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## Requests for Cancer Prevention Information: The Cancer Information Service (2002–2006)

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### Abstract

**Background**—Prevention is crucial to reducing cancer burden. Awareness of prevention information is critical to engaging the public in prevention activities.

**Methods**—We examined 106,610 information requests from the general public to the Cancer Information Service from 2002 to 2006.

**Results**—The percent of requests related to primary prevention decreased in 2003, but otherwise remained stable around 19%. The percent of requests related to secondary prevention decreased over time, from 38% (2003) to 14% (2006). Demographic characteristics were associated with patterns of change across time.

**Conclusions**—Results suggest that efforts are needed to increase public awareness of cancer prevention, particularly among certain populations.

Primary prevention, or activities that reduce the risk of disease, has been recognized as a crucial component of efforts to reduce population cancer burden (1). It has been estimated that potentially 75% of cancer deaths could be prevented through changes to health behaviors (2). Similarly, secondary prevention, or early detection of disease, has shown great potential to reduce cancer mortality (3). Therefore, public awareness of primary and secondary prevention information is critical to engaging the public in prevention and detection activities to reduce cancer-related suffering and death. In order to develop and disseminate cancer prevention and detection information effectively, it is necessary for public health agencies to increase their understanding of the information needs of the general public.

The National Cancer Institute's Cancer Information Service (CIS) is an information service designed to help meet the public's cancer information needs. Established in 1975, the CIS has been a leading resource for cancer information and education in the United States, using NCI resources to educate people on cancer prevention, early detection, treatment, rehabilitation, and smoking cessation. The CIS is a health communication program that utilizes highly trained information specialists to provide cancer information to individuals contacting the service via telephone (1-800-4-CANCER), *LiveHelp* (an instant messaging service available through NCI's website cancer.gov), mail, and email. Services are available to all individuals contacting the CIS including cancer patients, family members and friends of patients, health professionals, and the general public (4).

Considerable research has been conducted on the cancer information needs of cancer patients (5); however, less is known about the cancer information needs of the general public (6). A prior analysis of the CIS call data from 2002–2003 confirmed that there is a public interest in prevention and early detection (6). In that study, the most frequent requests from general public callers fell into two categories, “prevention and risk factors” and “cancer screening and diagnosis.” These results were in contrast to previous analyses of CIS call data, wherein cancer patient and caregiver callers most often requested specific treatment information and general cancer site information (5,7). In addition, men, callers with higher educational attainment, older callers, non-Hispanic callers, and White callers had a higher percent of requests related to primary prevention. Women, callers with lower educational attainment, middle-aged callers, Hispanic callers, and Black or African American callers had a higher percent of requests related to screening and diagnosis. These results suggest that the general public has information needs that are distinct from the information needs of cancer patients (5) and their caregivers (7) and therefore warrant further research attention.

Because there have been rapid developments in the communication channels and the amount of cancer prevention information available in recent years (8), patterns in the general public’s cancer prevention information seeking may have changed over time. In addition, understanding how information seeking has changed among different demographic groups may illuminate continuing disparities in information seeking and access (9). The goal of the current study was to determine whether general public information seekers’ requests for information about primary and secondary cancer prevention varied across time, and whether demographic characteristics such as sex, age, race, ethnicity, and education were associated with different patterns of change across time.

## Methods

### Data Source

The current study examined requests from the general public to the CIS’s telephone and instant message (*LiveHelp*) services from 2002 to 2006. Information Specialists record call and *LiveHelp* information on an Electronic Call Record Form (ECRF). They determine and record the type of information seeker (e.g., general public, cancer patient, friend or family of cancer patient) and the main subject of the interaction passively based on the information shared during the interaction. They can record up to five subjects of interaction per contact using a pre-coded list of categories and subcategories. We examined this list and selected codes related to primary and secondary prevention for our analyses (see Table 1 for list of prevention codes). Information on CIS data quality has been published elsewhere (6).

