

HEALTH POLL:

Genetic testing

February 2018

Survey overview

Every other month, the Truven Health Analytics®-NPR Health Poll surveys approximately 3,000 Americans to gauge attitudes and opinions on a wide range of healthcare issues. Poll results are reported by NPR on the health blog, “Shots,” (<http://www.npr.org/blogs/health/>) and on air.

The Truven Health Analytics-NPR Health Poll is powered by the Truven Health Analytics PULSE® Healthcare Survey, an independently funded, multi-modal (land line, cell phone, internet) survey that collects information from approximately 80,000 US households annually.

The results depicted here represent responses from 3,004 survey participants interviewed from December 1 – 14, 2017, and 3,009 participants interviewed from February 1 – 16, 2016. NPR’s reports on the findings are archived here: <http://www.npr.org/templates/search/index.php?searchinput=truven>.

2017 Genetic Testing

Sample size = 3,004

Sample date: 12/1/2017 – 12/14/2017

Margin of error: +/- 1.8%

2016 Genetic Testing

Sample size = 3,009

Sample date: 2/1/2016 – 2/16/2016

Margin of error: +/- 1.8%



Transformational healthcare solutions from Truven Health Analytics®, now offered by IBM Watson Health™.

Executive summary

This month's Truven Health Analytics-NPR Health Poll asked Americans about their experiences with and attitudes toward genetic testing. Respondents were asked identical questions to a study conducted in 2016, providing a comparison.

Findings include:

- Overall, 47% of respondents said they have privacy concerns regarding genetic testing, down from 59% in 2016.
- Despite these privacy concerns, 82% said they'd be willing to share the results with their physician (down from 88%) and 60% said they'd share with an insurer (down from 70%).
- 29% of all respondents said either they or a family member had considered genetic testing, up from 23% in 2016.
- However, the total number of respondents who said they had ordered a genetic test declined from 55% in 2016 to 47% in 2017.
- The most cited reason for ordering genetic testing was ancestry/genealogy (25%), followed by diagnostic purposes (24%). In 2016, just 15% of respondents had these tests conducted based on ancestry/genealogy, and 11% for diagnostic purposes.
- In 2016, 25% of respondents said they had ordered genetic testing based on carrier/family history. That rate fell to 7% in 2017.
- 56% of respondents who underwent genetic testing took action based on their results, down from 61% in 2016.
- Cost was the most frequent answer given (32%) for having forgone genetic testing in 2017, down from 41% in 2016.

The 2017 survey also expanded on the 2016 survey with regard to respondents' overall level of comfort in sharing the results of their genetic tests with third parties. In addition to asking about sharing results with physicians and insurers, the 2017 survey also asked whether respondents were comfortable sharing their results with relatives (81%), a healthcare research project (77%), for-profit testing companies (50%) and employers (39%).

Survey data

Question 1

Have you or a family member ever considered genetic/DNA testing?

Considered genetic testing	2017	2016
Age		
<35	43.4%	33.8%
35 – 64	24.9%	19.7%
65+	18.3%	15.1%
Total	28.8%	23.4%
Education		
High school (HS) or Less	14.2%	17.9%
Some College/Associate	26.9%	19.9%
College+	39.8%	29.1%
Total	28.8%	23.4%
Generation		
Silent Generation	15.9%	14.9%
Baby Boomers	17.7%	14.8%
Generation X	30.2%	23.3%
Millennials	43.4%	34.0%
Total	28.8%	23.4%
Income		
<\$25,000	19.3%	15.4%
\$25,000 – \$49,900	30.1%	16.4%
\$50,000 – \$99,900	34.3%	30.1%
\$100,000+	38.2%	34.5%
Total	28.8%	23.4%

Bolded figures are statistically significant.

Findings: 2017

- 29% of all respondents indicated that they or a family member have considered genetic testing
- This rate tends to decrease with increasing age
- This rate tends to increase with increasing levels of both education and income
- The highest rate (43%) was for both millennials and respondents less than 35; both are statistically significant
- The lowest rate (14%) was for respondents with a high school or less education level and is statistically significant

Findings: 2017 versus 2016

- There was an observed increase in respondents saying that they or a family member considered genetic testing from 2016 to 2017 (23% vs. 29%)
- Although there was an observed increase, the difference is not statistically significant
- The rates tend to decrease with increasing age in both 2016 and 2017
- The rates tend to increase with increasing levels of education and income in both 2016 and 2017

Questions 2 and 3

2) Have you or a family member ever had genetic/DNA testing ordered through a physician?

