ISSUE BRIEF

Genetic Testing: Ancestry Interest, But Privacy Concerns

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The Associated Press-NORC Center for Public Affairs Research

INTRODUCTION

> Only a small number of Americans have had their DNA tested to discover their genealogy or detect any disease risks, but a majority say they would be interested in one day taking a genetic test. However, Americans are not entirely convinced about the reliability of genetic testing, and there is some apprehension about the confidentiality of their genetic information.

THREE THINGS YOU SHOULD KNOW ABOUT THE AP-NORC POLL ON GENETIC TESTING

Among Adults Age 18 and Older:

1. **Seventeen percent have been genetically tested, and another 52 percent are interested in having it done.**
2. **Fifty percent are extremely or very concerned that for-profit DNA testing companies would share genetic information; 36 percent say the same about medical researchers and 32 percent about medical doctors.**
3. **Fifty-one percent say genetic information should be shared with the police only with consent of the person tested, while 33 percent say consent is not necessary and 13 percent oppose law enforcement's use of genetic testing information.**

The latest national poll conducted by The Associated Press-NORC Center for Public Affairs Research also finds that the public supports the use of genetic information in criminal investigations. Fifty-one percent say genetic information should be shared with the police only with consent of the person tested, while 33 percent say consent is not necessary and 13 percent oppose law enforcement's use of genetic testing information altogether.

Seventeen percent of adults have undergone genetic testing. Of that group, 65 percent wanted to learn more about their ethnic heritage. Only 39 percent say their motive was to learn about their own or

future children's disease risk. Similar motivations are cited by the 52 percent who express interest in doing a test at some point.

The nationwide poll was conducted by The Associated Press-NORC Center for Public Affairs Research June 13-18, 2018, using AmeriSpeak®, the probability-based panel of NORC at the University of Chicago. Online and telephone interviews using landlines and cell phones were conducted with 1,109 adults. The margin of sampling error is +/- 4.1 percentage points.

Other key findings from the poll include:

- The public has some concerns about the confidentiality of genetic information, particularly with the for-profit companies that sell testing services directly to the public. Fifty percent are extremely or very concerned that companies that market direct-to-consumer DNA tests might share a person's genetic information without consent. About a third have the same fears about medical doctors and researchers.

- About 4 in 10 say a DNA test can be trusted to identify ethnic heritage, diagnose disease, or reveal if someone is a carrier of a genetic disorder. Only about a third are convinced about its reliability in screening for inherited diseases or identifying the most beneficial treatment for an illness.

- Still, 60 percent of the public would want to be informed if they carried the gene for an incurable disease, although 39 percent would prefer to remain in the dark. Regardless of their preference, 82 percent would notify siblings and children if made aware of a possible hereditary disease.

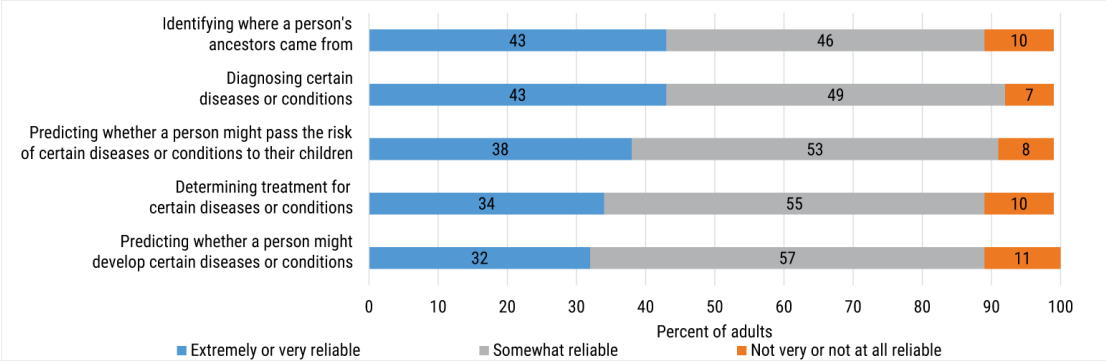
- The number of companies marketing genetic testing directly to the consumer has swelled in recent years, yet 54 percent of Americans say they have heard little or nothing about genetic testing.