A percentage of callers and *LiveHelp* users were randomly selected each year to complete demographic information. The percentages varied across years according to CIS needs and resources. Information Specialists directly assessed demographic information for a random sample of contacts. This sample of information seekers was asked to report sex, age, race, ethnicity, and education level.

### Analyses

First, we used chi-square tests to determine the sample’s demographic characteristics. Next, we used logistic regression to predict primary prevention requests from year (2002–2006). We repeated this analysis for secondary prevention requests. We tested interactions in logistic regression models to explore patterns in requests for information on primary and secondary cancer prevention. Specifically, we conducted bivariate logistic regressions to predict primary prevention requests from year, each demographic characteristic (i.e., sex, age, race, ethnicity, and education), and the interaction between year and each demographic characteristic. In

addition, we conducted a multivariate logistic regression to predict primary prevention requests from year, all demographic characteristics, and the interactions between year and all demographic characteristics. We repeated the bivariate and multivariate logistic regressions for secondary prevention requests.

## Results

### Sample Characteristics

A total of 801,830 information requests were made between 2002 and 2006. Of those, 266,508 (33.2%) were sampled for demographic information. Of the sampled information requests, 106,610 (40.0%) came from the general public. The majority were women, over 40 years of age, White, non-Hispanic, and English speakers. Roughly one third had a high school education or less, one third had some college education, and one third had a college degree or more (see Table 2).

### Prevention Requests over Time

The absolute number of requests for prevention information was highest in 2003 but decreased every year thereafter. Among all requests for information by the general public, 43% were prevention requests in 2002. This increased to 52% in 2003, but decreased to 38% in 2004, 37% in 2005, and 32% in 2006. Requests for secondary prevention information accounted for a larger percent of all prevention calls than did requests for primary prevention information (58% vs. 42%, respectively). Furthermore, patterns over time differed for primary and secondary prevention requests. The percent of all requests related to primary prevention was 21% in 2002, 15% in 2003, 22% in 2004, 19% in 2005, and 18% in 2006 ( $p < .001$ ). The percent of all requests related to secondary prevention was 38% in 2002, 38% in 2003, 17% in 2004, 19% in 2005, and 14% in 2006 ( $p < .001$ ).

### Prevention Requests by Demographic Characteristics over Time

**Sex**—Although a higher absolute number of women, compared to men, requested primary prevention information, a higher percent of men who contacted CIS requested primary prevention information (26%) compared to women (16%). The pattern did not significantly change across time ( $p = .60$ ). See Figure 1 to examine the pattern across time.

A higher absolute number of women, compared to men, requested secondary prevention information. Overall, a similar percent of men's (26%) and women's (28%) requests were for secondary prevention information. There was a significant interaction between sex and year ( $p < .001$ ). See Figure 1 to examine the pattern across time.

### Age

A higher absolute number of information seekers younger than 60 years of age, compared to information seekers 60 years and older, requested primary prevention information. Only 15% of requests from users 60 years and older were for primary prevention information, compared to 19% of requests from information seekers 40–59, and 22% of requests from information seekers younger than 40 years. There was a significant interaction between age and year ( $p < .001$ ). See Figure 2 to examine the pattern across time.

A higher absolute number of information seekers 40 years and older, compared to information seekers younger than 40 years of age, requested secondary prevention information. Only 14% of requests from information seekers younger than 40 years were for secondary prevention information, compared to 32% of requests from information seekers 40–59 years, and 38% of requests from information seekers 60 years and older. There was a significant interaction between age and year ( $p < .001$ ). See Figure 2 to examine the pattern across time.

## Ethnicity

A higher absolute number of non-Hispanics, compared to Hispanics, requested primary prevention information. Overall, a similar percent of non-Hispanics' requests (19%) and Hispanics' requests (17%) were for primary prevention information. There was a significant interaction between ethnicity and year ( $p < .001$ ). See Figure 3 to examine the pattern across time.