3) Have you or a family member ever ordered genetic/DNA testing without a physician's prescription?

Had genetic testing	2017 through a physician	2017 without a physician
Age		
<35	38.4%	40.9%
35 – 64	33.2%	27.4%
65+	25.0%	15.8%
Total	34.3%	31.7%
Education		
HS or Less	30.8%	26.0%
Some College/Associate	22.1%	25.4%
College+	41.0%	36.1%
Total	34.3%	31.7%
Generation		
Silent Generation	23.1%	9.4%
Baby Boomers	22.6%	20.3%
Generation X	37.5%	29.7%
Millennials	38.4%	40.9%
Total	34.3%	31.7%
Income		
<\$25,000	14.0%	20.8%
\$25,000 – \$49,900	28.2%	16.3%
\$50,000 – \$99,900	42.6%	38.3%
\$100,000+	49.3%	47.6%
Total	34.3%	31.7%

Bolded figures are statistically significant.

Findings: 2017

- 34% of respondents who considered genetic testing indicated that they or a family member had genetic testing prescribed by a physician
- This rate tends to decrease with increasing age
- This rate tends to increase with increasing levels of both education and income
- The lowest rate (14%) was for those with an income of less than \$25,000 and is statistically significant

Findings: 2017 versus 2016

- There was an observed decrease in respondents saying that they or someone in their family had genetic testing from 2016 to 2017 (55% vs. 47%)
- Although there was an observed decrease, the difference is not statistically significant
- The rates tend to decrease with increasing age in both 2016 and 2017
- The rates tend to increase with increasing level income in both 2016 and 2017

Question 4

What was the primary reason you or a family member had a genetic/DNA test?

- a) Diagnostic – determine what disease or condition you have
- b) Predictive – determine if you are at risk for diseases or conditions
- c) Treatment – determine best method of treatment for a disease or condition
- d) Lifestyle – recommendations on diet and exercise
- e) Carrier/family history – determine if you would pass the risk of a disease or condition to children
- f) Prenatal testing – determine if child has a disease or condition prior to being born
- g) Ancestry or genealogy – determine family history
- h) Paternity testing – determine parents of child
- i) Other

Bolded figures are statistically significant.

Note: Bolded purple figures are statistically significant between 2017 and 2016.

Note: Caution should be taken when interpreting results due to small sample sizes.

	2017						
	Diagnostic	Predictive	Treatment	Carrier/family history	Prenatal	Ancestry	Other
Primary reason for genetic testing							
Age							
<35	33.3%	11.8%	9.2%	6.5%	1.9%	17.8%	7.1%
35 – 64	15.5%	22.8%	10.3%	7.6%	2.7%	26.6%	3.3%
65+	8.2%	10.8%	3.2%	7.6%	0.0%	52.3%	17.9%
Total	23.7%	15.9%	9.0%	7.0%	2.0%	24.9%	6.8%
Education							
HS or Less	6.6%	16.7%	21.5%	0.0%	0.9%	23.3%	9.0%
Some College/Associate	17.7%	18.1%	6.6%	14.9%	1.7%	22.6%	5.8%
College+	28.4%	15.1%	7.6%	5.9%	2.3%	25.8%	6.7%
Total	23.7%	15.9%	9.0%	7.0%	2.0%	24.9%	6.8%
Generation							
Silent Generation	1.3%	18.3%	1.3%	3.7%	0.0%	54.2%	21.2%
Baby Boomers	11.0%	14.6%	7.7%	8.6%	0.5%	44.4%	10.8%
Generation X	16.9%	22.9%	10.2%	7.7%	3.2%	23.8%	2.5%
Millennials	33.3%	11.8%	9.2%	6.5%	1.9%	17.8%	7.1%
Total	23.7%	15.9%	9.0%	7.0%	2.0%	24.9%	6.8%
Income							
<\$25,000	8.8%	18.3%	3.9%	18.5%	2.3%	27.9%	4.3%
\$25,000 – \$49,900	9.6%	12.1%	7.7%	4.2%	1.8%	51.1%	3.5%
\$50,000 – \$99,900	19.7%	13.3%	13.1%	7.3%	3.1%	24.4%	3.4%
\$100,000+	46.5%	22.3%	8.6%	4.9%	0.9%	9.3%	1.8%
Total	23.7%	15.9%	9.0%	7.0%	2.0%	24.9%	6.8%

