monitored and supervised.

Each OMNITEL study is based on a random digit dialing (RDD) probability sample of all telephone households in the continental United States. The RDD sampling system is totally computer based and provides an equal probability of selection for each and every telephone household. Thus, the sample represents telephone households with both listed and unlisted phones in their proper proportions.

The sample numbers selected by this procedure are subject to an original and at least four follow-up attempts to complete an interview. All data are entered and cleaned through the CATI system during the interviewing process. Thus, this process eliminates the editing and keypunch operations. All completed interviews are weighted to ensure accurate and reliable representation of the total population, 18 years and older.

The raw data are weighted by a custom designed computer program, which automatically develops a weighting factor for each respondent. This procedure employs five variables: age, sex, education, race and geographic region. Each interview is assigned a single weight derived from the relationship between the actual proportion of the population with its specific combination of age, sex, education, race and geographic characteristics and the proportion in the sample.

ANNOTATED QUESTIONNAIRE

Next,

Base: Total respondents (n=1,000)

Q1. Would you consider having your genetic profile analyzed to learn if you are susceptible to diseases such as Alzheimer's, cancer and diabetes?

29%	Yes
70%	No
2%	Don't know – DO <u>NOT</u> READ

Q2. Have you ever undergone any type of genetic testing?

8%	Yes
92%	No
0%	Don't Know – DO <u>NOT</u> READ

PROGRAMMER: IF Q2 = 1 (YES) SKIP TO Q4, OTHERWISE CONTINUE.

Base: Not undergone genetic testing (n=921)

Q3. Which of the following items are reasons why you haven't been tested? How about...?

INTERVIEWER: READ LIST. SELECT AS MANY AS APPLY.

PROGRAMMER: ROTATE LIST. ANCHOR "OTHER" CODE 06 LAST.

32%	The cost
12%	You're skeptical of science
21%	You don't want to know results
20%	You're concerned that someone else may get the results
63%	You never given it any thought/never thought about it
3%	Or, some other reason (specify)
8%	Don't want to/not interested/don't see the need/it's not a concern
2%	Doctor never recommended it/never had the opportunity
1%	It's not available in my area/don't know of a doctor that does i
1%	Don't know what it is/don't know enough about it
0.3%	Don't have the time
3%	None
2%	Don't Know – DO <u>NOT</u> READ

PROGRAMMER: ASK EVERYONE.

Q4. Who do you think should have access to your genetic information besides your doctor?

INTERVIEWER: DO NOT READ LIST. PROBE FOR MORE THAN ONE ANSWER. SELECT AS MANY AS APPLY.

1%	Insurers
0%	Employers
0.1%	Schools
0.1%	Adoption agencies
0.3%	Military
66%	Only you
29%	Family members
0.2%	Research/for research purposes
3%	No one else
0.4%	Anyone
1%	None
1%	Don't Know/No response
1%	Other (Specify)

Q5. When thinking about genetic testing, if a genetic test showed that you could live to be 100, would you...?

INTERVIEWER: READ LIST. SELECT AS MANY AS APPLY.

PROGRAMMER: DO NOT ROTATE LIST.

49%	Take better care of yourself.
22%	Live a wilder/adventurous life.
19%	Start another career.
10%	Start another romance.
45%	Save more money
35%	Not change a thing

Q6. Sometimes we contact survey respondents to conduct a brief follow-up interview. In order to do this, we would need your permission to collect your name and phone number for this follow up. This information would be confidential and used for this study only. Your name and information would never be passed along to any third party without your permission. Would you be willing to be contacted by one of our associates for this follow up survey?

INTERVIEWER: IF YES, RECORD NAME AND PHONE NUMBER.

34%	Yes
67%	No