A higher absolute number of non-Hispanics, compared to Hispanics, requested secondary prevention information. Approximately 30% of requests from non-Hispanics and 20% of requests from Hispanics were for secondary prevention information. There was a significant interaction between ethnicity and year ( $p < .001$ ). See Figure 3 to examine the pattern across time.

**Race**—A higher absolute number of White information seekers, compared to all other racial groups, requested primary prevention information. Overall, multiracial information seekers had the highest percent of requests for primary prevention information (22%), whereas Asian, Native Hawaiian, or other Pacific Islander information seekers had the lowest percent (15%). For all other groups, roughly 19% of requests were for primary prevention information. There was a significant interaction between race and year ( $p < .001$ ). See Figure 4 to examine the pattern across time.

A higher absolute number of White information seekers, compared to all other racial groups, requested secondary prevention information. Overall, roughly 30% of requests by Black or African American and White information seekers were for secondary prevention information. For all other groups, this was approximately 21%. There was a significant interaction between race and year ( $p < .001$ ). See Figure 4 to examine the pattern across time.

**Education**—A higher absolute number of information seekers with education ranging from high school graduate to college graduate, compared to information seekers with less than a high school degree or post-graduate training, requested primary prevention information. Overall, the percent of total requests related to primary prevention did not show a clear relation to education. However, there was a significant interaction between education and year ( $p < .001$ ). See Figure 5 to examine the pattern across time.

A higher absolute number of information seekers with education ranging from high school graduate to college graduate, compared to information seekers with less than a high school degree or post-graduate training, requested secondary prevention information. The percent of total requests related to secondary prevention increased with increased educational attainment. However, there was a significant interaction between education and year ( $p < .001$ ). See Figure 5 to examine the pattern across time.

**Multivariate Analyses**—When all demographic characteristics were included in the same analysis, the patterns did not change. For primary prevention requests, the interaction between year and sex remained nonsignificant, while all other interactions remained significant. For secondary prevention requests, all interactions remained significant.

## Discussion

Requests from the general public made to CIS for information about primary prevention (i.e., activities that reduce the risk of disease) and secondary cancer prevention (i.e., early detection of disease) varied from 2002 to 2006. Results suggest that interest in primary cancer prevention information did not change dramatically from 2002 to 2006. However, there was a pattern observed for secondary cancer prevention information. In 2002 and 2003 a high percent of

information requests were for secondary prevention information, but this decreased significantly from 2003 to 2006. One explanation for this pattern may be found in screening trial recruitment. The NCI-sponsored National Lung Screening Trial enrolled nearly 50,000 participants from September, 2002 to February, 2004, and the CIS phone number was listed as a source of information on the trial. It may be that calls for information on this trial contributed to the higher percent of secondary prevention information requests in 2002 and 2003. This suggests that active promotion of CIS as a source of cancer prevention information could increase requests for this information.

In addition to the overall pattern, demographic characteristics were associated with different patterns of change across time. Some of these patterns suggest areas for intervention. For instance, although it is unsurprising that people younger than 40 years of age are less likely to request secondary prevention information, it is troubling that people 60 years and older are requesting this information less frequently over time. People 60 years and older were also the least likely to request primary prevention information. These results suggest that older people are not using the service for prevention information in a manner consistent with their level of cancer risk, and efforts may need to be made to convince older individuals that prevention is important at any age.

Other patterns associated with demographic characteristics might reflect changes in the communication landscape (8). For instance, the most educated information seekers had the highest percent of secondary prevention requests in 2002 and 2003, but by 2005 and 2006 they represented the least percent of requests. It may be that people with the highest education are most likely to have access to other resources and are seeking this information online, rather than using services provided by CIS.

