

Home Genetic Testing:

A Nationally Representative Multi-Mode Survey

October 2020 Results

Overview of Methodology

Consumer Reports fielded a nationally-_representative survey of Americans to understand experiences with, attitudes toward, and knowledge about home genetic tests. These are services like 23andme, AncestryDNA, and MyHeritageDNA, in which consumers send in a genetic sample and receive a report about their DNA from a laboratory. The results are based on interviews conducted October 5, 2020 through October 16, 2020.

The survey was administered by SSRS to a nationally representative sample of American adults. Interviews were conducted in English and in Spanish, and were administered both online and by phone. In total SSRS collected 2,000 interviews, 1,860 by web mode and 140 by phone mode. Final data are weighted by sex, age, education, race/ethnicity, census region, civic engagement, internet access, and population density.

TOPLINE RESULTS

The questions presented below were shown to respondents in the order shown, unless noted otherwise. Where appropriate, question order, question verbiage, response answer choices, or direction of scales were randomized or rotated and those instances are noted below.

Respondents who identified as Hispanic were offered the opportunity to take the survey in Spanish or English.

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HOME GENETIC TESTING

GEN1. [FOR PHONE RESPONDENTS, THE ONLY RESPONSE OPTIONS READ OFF A LIST WERE "YES" AND "NO." INSTEAD, AFTER "...GENETIC TEST?", THIS ADDITIONAL INSTRUCTION WAS READ: "IF YOU HAVE A KIT BUT HAVE NOT USED IT, PLEASE SAY SO."]

Have you ever taken a home genetic test, also known as a direct	-to-consumer genetic test?
This refers to services such as 23andme, AncestryDNA, and MyHeritageDI genetic sample, such as a cheek swab, and a laboratory reports findings b tests ordered by a doctor.	0
	Total
	%
Yes	19
No	78
You have a kit, but haven't used it	3
Base: All respondents	2,000

GEN2. [SHOW ONLY IF GEN1 = "YES." SELECT ALL THAT APPLY. RANDOMIZE ITEMS; HOLD "SOME OTHER REASON" AT END. "NO REASON IN PARTICULAR" WAS NOT PROVIDED AS A RESPONSE OPTION, BUT RESPONDENTS WERE CODED AS SUCH IF NO OTHER RESPONSE WAS GIVEN.]

You said you've taken a home genetic test. Please indicate which, if an you did so.	ny, of the following are reasons
	Total
	%
To learn about your ancestry	66
General curiosity	56
It was given to you as a gift	24
A friend or family member recommended you do it	20
To find relatives	20
To learn more about your health	18
To learn if you have or are a carrier for any medical conditions	11
Saw an ad	7
To get a medical test you couldn't get through a doctor	3
Some other reason (Please specify)	4
No reason in particular	1
Base: Respondents who have taken a home genetic test	448

GEN3. [SHOW IF GEN1 = "NO" OR "HAVE ONE BUT HAVEN'T USED IT." SELECT ALL THAT APPLY. RANDOMIZE ITEMS; HOLD "SOME OTHER REASON" AT END.]

Why not?	,
	Total
	%
No interest	33
It's too expensive*	27
Worried about the privacy of your data or genetic material	24
Just haven't gotten around to it	18
Don't believe results would be accurate	10
Worried about what you might find out about relatives/ancestry	4
Worried about what you might find out about your health	3
Some other reason (specify)	5
No reason in particular	16
Base: Respondents who have not gotten a home genetic test or have one but have not yet used it	1,552

You said you have not gotten a home genetic test, or that you have one but have not yet used it. Why not?

*Note: "It's too expensive" base = 1,486 respondents (item did not show to respondents where GEN1 = "Have one but haven't used it.")

GEN4. [QUESTION DISPLAYED AS "RESULTS OF YOUR HOME GENETIC TEST" IF GEN1 = "YES." ROTATE ANSWER CHOICES.]

How accurate do you believe the results of home ge	netic tests are?
	Total
	%
Very inaccurate	5
Somewhat inaccurate	16
Somewhat accurate	61
Very accurate	18
Base: All respondents	1,972

GEN5. [SHOW IF GEN1 = "YES" AND GEN4 = "SOMEWHAT" OR "VERY" INACCURATE. OPEN-ENDED.]

You said that you believe the results of your genetic test are inaccurate. Please briefly explain why.

[41 OPEN-ENDED RESPONSES PROVIDED.]

GEN6. [SHOW IF GEN1 = "YES."]

Sometimes people discover unsettling information through home genetic tests, suc genetically related to people they thought they were or that their significant other i also be contacted by relatives they do not want to be contacted by who found them	s a distant relative. They may
Has anything like that happened to you?	
	Total
	%
Yes	9
No	91
Base: Respondents who have taken a home genetic test	448

GEN7. [SHOW IF GEN6 = "YES." OPEN-ENDED.]