Findings: 2017

- The top two reasons for genetic testing cited by respondents that had a family member or themselves tested were:
 - Ancestry: 25%
 - Diagnostic: 24%
- Other reasons cited were, in descending order:
 - Predictive: 16%
 - Treatment: 9%
 - Carrier/family history: 7%
 - Paternity: 7%
 - Other: 7%
 - Lifestyle: 4%
 - Prenatal: 2%
- The highest rate for any reason was 52% for respondents 65+ for ancestry purposes and is statistically significant

Question 4 continued

What was the primary reason you or a family member had a genetic/DNA test?

- a) Diagnostic – determine what disease or condition you have
- b) Predictive – determine if you are at risk for diseases or conditions
- c) Treatment – determine best method of treatment for a disease or condition
- d) Lifestyle – recommendations on diet and exercise
- e) Carrier/family history – determine if you would pass the risk of a disease or condition to children
- f) Prenatal testing – determine if child has a disease or condition prior to being born
- g) Ancestry or genealogy – determine family history
- h) Paternity testing – determine parents of child
- i) Other

Bolded figures are statistically significant.

Note: Bolded purple figures are statistically significant between 2017 and 2016.

Note: Caution should be taken when interpreting results due to small sample sizes.

Primary reason for genetic testing	2016						
	Diagnostic	Predictive	Treatment	Carrier/family history	Prenatal	Ancestry	Other
Age							
<35	13.5%	14.7%	17.2%	17.9%	22.6%	13.6%	0.5%
35 – 64	8.4%	20.9%	8.2%	31.3%	11.7%	12.0%	7.5%
65+	9.0%	24.5%	3.5%	30.7%	0.3%	28.1%	4.0%
Total	10.9%	18.4%	11.9%	24.9%	15.5%	14.8%	3.7%
Education							
HS or Less	10.4%	11.2%	23.5%	15.6%	19.2%	17.6%	2.5%
Some College/Associate	3.8%	16.0%	4.4%	42.5%	10.4%	21.2%	1.8%
College+	13.6%	21.7%	10.5%	21.9%	16.0%	11.5%	4.8%
Total	10.9%	18.4%	11.9%	24.9%	15.5%	14.8%	3.7%
Generation							
Silent Generation	8.8%	36.4%	0.6%	43.4%	0.0%	6.4%	4.5%
Baby Boomers	10.7%	16.4%	5.8%	16.8%	4.8%	26.3%	19.2%
Generation X	8.0%	20.5%	10.9%	34.5%	12.3%	12.5%	1.3%
Millennials	13.6%	14.7%	16.4%	17.3%	23.9%	13.9%	0.2%
Total							
Income							
<\$25,000	6.8%	9.2%	21.5%	26.0%	13.3%	16.2%	6.9%
\$25,000 – \$49,900	6.1%	38.3%	14.8%	19.0%	12.5%	8.4%	0.9%
\$50,000 – \$99,900	13.1%	17.2%	9.6%	27.3%	17.3%	14.1%	1.4%
\$100,000+	11.8%	14.8%	11.9%	26.5%	16.6%	11.4%	6.9%
Total	10.9%	18.4%	11.9%	24.9%	15.5%	14.8%	3.7%

Findings: 2017 versus 2016

- There was an observed increase in respondents citing diagnostic as the primary reason for having had genetic testing (2016: 11%, 2017: 24%)
 - This observed increase is statistically significant
- There was an observed decrease in respondents citing carrier/family history as the primary reason for having had genetic testing (2016: 25%, 2017: 7%)
 - This observed decrease is statistically significant
- There was an observed decrease in respondents citing prenatal as the primary reason for having had genetic testing (2016: 15%, 2017: 2%)
 - This observed decrease is statistically significant
- Although there were observed changes for the other responses, the changes are not statistically significant

Question 5

Did you or a family member take any action based on the results of the genetic/DNA testing?