### Limitations

Although the CIS data provide a snapshot of cancer information seeking at a national level, there are a few limitations worth noting. These findings are limited by the nature of the data that are routinely collected by the CIS. For instance, demographic information is only collected for a random sample of contacts; our analyses were restricted to this subset. Furthermore, data that were not routinely gathered by the CIS during the timeframe of this study, such as income and health status, would help assess the interaction between race, education, and SES and augment our understanding of users' information needs. Because the subject of interaction is summarized by CIS Information Specialists, the coding of requests may be incorrect. Therefore, it is possible that information requests that were relevant to cancer prevention may have been miscoded. In addition, these findings are generalizable only to those who call 1-800-4-CANCER or use *LiveHelp* and not to all of the general public.

### Implications

These results can be used to help CIS promote their resources, shape the type of information made available to the general public, and inform the manner in which information is delivered. For example, CIS Information Specialists can be sensitized to the information needs of general public information seekers and given some training around how such needs may vary over time and by sociodemographic subgroups. Furthermore, the CIS may consider providing information about primary and secondary cancer prevention strategies proactively, according to evidence-based guidelines.

### Conclusions

There is a growing awareness among policy makers and researchers that cancer prevention is critical to reducing the nation's cancer burden (1). However, these findings demonstrate that this awareness has not been accompanied by an increase in the general public seeking cancer

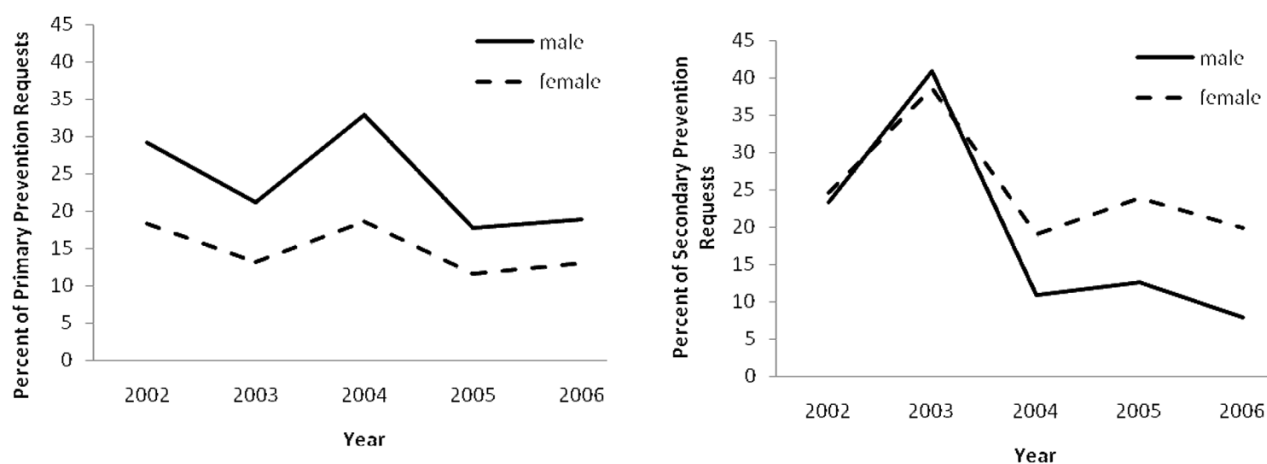
prevention information from CIS. These data speak to the need for additional efforts to support and increase public awareness of cancer prevention and early detection, particularly among certain populations. Understanding the demographic characteristics of individuals who seek cancer prevention information informs efforts to target public health messages and interventions.

