

ASHG Survey Finds Americans Strongly Support Human Genetics Research

This executive summary represents an initial analysis of a nationwide survey, conducted by Zogby Analytics, December 2019, consisting of telephone interviews of 1,100 American adults, plus 775 additional adults for minority oversampling. The margin of error for this survey is +/- 3.1 percent. The margin of error is higher for subgroups. African Americans: sample size = 405, margin of error = +/- 4.9 percentage points. Hispanic: sample size = 409, margin of error = +/- 4.8 percentage points. Asian: sample size = 303, margin of error = +/- 5.6 percentage points.

As genetics and genomics knowledge expands rapidly across research and medicine, Americans are excited and optimistic about this area of research and its possible benefits, according to a new survey released by the American Society of Human Genetics (ASHG) in partnership with Research!America. The survey finds the large majority of Americans agree genetic knowledge will be important to their own health and their families' health. The following are some of the key findings of the survey data:

KEY FINDINGS

1. Americans Are Curious and Hopeful About Human Genetics Research
2. Americans Support Federal Funding for Genetic Research
3. Americans Think Genetic Research is Important to Improving Family Health
4. Consent and Privacy Are Important for Participation in Genetic Research
5. Most Americans Have Misconceptions About Some Concepts of Human Genetics
6. Most Americans Are Not Familiar with Key Promising Areas of Research Like Precision Medicine
7. The Ancestry and Background of Respondents Inform Some of These Findings

1. Americans Are Curious and Hopeful About Human Genetics Research

AMERICANS ARE CURIOUS AND HOPEFUL ABOUT HUMAN GENETICS RESEARCH

Please select from the following the top five words that best reflect your attitudes towards human genetics research:



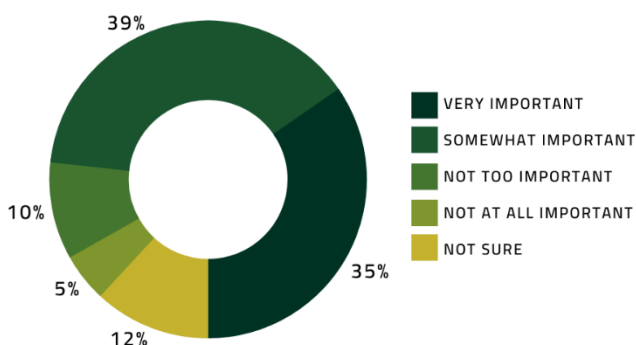
Source: A ResearchAmerica poll of U.S. adults conducted in partnership with Zogby Analytics with support from American Society of Human Genetics in December 2019.

A strong majority of Americans (77 percent) indicate positive feelings about human genetic research (34 percent “mostly positive” and 43 percent “somewhat positive”). Positive feelings are fairly consistent across minorities. However, higher numbers of Hispanic respondents report feeling “mostly positive” compared to those of other backgrounds (41 percent of Hispanic respondents vs. 27 percent of African Americans and Asians and 35 percent of white respondents). Those surveyed expressed great curiosity about genetics and interest in what it tells us about human history and our common heritage as a species. For example, the majority of survey respondents selected

the words “curious,” “hopeful,” and “amazed” as the top three words to describe their attitudes towards human genetics research. African American respondents selected the word “skeptical” to describe their attitude when compared to respondents of other backgrounds (23 percent vs. 8 percent of Asians, 11 percent of Hispanics, and 17 percent of white respondents). Furthermore, despite their overall positive views, few respondents have encountered genetics directly – only 13 percent report having taken a direct-to-consumer genetic test; 8 percent have taken a genetic test through a hospital or research center; 5 percent have participated in genetic counseling; and 5 percent have taken part in research requiring a blood or saliva sample.

2. Americans Support Federal Funding for Genetic Research

AMERICANS SUPPORT FEDERAL FUNDING FOR GENETIC RESEARCH



How important is it to increase federal funding to support genetic research?



Source: A ResearchAmerica poll of U.S. adults conducted in partnership with Zogby Analytics with support from American Society of Human Genetics in December 2019.