Bolded figures are statistically significant.

Took action based on genetic testing	2017	2016
Age		
<35	68.7%	67.3%
35 – 64	48.2%	62.8%
65+	22.6%	31.1%
Total	56.0%	61.1%
Education		
HS or Less	64.6%	81.0%
Some College/Associate	65.1%	34.9%
College+	51.9%	65.2%
Total	56.0%	61.1%
Generation		
Silent Generation	14.9%	42.0%
Baby Boomers	34.5%	37.3%
Generation X	49.8%	69.4%
Millennials	68.7%	65.5%
Total	56.0%	61.1%
Income		
<\$25,000	49.9%	67.0%
\$25,000 – \$49,900	37.5%	74.9%
\$50,000 – \$99,900	57.7%	55.5%
\$100,000+	74.7%	67.2%
Total	56.0%	61.1%

Findings: 2017

- 56% of respondents indicated some action was taken based on the results of the genetic test
- This rate tends to decrease with increasing age
- The lowest rate (15%) was for the Silent Generation and is statistically significant

Findings: 2017 versus 2016

- There was an observed decrease in respondents saying action was taken based on the genetic testing
 - Although there was an observed decrease, the difference is not statistically significant
- In both 2016 and 2017, the observed rate tends to decrease with increasing age

Question 6

What was the primary reason you or a family member did not have a genetic/DNA test performed?

- a) Cost
- b) Not ready
- c) Concerned about what it would reveal about family/relationships/paternity
- d) Felt I didn't need it
- e) Didn't want to know the results
- f) Uncertain results would be meaningful
- g) Don't know how to get test
- h) Other

Bolded figures are statistically significant.

Note: Caution should be taken when interpreting results due to small sample sizes.

Primary reason for no genetic testing	2017							
	Cost	Not ready	Concerned about family results	Didn't need	Didn't want to know	Uncertain meaningful	Don't know how	Other
Age								
<35	36.9%	11.1%	5.4%	13.8%	0.6%	5.6%	3.3%	23.2%
35 – 64	31.5%	8.2%	2.3%	31.0%	5.4%	3.1%	9.9%	8.5%
65+	20.8%	4.7%	0.0%	41.1%	1.0%	12.7%	2.2%	17.4%
Total	31.8%	8.8%	3.1%	26.0%	2.8%	5.7%	6.0%	15.8%
Education								
HS or Less	48.7%	4.6%	2.5%	30.1%	0.0%	0.0%	10.3%	3.9%
Some College/Associate	43.8%	6.0%	5.3%	22.3%	3.2%	5.8%	6.5%	7.1%
College+	18.5%	11.9%	1.8%	27.4%	3.4%	7.4%	4.4%	25.3%
Total	31.8%	8.8%	3.1%	26.0%	2.8%	5.7%	6.0%	15.8%
Generation								
Silent Generation	20.7%	4.5%	0.0%	22.4%	1.5%	27.3%	4.8%	18.7%
Baby Boomers	26.2%	7.9%	0.7%	37.8%	0.7%	2.7%	10.2%	13.8%
Generation X	31.9%	7.5%	2.6%	34.0%	7.0%	2.6%	6.9%	7.4%
Millennials	36.9%	11.1%	5.4%	13.8%	0.6%	5.6%	3.3%	23.2%
Total	31.8%	8.8%	3.1%	26.0%	2.8%	5.7%	6.0%	15.8%
Income								
<\$25,000	41.0%	5.0%	2.2%	21.7%	4.7%	7.6%	7.9%	9.8%
\$25,000 – \$49,900	40.0%	4.5%	1.1%	22.5%	0.6%	2.2%	6.3%	22.8%
\$50,000 – \$99,900	30.0%	5.3%	5.8%	30.7%	4.2%	12.0%	4.1%	8.0%
\$100,000+	2.9%	28.1%	4.9%	33.7%	3.3%	2.2%	6.3%	18.7%
Total	31.8%	8.8%	3.1%	26.0%	2.8%	5.7%	6.0%	15.8%

Findings: 2017

The two most frequently cited reasons for not having had genetic testing are:

- Cost: 32%
- Didn't need: 26%

Other reasons cited were, in descending order:

- Other: 16%
- Not ready: 9%
- Didn't know how to get tested: 6%
- Uncertain results would be meaningful: 6%
- Concerned what testing would reveal about family: 3%
- Didn't want to know results: 3%

Question 6 continued

What was the primary reason you or a family member did not have a genetic/DNA test performed?