## Acknowledgments

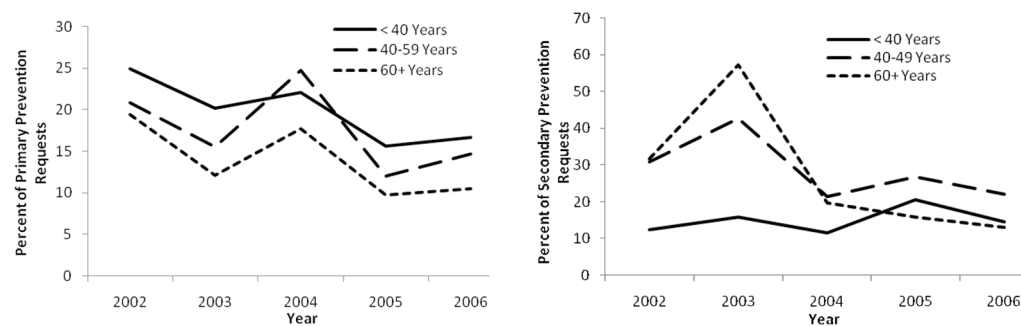
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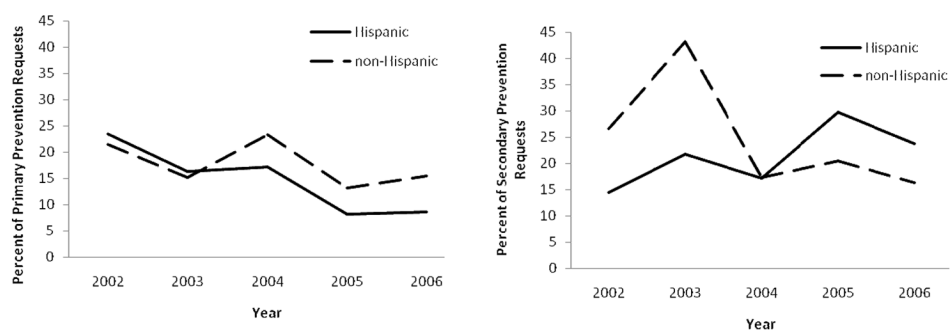


**Figure 1.**  
Percent of Primary and Secondary Prevention Requests to the Cancer Information Service from 2002–2006, by Sex.

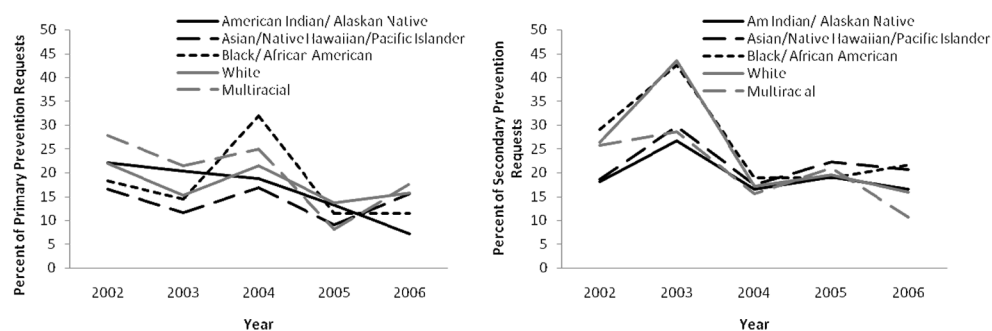


**Figure 2.**  
Percent of Primary and Secondary Prevention Requests to the Cancer Information Service from 2002–2006, by Age.