Americans agree that continued research is important and believe that the U.S. is not making enough progress in genetic research to date. A strong majority of people surveyed agree (84 percent) that more research is needed in human genetics specifically, and 74 percent of Americans report that increased federal funding for genetic research is important. Both of these strong majorities hold across all ancestry subgroups surveyed, though African Americans agree that more research in human genetics is needed than respondents of other backgrounds (76 percent vs. 84 percent of Hispanics, 88 percent of whites, and 89 percent of Asian respondents).

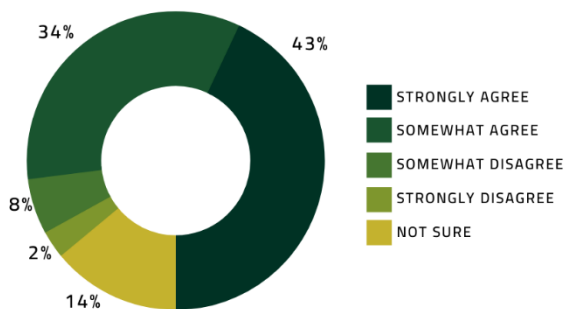
Additionally, Asians and Hispanics are 7 and

11 percent more likely than average to state that it is important to increase federal funding for genetic research (responses from African Americans and white groups are consistent with the average).

3. Americans Think Genetic Research is Important to Improving Family Health

Survey participants believe genetic research is critical to improving their families’ health with 77 percent agreeing that it is important. Hispanic respondents are 10 percent more likely to agree with this statement, while respondents of other backgrounds are consistent with the average. Respondents also feel positive about the possibility that physicians treating them will have access to their genetic information (71 percent) and that researchers will use genetics to find cures for diseases like cancer or Alzheimer’s (78 percent) and prevent severe diseases such as sickle cell disease, cystic fibrosis, or muscular dystrophy (60 percent). African American respondents, however, felt slightly

AMERICANS THINK GENETIC RESEARCH IS IMPORTANT TO IMPROVING FAMILY HEALTH



Do you agree or disagree that genetic research is important to improving your family’s health?



Source: A ResearchAmerica poll of U.S. adults conducted in partnership with Zogby Analytics with support from American Society of Human Genetics in December 2019.

less positive than the average respondent about these ideas at 60, 62, and 53 percent, respectively, while respondents of other subgroups felt either as or more positive than average. American adults also largely believe that it is a positive outcome that people will learn “surprising information” about their heritage or backgrounds (69 percent).

4. Consent and Privacy Are Important for Participation in Genetic Research

CONSENT AND PRIVACY ARE IMPORTANT FOR PARTICIPATION IN GENETIC RESEARCH

Which of the following factors would be included in your own decision to participate in genetic research? (Choose all that apply)

Confidentiality: knowing that your information will not be shared without your consent	66%
Privacy: knowing that your information will not be shared publicly	66%
Potential for your information to lead to an important cure or treatment for yourself or a family member	60%
Potential for your information to lead to an important cure or treatment for others	55%
Potential payment or reimbursement	48%
Confidence that your genetic information will be protected by current laws and policies	47%
Convenience of participating in the study	33%

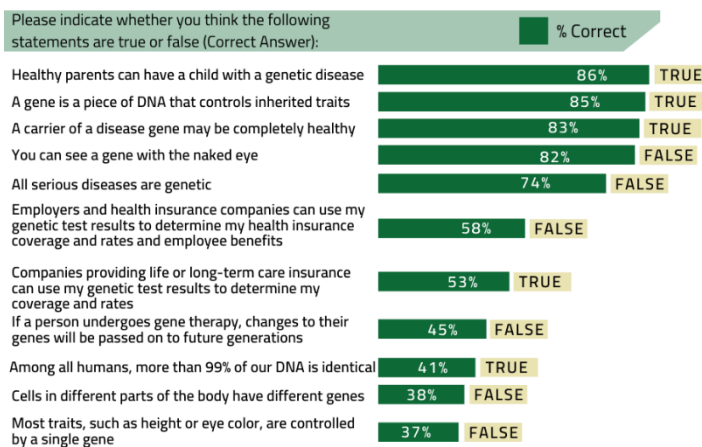
RESEARCH AMERICA Source: A Research/America poll of U.S. adults conducted in partnership with Zogby Analytics with support from American Society of Human Genetics in December 2019. ASHG American Society of Human Genetics

