

Cancer-related Information Seeking among Cancer Survivors

The number of cancer survivors in the U.S. continues to increase due to the aging of the population, advancements in the early detection and treatment of cancer, and because people are living longer after a cancer diagnosis. Cancer survivors may face physical, emotional, social, and financial challenges as a result of their diagnosis and treatment. Those survivors and their caregivers who seek to participate actively in decision making and care planning during and after treatment are faced with an array of issues that must be addressed, including accessing medical and support services, getting follow-up care, returning to work, managing late effects or chronic conditions, and handling financial or legal matters. Many people seek information from a variety of sources to cope with this “new normal.”

Increasing attention is being given to cancer survivors’ long-term well-being and health behaviors, and to developing interventions that promote healthy lifestyles that best meet the unique needs of this population. Apart from psychological and physical effects from cancer treatment, they may have experienced weight gain, have stopped or limited exercise during treatment, or have multiple co-morbid health conditions as a result of tobacco use, alcohol use, or poor diet.

Technological advances and mandates from recent legislation have contributed to significant changes in how and what information is accessible to and shared with patients. Just as health information seeking has increased generally in the population, cancer-related information seeking has also grown. The percentage of cancer survivors who reported seeking cancer-related information increased from 67 percent in 2003 to 81 percent in 2013.

A study using HINTS data collected across a decade (2003-2013) compared cancer-related information seeking patterns among cancer survivors to those with only a family history of cancer and those with neither a personal nor family history of cancer.

Cancer information seeking increased significantly between 2003 and 2013, and was influenced by one’s relationship to cancer. Cancer survivors more frequently sought information than those with a family history of cancer or no cancer history. Less information seeking was found among survivors who were older or had lower levels of education or household income.

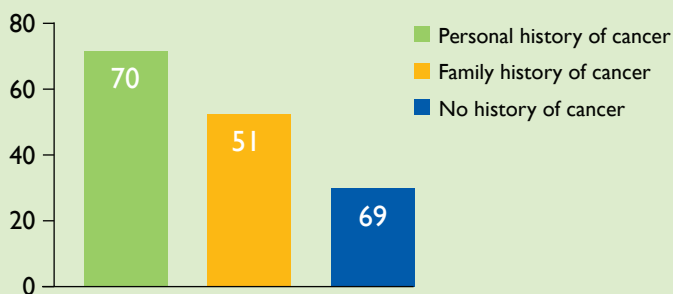
Quick Facts

- Currently, there are more than 14.5 million cancer survivors in the U.S., and this number is expected to reach 19 million by 2024.
- Despite having higher risks for cancer and other chronic diseases, cancer survivors are no more likely than the general public to engage in health protective behaviors.
- About two out of every three people diagnosed with cancer are expected to live at least 5 years after diagnosis.

First Source of Cancer Information among Survivors

The percentage of survivors reporting that health care providers were their first source of cancer information increased significantly from 20 percent in 2003 to 44 percent in 2008. The percentage reporting use of Internet as the first source remained relatively stable over this period, decreasing from 44 percent to 36 percent. Survivors who were ages 75 or older or had lower education attainment were more likely to rely on a health care provider first for cancer information. Conversely, individuals who were younger or who had higher levels of education were more likely to use the Internet first to seek cancer information. No significant differences were found between gender, race, income, health insurance, time since diagnosis, or cancer site in determining where people went first when seeking cancer information.

Cancer history and likelihood of cancer information seeking

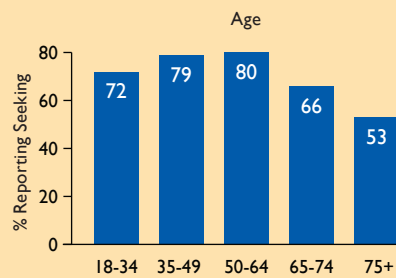


HINTS data on first source of information was available from 2003-2008.