GENETIC TESTING RELIABILITY

Americans express skepticism when it comes to the reliability of genetic testing.

Although genetic testing has become increasingly more accessible and sophisticated in recent years, most people are not very familiar with or entirely persuaded by its trustworthiness. While about 4 in 10 say a DNA test can be relied on to identify ethnic heritage or diagnose disease, fewer are convinced about its ability to predict disease or identify proper treatment.

The public is not convinced on the accuracy of genetic testing.



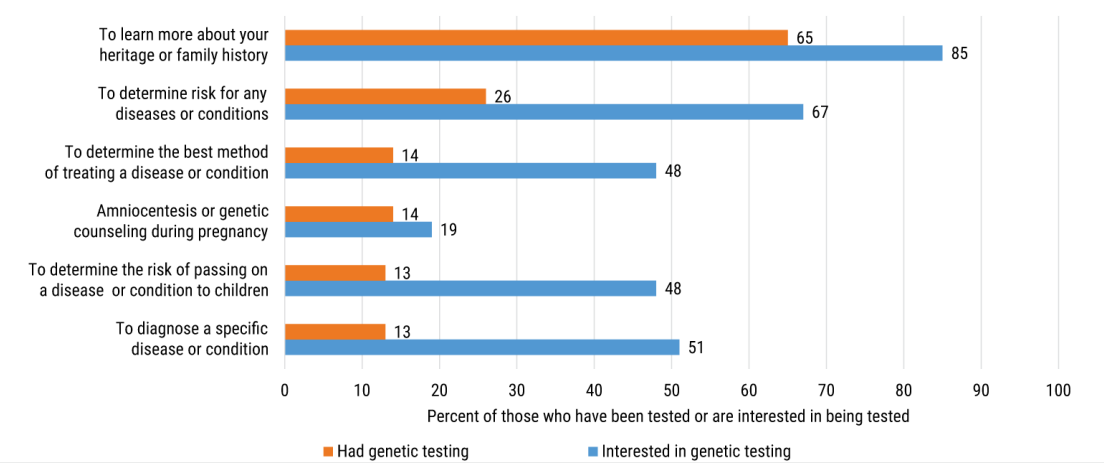
Question: As you may know, scientists have developed tests that can use the DNA sequence of a person's genes to help predict whether an individual, or their future children, might develop certain diseases, as well as to diagnose whether they have certain diseases. Similar tests can also be used to identify where a person's ancestors came from. How reliable would you say these genetic or DNA tests are at the following? Source: AP-NORC Center Poll conducted on June 13-18, 2018, with 1,109 adults nationwide

UNDERGOING TESTING

Few have undergone genetic testing, though many would be interested in doing so.

While only 17 percent of Americans have actually undergone genetic testing, 52 percent report interest in such a test. Sixty-five percent of those who have been tested are interested to learn more about their ethnic or family background. About a quarter of Americans have a desire to discover if they are at risk for a disease or genetic condition.

Americans are motivated to take DNA tests to learn about their heritage.



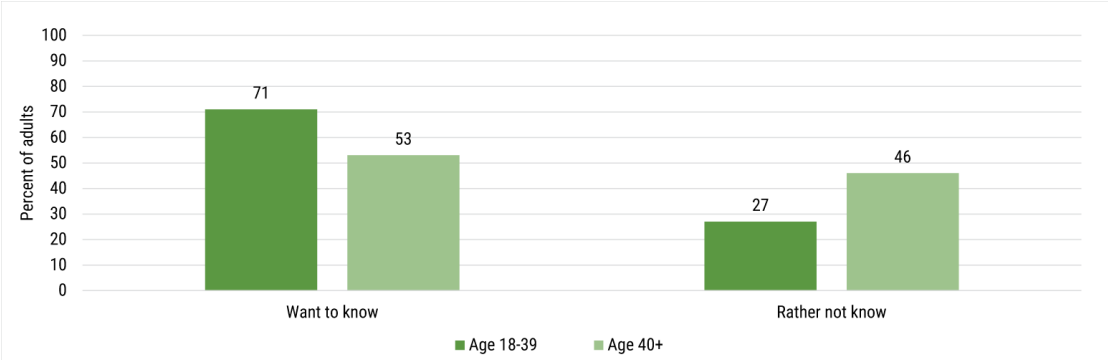
Questions: Why did you have this genetic or DNA testing? Why might you be interested in having genetic or DNA testing? Source: AP-NORC Center Poll conducted on June 13-18, 2018, with 1,109 adults nationwide

