Health Information National Trends Survey

hints briefs

NUMBER 43

Genetic Testing Awareness Among American Adults

Different types of genetic tests can provide information regarding personal risk of developing disease, the likelihood of passing heritable conditions to children, and targeted treatment options for some conditions. Two different kinds of genetic tests are performed in the cancer context: germline testing and somatic testing.

Germline genetic testing is done to determine whether a person has inherited a genetic mutation from their mother or father that is known to increase the risk of developing cancer. Overall, inherited mutations are thought to play a role in 5–10% of all cancers. Results from germline genetic testing can help individuals make informed decisions about cancer prevention opportunities for themselves and their family members, including more frequent screening, chemoprevention, prophylactic surgery, and behavioral changes.

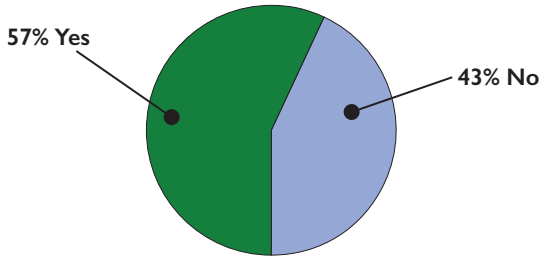
Somatic testing refers to testing of cancer cells, which is done at the time of cancer diagnosis or if a cancer has recurred. Somatic testing may provide information relevant to diagnosis, prognosis, and the most appropriate treatment regimen for a specific patient. This approach is sometimes referred to as precision medicine. Knowing the results of these tests can help people better understand their prescribed treatment protocol (for example, why their treatment might differ from another patient's or why certain novel therapies may not be well-suited for them).

Genetic testing is complex, and research suggests that the general population currently has low genetic literacy. Furthermore, genetic testing awareness has been found to be especially low among underserved populations. Assessing public awareness and knowledge of genetic testing for both disease prevention and treatment, especially among underserved populations, is vital for improving the quality of patient–provider communication and supporting informed decision-making to ensure that all groups benefit equally from advances in genetic testing.

Quick Facts

- Genetic testing can improve clinical care by providing information on personal disease risk, the likelihood of passing heritable conditions to children, and treatment options.
- In the cancer context, genetic testing can provide information regarding the risk of developing cancer, as well as information regarding diagnosis, prognosis, and treatment once a cancer has been detected.
- Studies show that awareness and knowledge of genetic testing is low, particularly among underserved groups.

Percentage of Americans Who Have Heard of or Read About Genetic Testing



Awareness of Different Genetic Testing Applications Among Americans Who Have Heard of or Read About Genetic Testing

Which of the following uses of a genetic test have you heard of?

Determining risk or likelihood of getting a particular disease	83%
Determining the likelihood of passing an inherited disease to your children	81%
Determining which drug(s) may or may not work for an individual	41%
Determining how a disease should be treated after diagnosis	38%

Source: HINTS 5 Cycle 1, 2017

This HINTS[SM] *Brief* looks at awareness of genetic testing among US adults.

Prevalence and Predictors of Genetic Testing Awareness

A recently published study used HINTS 5 Cycle1data (2017) to assess awareness and use of genetic testing among US adults and identify disparities in genetic testing awareness. The study found that, overall, 57% of American adults had heard of or read about the use of genetic tests for health reasons, but awareness varied significantly by age, income, and race. Adults aged 75 or older were less likely to be aware of genetic tests compared to individuals aged 18–34; individuals with household incomes of at least $75,000 were more likely to be aware of genetic tests compared to those earning less than $20,000; and non-Hispanic Asian and non-Hispanic Black individuals were less likely to report genetic testing awareness compared to non-Hispanic white individuals. No significant differences in genetic testing awareness were found by personal or family cancer history.

The study also found that most people who reported genetic testing awareness had heard of tests for determining personal disease risk (83%) or inherited disease risk in children (81%), but fewer were familiar with the use of genetic tests for determining drug efficacy (41%) or guiding treatment decisions (38%). The study also analyzed genetic testing uptake among those who reported overall genetic testing awareness, finding low prevalence of genetic testing in general (21%), and of BRCA testing for hereditary breast and ovarian cancer (5%) and Lynch syndrome testing for hereditary colorectal cancer (3%) in particular.

How Can This Inform Your Work?

These HINTS data suggest that many Americans (particularly older and lower income individuals, and those from non-white racial/ethnic groups) may benefit from targeted, accessible, culturally sensitive educational messages that provide accurate information about the benefits and limitations of genetic testing. The use of simple infographics, fact sheets, and videos to communicate information about genetic tests could help increase public understanding of these services. Providers can also help increase awareness and appropriate use of genetic testing by offering patients information on the clinical utility of genetic tests and explaining what the implications of receiving a negative, inconclusive, or positive test result would be, including any follow-up that may be necessary.

Genetic testing has the potential to advance public health by identifying individuals who are at high risk for developing a particular disease and applying appropriate prevention and surveillance interventions. Genetic testing may also improve individual health outcomes by informing treatment decisions. However, to ensure that advances in genetic testing technology translate into real-world benefits, is important to improve the public's understanding of different types of genetic tests (germline vs. somatic), different testing applications (such as commercial ancestry testing, pharmacogenetic testing, and testing for hereditary cancer predisposition syndromes), and to encourage uptake where appropriate. However, if the full potential of genetic testing is to be realized, it will also be necessary to provide individuals with access to genetic counselors who can help them understand the risks and benefits of testing, ensure that the proper test is used, and assist with the interpretation of test results.

About HINTS

hints.cancer.gov

The National Cancer Institute (NCI) created the Health Information National Trends Survey (HINTS) to monitor changes in the rapidly evolving field of health communication. The survey data can be used to understand how adults use communication channels to obtain health information for themselves and their loved ones. HINTS data can also help practitioners create more effective health communication strategies. The HINTS survey has been fielded 12 times to date.

HINTS *Briefs* provide a snapshot of noteworthy, data-driven research findings. They introduce population-level estimates for specific questions in the survey and summarize significant research findings resulting from analyses of how certain demographic characteristics influence specific outcomes.

Many *Briefs* summarize research findings from recent peer-reviewed journal articles that have used HINTS data.

For More Information on Cancer

- Call the NCI Cancer Information Service at 1-800-4-CANCER
- Visit https://www.cancer.gov
- Order NCI publications at https://pubs.cancer.gov/ncipl/home.aspx
- Visit Facebook.com/cancer.gov and https://www.youtube.com/ncigov

NATIONAL CANCER INSTITUTE
Division of Cancer Control & Population Sciences

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