With previous surveys finding Americans open to participating in medical research,ⁱ this survey indicates respondents of all backgrounds would be more motivated to participate in genetic research specifically if they knew their information would be shared only with their consent; their information would be kept private; and if their participation would help themselves, a family member or another person. Additionally, those surveyed strongly believe that insurance should cover genetic tests that their doctor believes are necessary for their health (77 percent agree); oppose the use of genetic information to set insurance coverage

rates (63 percent oppose); and oppose the required disclosure of genetic information for corporate wellness programs (64 percent oppose).

5. Most Americans Have Misconceptions About Some Concepts of Human Genetics

MOST AMERICANS HAVE MISCONCEPTIONS ABOUT SOME CONCEPTS OF HUMAN GENETICS



RESEARCH AMERICA Source: A Research/America poll of U.S. adults conducted in partnership with Zogby Analytics with support from American Society of Human Genetics in December 2019. ASHG American Society of Human Genetics

Americans have some misconceptions about several key genetic concepts, suggesting a need for continued, greater public information and engagement surrounding genetics. Those surveyed have misconceptions about human genetics basics, the commonalities humans share as a single species, and the implications of gene therapies. The majority of respondents incorrectly believed that cells in different parts of the body have different genes, with only 37 percent knowing this statement to be false. Just 41 percent knew that humans share more than 99 percent of our DNA. Additionally, less than half (45 percent) correctly answered “false” to the question of whether gene therapy creates genetic

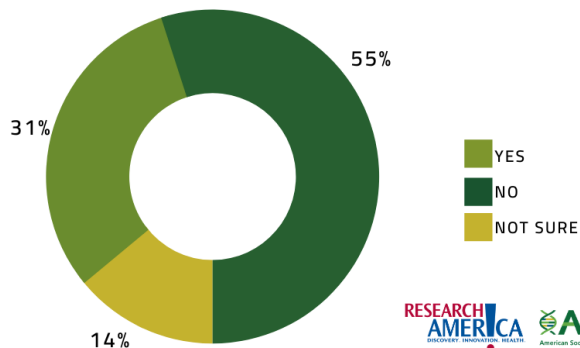
changes that are passed on to future generations (in reality, such changes are *not* heritable). On the other hand, the majority of respondents demonstrated an understanding of what genes are and an

awareness of the fact that healthy parents can have a child with a genetic disease and that carriers of a disease may nonetheless be healthy.

6. Most Americans Are Not Familiar with Key Promising Areas of Research Like Precision Medicine

MOST AMERICANS ARE NOT FAMILIAR WITH KEY PROMISING AREAS OF RESEARCH LIKE PRECISION MEDICINE

Personalized medicine involves testing genetic and other factors to help determine which medical treatments will work best for each patient. Have you heard of precision medicine?



Source: A ResearchAmerica poll of U.S. adults conducted in partnership with Zogby Analytics with support from American Society of Human Genetics in December 2019.

While 71 percent of survey respondents had heard about human genetics in the past year, about one-third of respondents had heard at all of the concept of “precision medicine,” a fast-paced area of research that seeks to create new diagnostic and treatment options based on an individual’s genetic composition. Fifty-five percent of people surveyed had not heard of this concept, which involves testing genetic and other factors to help determine which medical treatments will work best for each patient. At 40 percent, Hispanic respondents were about 10 percent more likely to have heard of precision medicine than African American, Asian, and white respondents.

These results show the importance of genetic research to a wide range of Americans. These data and a literature review can be found at <https://www.ashg.org/discover-genetics/public-views-of-genetics-survey/>.

ⁱ <https://www.researchamerica.org/news-events/news/overwhelming-majority-americans-say-discussions-about-clinical-trials-should-be>