Eighty-five percent of those who have been tested regard the results as helpful. In general, 60 percent of the public would want to be informed if they carried the gene for an incurable disease, although

39 percent would prefer to remain in the dark. No matter their preference about knowing, in the event they did learn about a possible hereditary disease, 82 percent would notify siblings and children.

Adults under age 40 are particularly interested in learning about any predisposition they may have for a genetic disorder: 71 percent would rather know if they carried a gene for a disease. Older Americans are torn: 53 percent of those age 40 and older would want to know if they had a genetic predisposition for a disease, and 46 percent would prefer not to.

Young adults would rather know if they carried the gene for an incurable disease.



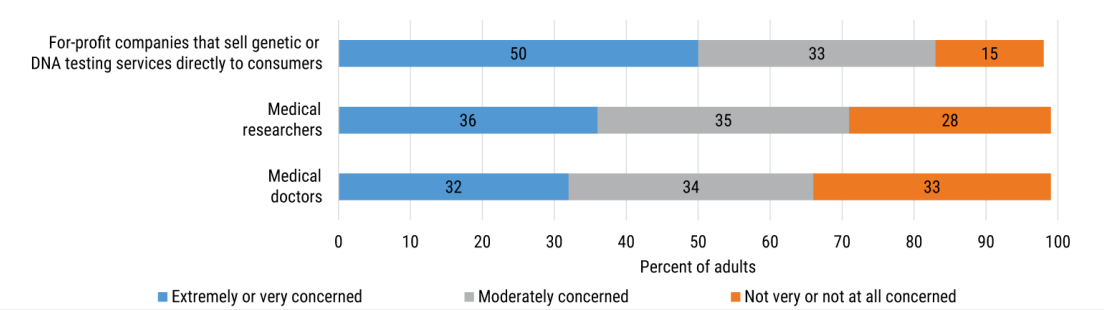
Question: Would you want to know if you carried a gene associated with an incurable disease, or would you rather not know that? Source: AP-NORC Center Poll conducted on June 13-18, 2018, with 1,109 adults nationwide

DATA PRIVACY CONCERN

> The public expresses some concern about genetic data privacy.

The public has some concerns about the confidentiality of their information, particularly with the for-profit companies that sell testing services directly to the public. While the Genetic Information Nondiscrimination Act of 2008 protects Americans from discrimination from employers or health insurance based on genetic information, it does not shield people from trouble with life insurance, disability insurance, or long-term care insurance.[1]

Americans are uneasy about the confidentiality of genetic data.



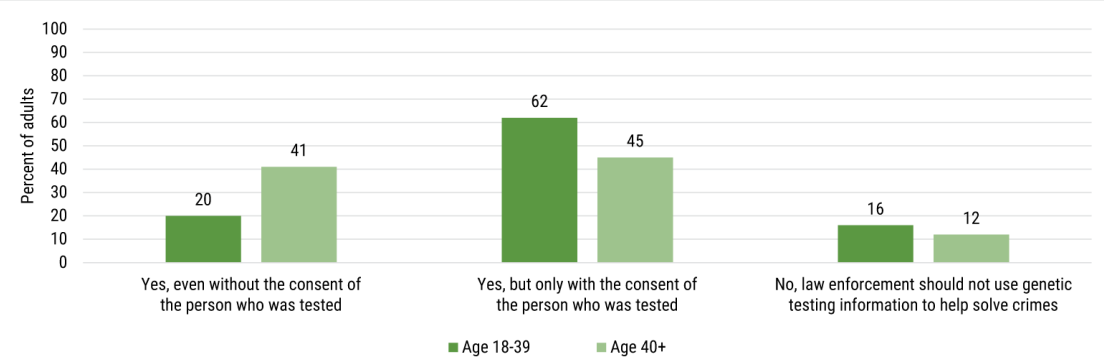
Question: How concerned are you that each of the following might share the genetic data they've collected that is linked to a specific person without that person's knowledge? Source: AP-NORC Center Poll conducted on June 13-18, 2018, with 1,109 adults nationwide

