

## Developing an Electronic Health Information System for High-Quality Cancer Care

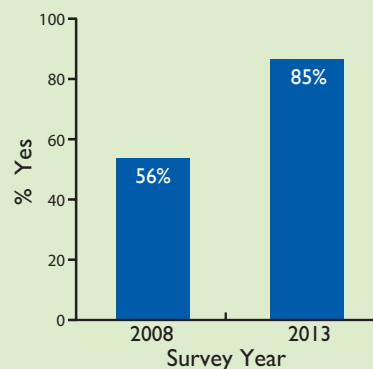
The delivery of cancer care faces significant challenges in light of increased demand due to an aging population, decreases in the number of health care providers who are skilled in providing cancer care, rising care costs, and other factors. In 2013, the Institute of Medicine released a [report](#) on the state of cancer care delivery in the United States and recommended strategies for improving care to be more patient-centered, accessible, coordinated, and evidence-based.

Six foundational components were deemed essential in improving knowledge and informing medical decisions. One of these six priority areas is “developing an ethically sound learning health care information technology system for cancer care that enables real-time analyses of data from cancer patients in a variety of care settings.” The system envisioned does not yet exist, but would build upon existing electronic health information technologies (e.g., electronic health records, cancer registries) to better integrate and use cancer health information. The U.S. Department of Health and Human Services (HHS), with assistance from professional organizations, has been encouraged to support the development and integration of such a system.

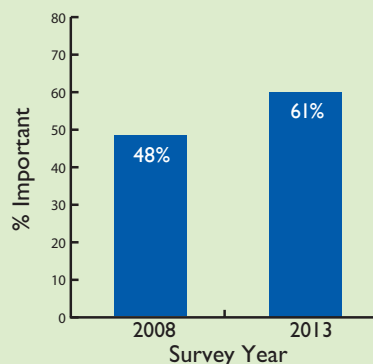
HHS, through the Office of the National Coordinator for Health Information Technology (ONC), has led nationwide efforts to create private, secure health information systems supporting the widespread, meaningful use of health information technology since the passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act in 2009. In addition to incentivizing providers to adopt useful information technology strategies, ONC has also sought to establish standards and guidelines for the privacy and security of private health information.

Since 2008, HINTS has investigated the public’s perception and use of electronic health information and technology. For example, in 2008 roughly 56 percent of American adults reported a perception that their providers were maintaining information in a computerized system. By 2013, that percentage rose to 85 percent. When asked in 2008 how important it was for health care providers to share information electronically, 48 percent indicated that such a capability was “very important.” That percentage rose to 61 percent in 2013.

**Do any of your doctors or other health care providers maintain your medical information in a computerized system?**



**How important is it to you that your health care providers are able to share your medical information with each other electronically?**



### Quick Facts

- In 2013, 78% of office-based physicians used any type of electronic health record (EHR) system (48% were using systems that met the criteria for a basic system), up from 18% in 2001.
- Adoption of basic EHR systems and any EHR system varies widely across states. The percentage of physicians with basic systems by state ranged from 21% in New Jersey to 83% in North Dakota.
- In 2013, nearly 6 in 10 nonfederal, acute-care hospitals had adopted at least a basic electronic health record system.
- In the United States, more than 1.6 million new cancer cases are diagnosed each year, and by 2030 cancer incidence is expected to rise by 45 percent to 2.3 million new diagnoses per year.

## Concern About Security, Privacy, and Control Over Electronic Health Information

A study using HINTS 2012 data examined the public's perceptions about the security and privacy of their electronic health information; their perceived control over the collection, use, and sharing of this information; and the likelihood of their withholding health information from their health care providers.

### Privacy and security of electronic health information

Three-quarters of respondents were very or somewhat confident that safeguards were in place to protect their electronic health information. Sharing information between health care providers increased concern. Nearly two-thirds (65 percent) of respondents were very or somewhat concerned that an unauthorized person would see their electronic health information if it was shared between providers.

### Perceived control over collection, use, and sharing of electronic health information

Seventy-five percent of respondents were confident that they had a say in the collection, use, and sharing of their electronic health information.

### Privacy and security concerns as a predictor of nondisclosure of medical information

Overall, 12 percent of respondents reported ever withholding information from a health care provider out of concern for the security and privacy of their electronic health information. Respondents had significantly higher odds of withholding medical information if they indicated concern about a breach in the security of their electronic health information when shared between providers or the perception that they had very little say in how their electronic health information is used.

Never smokers were significantly less likely to withhold medical information compared to current or former smokers. No differences in withholding medical information because of security and privacy concerns were found by gender, general health condition, age, birthplace, education level, race/ethnicity, or marital status.

## How Can This Inform Your Work?

The use of electronic health information systems has grown rapidly in a short time, and the use of such systems is a critical component in improving the quality of cancer care throughout the 21st century. As implementation of these systems continues to expand, opportunities exist to enhance their use and acceptance.

- Findings from HINTS suggest that understanding and addressing patients' concerns about privacy and security will be important for successful electronic health record systems adoption and to avoid undermining the public's trust in these systems and/or their providers.
- Developing patient-centered applications will be helpful for increasing acceptance of electronic health information systems, encouraging patient-provider communication, and enabling information-sharing among patients, providers, and caregivers.

### About HINTS

[hints.cancer.gov](http://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 Health Information National Trends Survey (HINTS) 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), and 2013 (3,185 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://pubs.cancer.gov>
- Visit [Facebook.com/cancer.gov](https://www.facebook.com/cancer.gov) and <http://www.youtube.com/ncigov>

## References Used in This HINTS Brief

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November 2014