Please briefly describe what happened, if you are comfortable doing so.

[47 OPEN-ENDED RESPONSES PROVIDED.]

GEN8. [SHOW IF GEN1 = "YES."]

Did you receive any upsetting or unsettling <u>health</u> information as a result of your home genetic test?	
	Total
	%
Yes	7
No	94
Base: Respondents who have taken a home genetic test	448

GEN9. [ROTATE RESPONSE OPTIONS.]

How concerned are you, if at all, about how home genetic test co customers?	ompanies protect the privacy of their
	Total
	%
Not at all concerned	19
Slightly concerned	15
Somewhat concerned	23
Moderately concerned	19
Extremely concerned	25
Base: All respondents	2,000

GEN10. [SHOW IF GEN1 = "YES."]

Did you ever ask a home genetic testing company to delete results?	your information after you received the
	Total
	%
Yes	6
No	94
Base: Respondents who have taken a home genetic test	448

GEN11. [RANDOMIZE ITEMS.]

Genetic tests reveal information not only about the person tak relatives. Which statement <u>best</u> describes how you would feel	9
	Total
	%
You would be interested in the results	77
You would be concerned	9
You would not want to know the results	6
You would want them not to do it	6
You would feel violated	2
Base: All respondents	1,987

INFO. [INTRO TEXT SHOWN TO RESPONDENTS; THEN SHOW GEN12 THROUGH GEN16 IN A RANDOM ORDER.]

For the following items, please indicate, to the best of your knowledge, whether they are true or false.

GEN12. [SHOW GEN12 THROUGH GEN16 IN A RANDOM ORDER. READ AS NECESSARY: "JUST YOUR BEST GUESS IS FINE." CORRECT ANSWER IS "FALSE."]

Federal medical privacy laws, such as HIPAA, protect the results of con Is this true or false?	nmercial home genetic tests.
	Total
	%
True	52
False	48
Base: All respondents	1,985

GEN13. [SHOW GEN12 THROUGH GEN16 IN A RANDOM ORDER. READ AS NECESSARY: "JUST YOUR BEST GUESS IS FINE." CORRECT ANSWER IS "TRUE."]

Genetic information collected by home genetic testing com scientific research. Is this true or false?	panies can be used for medical or other
	Total
	%
True	77
False	23
Base: All respondents	1,993

GEN14. [SHOW GEN12 THROUGH GEN16 IN A RANDOM ORDER. READ AS NECESSARY: "JUST YOUR BEST GUESS IS FINE." CORRECT ANSWER IS "FALSE," EXCEPT IN FLORIDA, WHERE IT WAS RECENTLY OUTLAWED.]

Genetic information collected by home genetic testing companie other companies, such as life insurance companies. Is this true or	0,0
	Total
	%
True	60
False	40
Base: All respondents	1,994

GEN15. [SHOW GEN12 THROUGH GEN16 IN A RANDOM ORDER. READ AS NECESSARY: "JUST YOUR BEST GUESS IS FINE." CORRECT ANSWER IS "TRUE."]

The privacy agreement between a person and a home genetic test comparison time. Is this true or false?	any can be changed at any
	Total
	%
True	54
False	46
Base: All respondents	1,991

GEN16. [SHOW GEN12 THROUGH GEN16 IN A RANDOM ORDER. READ AS NECESSARY: "JUST YOUR BEST GUESS IS FINE." CORRECT ANSWER IS "FALSE."]

It is illegal for home genetic testing companies to information, if they go out of business. Is this true	<u> </u>
	Total
	%
True	62
False	38
Base: All respondents	1,990

GEN17. [RESPONDENTS COULD SELECT MULTIPLE AMONG "CAT," "DOG," AND "ANOTHER KIND OF ANIMAL." RANDOMLY ROTATE "CAT" AND "DOG"; SHOW OTHERS IN ORDER SHOWN.]

Similar home genetic testing companies exist for pets tha they will determine your pet's breed or mix of breeds. Have y	5 0 1
	Total
	%
Yes, for a dog	4
Yes, for a cat	1
Yes, for another kind of animal	1
No, you don't have pets	34
No, you have pets but you have never done this	61
Base: All respondents	2,000

GEN18. [SHOW IF GEN17 = ANY KIND OF "YES." ROTATE RESPONSE OPTIONS.]

How accurate do you believe the results of your pet's genetic te	st are?
	Total
	%
Very inaccurate	6
Somewhat inaccurate	19
Somewhat accurate	45
Very accurate	30
Base: Respondents who had a genetic test for any kind of pet	99

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