- a) Cost
- b) Not ready
- c) Concerned about what it would reveal about family/relationships/paternity
- d) Felt I didn't need it
- e) Didn't want to know the results
- f) Uncertain results would be meaningful
- g) Don't know how to get test
- h) Other

Bolded figures are statistically significant.

Note: Caution should be taken when interpreting results due to small sample sizes.

Primary reason for no genetic testing	2016					
	Cost	Not ready	Didn't need	Didn't want to know	Didn't know how	Other
Age						
<35	35.1%	19.9%	18.2%	4.0%	12.5%	0.3%
35 – 64	49.3%	12.6%	7.1%	1.4%	11.1%	13.3%
65+	40.5%	8.4%	16.9%	1.4%	16.7%	15.2%
Total	41.3%	15.2%	13.8%	2.6%	12.7%	7.7%
Education						
HS or Less	44.7%	23.6%	5.4%	5.1%	10.2%	4.9%
Some College/Associate	50.4%	10.2%	8.5%	0.0%	17.6%	6.7%
College+	33.4%	15.1%	21.2%	3.3%	10.3%	9.6%
Total	41.3%	15.2%	13.8%	2.6%	12.7%	7.7%
Generation						
Silent Generation	18.2%	0.0%	18.9%	0.0%	34.6%	28.3%
Baby Boomers	41.9%	11.6%	12.4%	2.1%	6.2%	19.6%
Generation X	57.8%	13.9%	6.8%	1.0%	13.0%	5.0%
Millennials	34.1%	20.0%	18.1%	4.2%	13.0%	0.3%
Total	41.3%	15.2%	13.8%	2.6%	12.7%	7.7%
Income						
<\$25,000	58.5%	14.8%	8.6%	1.8%	2.7%	10.3%
\$25,000 – \$49,900	45.6%	15.6%	11.1%	3.4%	13.2%	5.9%
\$50,000 – \$99,900	40.8%	9.9%	16.7%	1.4%	17.3%	6.0%
\$100,000+	15.8%	28.7%	22.2%	1.8%	11.4%	7.0%
Total	41.3%	15.2%	13.8%	2.6%	12.7%	7.7%

Findings: 2017 versus 2016

- Although there were observed changes in the rates for each of the responses, none are statistically significant
- For both 2016 and 2017, cost was the reason most frequently cited as the primary reason for not having had genetic testing

Question 7

Do you have any privacy concerns regarding your or your family member's genetic information and how it could be used by others?

Bolded figures are statistically significant.

Have privacy concerns	2017	2016
Age		
<35	53.9%	70.0%
35 – 64	45.1%	49.9%
65+	23.0%	43.1%
Total	47.2%	59.1%
Education		
HS or Less	40.0%	69.7%
Some College/Associate	36.3%	45.0%
College+	51.6%	61.4%
Total	47.2%	59.1%
Generation		
Silent Generation	11.7%	70.4%
Baby Boomers	38.1%	19.8%
Generation X	45.1%	59.9%
Millennials	53.9%	69.1%
Total	47.2%	59.1%
Income		
<\$25,000	23.3%	44.7%
\$25,000 – \$49,900	21.5%	68.0%
\$50,000 – \$99,900	51.6%	68.6%
\$100,000+	62.3%	55.0%
Total	47.2%	59.1%

Findings: 2017

- 47% of respondents with a family member or themselves having had genetic testing indicated that they had privacy concerns
- This rate tends to decrease with increasing age
- The lowest rate (12%) was for the Silent Generation and is statistically significant

Findings: 2017 versus 2016

- There was an observed decrease in respondents saying they have a privacy concern regarding genetic testing
 - Although there was an observed decrease, the difference is not statistically significant
- In both 2016 and 2017, the rate tends to decrease with increasing age

Question 8

Would you or your family member be willing to share the results from the genetic testing with ... ? (Yes/No for each)

- a) The family physician
- b) The family health insurance company
- c) An employer
- d) Relatives
- e) A for-profit testing company
- f) A healthcare research project

Bolded figures are statistically significant.

