Health
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National
Trends
Survey

hints briefs

NUMBER 24

## Public Awareness of Direct-to-Consumer Genetic Tests

Genetic tests are tests on blood, tissue, and other specimens to detect the presence or absence of genes that may be associated with health. These tests are used for a variety of reasons, including testing for genetic diseases in unborn babies, assessing whether individuals carry a gene for a specific disease that may affect their own risk for a disease and that they may pass onto their children, and testing for genetic diseases before symptoms are present. Some genetic tests are relevant to the treatment of diseases, including cancer. Genetic tests have traditionally been available only through health care professionals, wherein a clinician, such as a physician, genetic counselor, or nurse would deliver and interpret the test results for patients. However, significant genetic discoveries coupled with dramatic technological innovations over the past decade have substantially expanded the availability of health-related genetic tests.

Many genetic tests are marketed directly to consumers through paid advertisements on television, radio, or the Internet. These direct-to-consumer genetic tests have become widely available, allowing consumers to purchase a range of genetic tests, often without the involvement of a health care professional.

The direct marketing and availability of genetic tests with health implications has been controversial. While advocates assert that individuals have the right to access their genetic information without going through a health care setting, opponents assert that direct-to-consumer genetic testing poses considerable risks to individuals and to the health care system. Risks include fear or anxiety for the individuals who receive the results of their genetic test without the assistance of a health care professional to interpret them, or requests for unnecessary or invasive testing that may lead to increased patient burden and health care costs. Uncertainty and controversy about the risks and benefits of direct-to-consumer genetic testing underscore the importance of tracking public awareness of direct-to-consumer genetic testing.

## Quick Facts

- Currently, approximately 2,000 genetic tests are available, and more are being developed. Such tests are increasingly directly marketed and available to consumers.
- Public awareness of direct-to-consumer genetic tests increased from slightly more than 29% in 2008 to almost 37% in 2011 and 2012.
- Awareness of direct-to-consumer genetic testing is higher among persons who have had prior cancer diagnoses and those who have usual sources of health care.

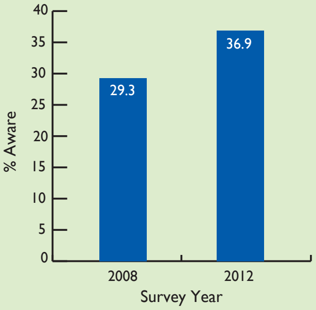
## Trends in Awareness of Direct-to-Consumer Genetic Tests

A recently published analysis of HINTS data from 2008 and 2011–2012 examined changes in awareness of direct-to-consumer genetic testing in the U.S. population and explored factors associated with awareness, including sociodemographic characteristics, personal cancer history, access to health care, Internet use, and geographic differences. This analysis of HINTS data revealed growing awareness of direct-to-consumer genetic testing that is unequally distributed in the population.

### Awareness of Direct-to-Consumer Genetic Tests: 2008–2012

While overall levels of awareness of direct-to-consumer genetic tests have increased over time, awareness is not equally distributed throughout the population. Differences in awareness have persisted from 2008 to 2012 and are patterned by age, education, geographic region, having a usual source of health care, and personal history of cancer.

**HINTS Question:** Genetic tests that analyze your DNA, diet, and lifestyle for potential health risks are currently being marketed by companies directly to consumers. Have you heard or read about these genetic tests?

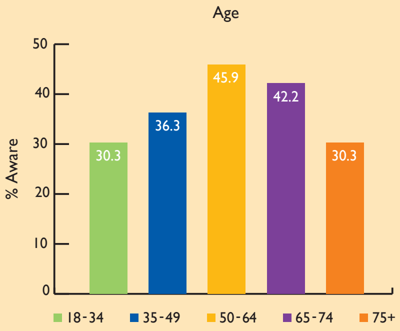


Data Source: Health Information National Trends Survey, 2008; 2011–2012.