The issue of genetic confidentiality was also raised recently when police used DNA found on a genealogy website to identify a suspect in the Golden State Killer case. Since then, additional arrests have been made with the help of the same open-source ancestry site.[2] Law enforcement's use of genetic testing information is supported by

most Americans. However, half say the person tested should provide consent to the police before its use, while a third regard genetic testing information to be fair game even without consent.

Adults under age 40 are more likely than older adults to favor the use of genetic information by the police only with the consent of the individual.

Young adults want the police to get permission to use genetic information.



Question: Should genetic testing information be shared with law enforcement to help solve crimes, or not? Source: AP-NORC Center Poll conducted on June 13-18, 2018, with 1,109 adults nationwide

STUDY METHODOLOGY

This survey was conducted by The Associated Press-NORC Center for Public Affairs Research and with funding from The Associated Press and NORC at the University of Chicago. Data were collected

using AmeriSpeak Omnibus®, a monthly multi-client survey using NORC's probability-based panel designed to be representative of the U.S. household population. The survey was part of a larger study that included questions about other topics not included in this report. During the initial recruitment phase of the panel, randomly selected U.S. households were sampled with a known, non-zero probability of selection from the NORC National Sample Frame and then contacted by U.S. mail, email, telephone, and field interviewers (face-to-face). The panel provides sample coverage of approximately 97 percent of the U.S. household population. Those excluded from the sample include people with P.O. Box only addresses, some addresses not listed in the USPS Delivery Sequence File, and some newly constructed dwellings.

Interviews for this survey were conducted between June 13 and 18, 2018, with adults age 18 and over representing the 50 states and the District of Columbia. Panel members were randomly drawn from AmeriSpeak, and 1,109 completed the survey—967 via the web and 142 via telephone. Interviews were conducted in both English and Spanish, depending on respondent preference. The final stage completion rate is 23.6 percent, the weighted household panel response rate is 33.7 percent, and the weighted household panel retention rate is 87.2 percent, for a cumulative response rate of 6.9 percent. The overall margin of sampling error is +/- 4.1 percentage points at the 95 percent confidence level, including the design effect. The margin of sampling error may be higher for subgroups.

Once the sample has been selected and fielded, and all the study data have been collected and made final, a poststratification process is used to adjust for any survey nonresponse as well as any non-coverage or under- and oversampling resulting from the study-specific sample design. Poststratification variables included age, gender, census division, race/ethnicity, and education. Weighting

variables were obtained from the 2017 Current Population Survey. The weighted data reflect the U.S. population of adults age 18 and over.

All differences reported between subgroups of the U.S. population are at the 95 percent level of statistical significance, meaning that there is only a 5 percent (or lower) probability that the observed differences could be attributed to chance variation in sampling.

A comprehensive listing of the questions, complete with tabulations of top-level results for each question, is available on The AP-NORC Center website: **www.apnorc.org** <http://www.apnorc.org>. For more information, email **info@apnorc.org**.

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- The Associated Press (AP) is the world's essential news organization, bringing fast, unbiased news to all media platforms and formats.
- NORC at the University of Chicago is one of the oldest objective and non-partisan research institutions in the world.

The two organizations have established The AP-NORC Center for Public Affairs Research to conduct, analyze, and distribute social science research in the public interest on newsworthy topics, and to use the power of journalism to tell the stories that research reveals.

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