Differences in Cancer Information Seeking Among Cancer Survivors

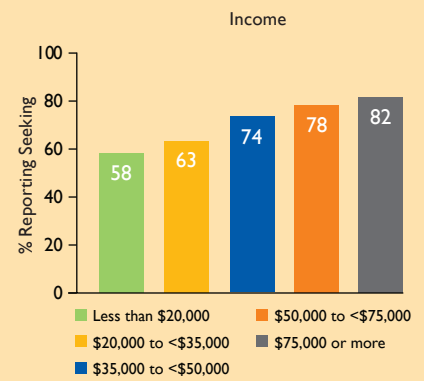
Age

The highest percentage of cancer information seeking was observed among survivors ages 35-64. Survivors ages 75 and older were less likely than all other age groups to seek cancer information from any source.



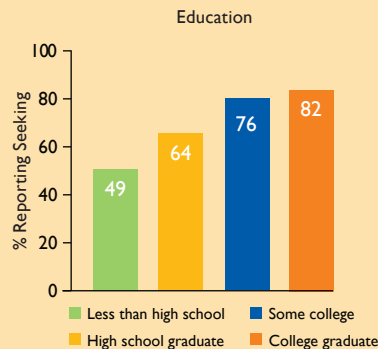
Income

Cancer information seeking rose as household income level increased, with the highest percentage of information seekers found in households with an income of \$75,000 or more. Survivors living in these households were more likely than those in households earning less than \$20,000 to report having sought cancer information.



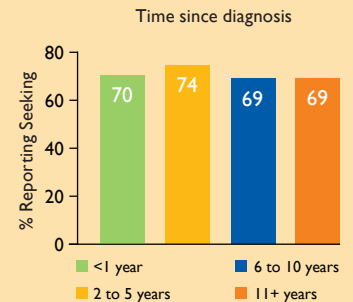
Education

Cancer-related information seeking rose as level of education increased. College graduates had the highest proportion of cancer information seeking compared to those with lower levels of educational attainment. They were more likely than those with a high school education or less to seek cancer information.



Time since diagnosis

The highest percentage of cancer information seeking was observed among survivors 2-5 years post-diagnosis. Survivors who were 6-10 years post-diagnosis had a lower likelihood of seeking cancer information compared to those patients one year or less post-diagnosis.



How Can This Inform Your Work?

The trends in survivors' cancer information seeking observed across the last decade point to interesting challenges and opportunities for health care providers who wish to support their patients' cancer information seeking experience.

- Survivors who are older, less well educated, or have a lower household income are less likely to seek cancer information. While patients' or survivors' desire for information may vary widely, these population characteristics are important for health care providers to consider when engaging cancer survivors and their families in care and treatment discussions.
- Despite the increasing variety of sources of health information, health care providers remain an important first source of cancer information. Providers are also well positioned to encourage appropriate cancer-related information seeking from credible sources to help survivors and family members better participate in their medical decision making, make healthier lifestyle choices, and improve their quality of life.

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 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.

NCI fielded the first HINTS survey in 2002–2003, surveying 6,369 Americans. Subsequent surveys followed in 2005 (5,586 Americans surveyed), 2008 (7,674 Americans surveyed), 2011–2012 (3,959 Americans surveyed), 2012–2013 (3,630 Americans surveyed), 2013 (3,185 Americans surveyed), and 2014 (3,677 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 resulting from analyses of 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://pubs.cancer.gov/ncipl/home.aspx>
- Visit [Facebook.com/cancer.gov](https://www.facebook.com/cancer.gov) and <http://www.youtube.com/ncigov>

References Used in This HINTS Brief

Finney Rutten, LJ, Agunwamba, AA, Wilson, P, Chawla, N, Vieux, S, Blanch-Hartigan, D, Arora, NK, Blake, K, Hesse, BW. Cancer-related information seeking among cancer survivors: Trends over a decade (2003-2013). *Journal of Cancer Education*. [published online February 26, 2015].