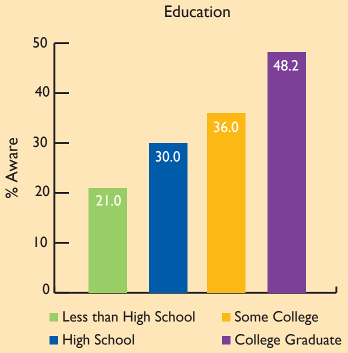
**In this HINTS *Brief*, we explore national trends over time in public awareness of direct-to-consumer genetic tests.**

# Differences in Awareness of Direct-to-Consumer Genetic Tests

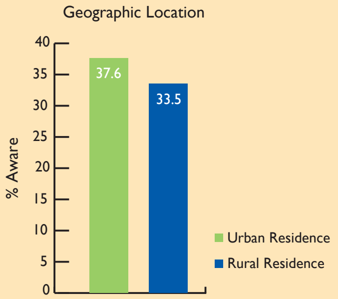
**Age:**
Awareness of direct-to-consumer genetic tests generally increased with age and was significantly higher among those aged 50–74 compared to those aged 18–34. For those over the age of 75, awareness was not significantly different than those aged 18–34.



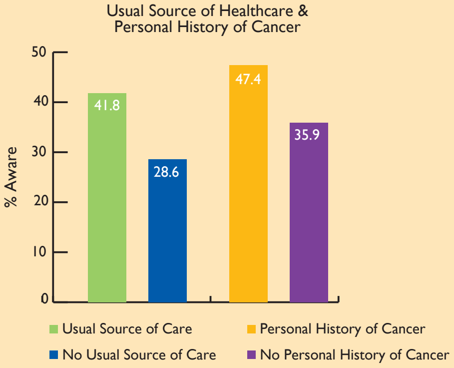
**Education:**
A general increase in awareness of direct-to-consumer genetic tests was observed with increasing levels of education. Those with some college education or a college degree had the highest level of awareness.



**Geographic Region:**
Greater awareness of direct-to-consumer genetic testing was observed among those living in urban areas compared to those living in rural areas.



**Health Care and Cancer History:**
Awareness of direct-to-consumer genetic tests was greater among those who reported having a regular source of health care than among those who did not. Higher levels of awareness were also observed among those with a prior cancer diagnosis compared to those who did not have a personal history of cancer.



## How Can This Inform Your Work?

- When genetic tests are performed in a clinical setting, a health care professional provides information about the risks and benefits of the tests and discusses the potential emotional and social consequences of testing, as well as any necessary follow-up care; this is not the case when individuals independently pursue genetic testing through direct-to-consumer means.
- As public awareness of direct-to-consumer genetic tests increases, efforts to educate the population about the positive and negative aspects of genetic testing will be increasingly needed.
- The National Human Genome Research Institute has developed a number of online and print educational resources to address frequently asked questions about genetic testing (http://www.genome.gov/19516567).

## About HINTS

hints.cancer.gov

HINTS was created to monitor changes in the rapidly evolving field of health communication. The survey data can be used to understand how adults use different communication channels to obtain health information for themselves and their loved ones. It can also help to create more effective health communication strategies across populations. The National Cancer Institute (NCI) fielded the first HINTS in 2002 and 2003, surveying 6,369 Americans. Subsequent surveys followed in 2005 (5,586 Americans surveyed) and 2008 (7,674 Americans surveyed), 2011 and 2012 (3,959 Americans surveyed), and 2012–2013 (3,630 Americans surveyed).

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 that are a result of analyzing how certain demographic characteristics influence specific outcomes. Many *Briefs* summarize research findings from recent peer-reviewed journal articles using HINTS data.

## For More Information on Cancer

- Call the NCI Cancer Information Service at 1-800-4-CANCER
- Visit http://cancer.gov
- Order NCI publications at https://cissecure.nci.nih.gov/ncipubs/
- Visit Facebook.com/cancer.gov and http://www.youtube.com/ncigov

## References Used in This HINTS *Brief*

Finney Rutten LJ, Gollust SE, Naveed S, Moser RP. Increasing public awareness of direct-to-consumer genetic tests: Health care access, Internet use, and population density correlates. J Cancer Epidemiol. 2012 Jul 30.

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