Note: Caution should be taken when interpreting results due to small sample sizes.

Would be willing to share genetic test results with ...	2017						2016	
	Physician	Insurer	Employer	Relatives	For-profit testing group	Healthcare research	Physician	Insurer
Age								
<35	83.0%	66.1%	42.2%	82.2%	60.4%	80.7%	85.6%	79.2%
35 – 64	76.4%	55.0%	36.8%	75.8%	42.9%	69.7%	88.0%	68.4%
65+	91.5%	48.9%	28.0%	94.1%	26.1%	81.2%	95.3%	37.7%
Total	81.6%	60.2%	38.5%	81.0%	50.2%	76.5%	87.7%	70.2%
Education								
HS or Less	80.9%	55.1%	53.0%	77.8%	42.1%	56.8%	83.2%	67.4%
Some College/Associate	86.7%	65.2%	48.0%	85.3%	53.9%	76.7%	87.5%	63.8%
College+	80.0%	59.5%	33.7%	80.2%	50.5%	79.8%	89.4%	73.8%
Total	81.6%	60.2%	38.5%	81.0%	50.2%	76.5%	87.7%	70.2%
Generation								
Silent Generation	88.6%	55.4%	47.1%	91.8%	23.5%	71.9%	97.0%	41.0%
Baby Boomers	89.4%	46.3%	19.3%	92.7%	30.6%	77.3%	91.6%	48.0%
Generation X	73.9%	56.9%	40.1%	72.4%	44.7%	70.1%	85.2%	72.3%
Millennials	83.0%	66.1%	42.2%	82.2%	60.4%	80.7%	87.0%	79.2%
Total	81.6%	60.2%	38.5%	81.0%	50.2%	76.5%	87.7%	70.2%
Income								
<\$25,000	87.2%	64.6%	26.8%	91.2%	29.6%	80.6%	87.8%	70.1%
\$25,000 – \$49,900	90.3%	38.9%	36.3%	81.4%	56.5%	74.1%	90.9%	55.5%
\$50,000 – \$99,900	67.6%	54.9%	36.0%	69.4%	43.0%	67.0%	89.0%	82.8%
\$100,000+	88.1%	75.4%	50.5%	87.2%	65.5%	85.7%	84.1%	70.5%
Total	81.6%	60.2%	38.5%	81.0%	50.2%	76.5%	87.7%	70.2%

Findings: 2017

- 82% of respondents who had genetic testing themselves, or had a family member who had genetic testing, would be willing to share test results with their physician
- Other results in descending order were:
 - Relatives: 81%
 - Healthcare research: 77%
 - Health insurer: 60%
 - For-profit testing group: 50%
 - Employer: 39%
- The lowest rate (19%) was for baby boomers for willingness to share with their employer and is statistically significant
- The highest rate (94%) was for respondents age 65+ for willingness to share with relatives and is statistically significant

Findings: 2017 versus 2016

- There were observed decreases for willingness to share genetic testing information with both the physician and the health insurer
- Although there were observed decreases, the differences are not statistically significant

About Truven Health Analytics, part of the IBM Watson Health business

Truven Health Analytics®, part of the IBM Watson Health™ business, provides market-leading performance improvement solutions built on data integrity, advanced analytics and domain expertise. For more than 40 years, our insights and solutions have been providing hospitals and clinicians, employers and health plans, state and federal government agencies, life sciences companies and policymakers the facts they need to make confident decisions that directly affect the health and well-being of people and organizations in the US and around the world. The company was acquired by IBM in 2016 to help form a new business, Watson Health. Watson Health aspires to improve lives and give hope by delivering innovation to address the world's most pressing health challenges through data and cognitive insights.

Truven Health Analytics owns some of the most trusted brands in healthcare, such as MarketScan®, 100 Top Hospitals®, Advantage Suite®, Micromedex®, Simpler® and ActionOI®. Truven Health has its principal offices in Ann Arbor, MI, Chicago, IL and Denver, CO. For more information, please visit truvenhealth.com.

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