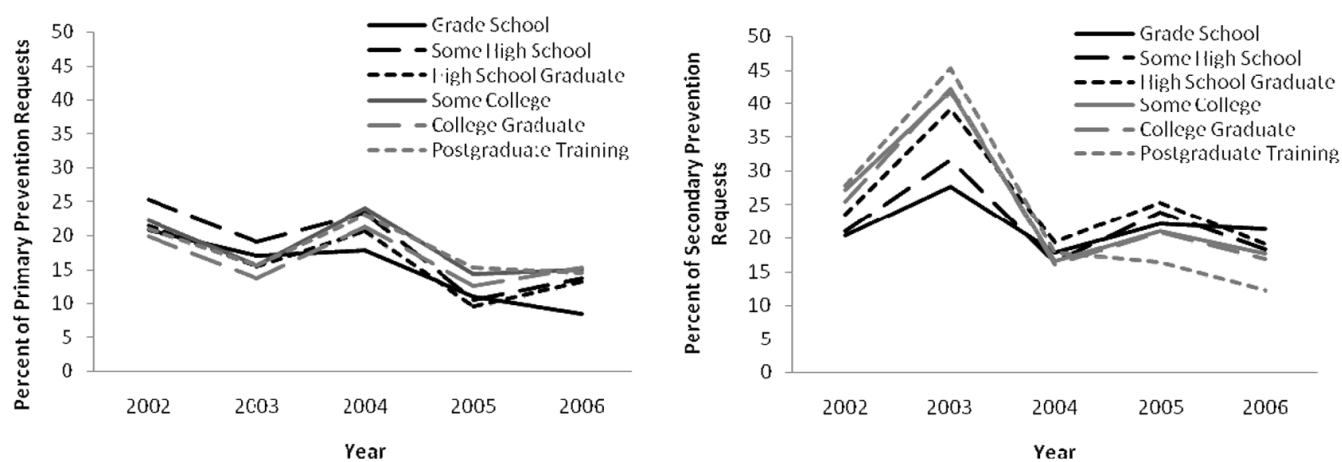




**Figure 3.**  
Percent of Primary and Secondary Prevention Requests to the Cancer Information Service from 2002–2006, by Ethnicity.



**Figure 4.**  
Percent of Primary and Secondary Prevention Requests to the Cancer Information Service from 2002–2006, by Race.



**Figure 5.**  
Percent of Primary and Secondary Prevention Requests to the Cancer Information Service from 2002–2006, by Education.

**Table 1**

Categories used to classify CIS users' subjects of interaction related to primary and secondary prevention

|  |
|--|
| Primary Prevention   |
| Diet and nutrition for prevention                          |
| Environmental risk factors                                 |
| Heredity/genetics  |
| Hormones   |
| HPV vaccine  |
| Other prevention/other risk factors                        |
| Prevention trials (including specific requests for         |
| Selenium and Vitamin E Cancer Prevention Trial             |
| [SELECT], and Study of Tamoxifen and Raloxifene            |
| [STAR])  |
| Smoking/tobacco use  |
| Secondary Prevention                                       |
| Colonoscopy  |
| Screening  |
| Screening mammograms                                       |
| Screening trials (including specific requests for National |
| Lung Screening Trial [NLST])                               |

*Note.* CIS = Cancer Information Service.

**Table 2**

Demographic characteristics of CIS general public users from 2002–2006

| Demographic                                       | Percent |       |       |       |       |        |
|---|---------|-------|-------|-------|-------|--------|
|   | Year    | 2002  | 2003  | 2004  | 2005  | 2006   |
| <i>n</i>  |         | 33316 | 33766 | 16505 | 12938 | 10085  |
| <i>Total</i>                                      |         |       |       |       |       | 106610 |
| Sex   |         |       |       |       |       |        |
| Female  |         | 73.3  | 72.4  | 75.2  | 77.9  | 78.9   |
| Male  |         | 26.7  | 27.6  | 24.8  | 22.1  | 21.1   |
| Age   |         |       |       |       |       |        |
| <40   |         | 29.6  | 25.0  | 35.1  | 30.5  | 31.0   |
| 40–59   |         | 43.5  | 41.6  | 43.8  | 44.5  | 44.4   |
| 60+   |         | 26.9  | 33.4  | 21.1  | 25.0  | 24.6   |
| Ethnicity   |         |       |       |       |       |        |
| Hispanic or Latino                                |         | 10.9  | 11.8  | 16.7  | 14.2  | 15.6   |
| Non-Hispanic                                      |         | 89.1  | 88.2  | 83.3  | 85.8  | 84.4   |
| Race  |         |       |       |       |       |        |
| American-Indian or Alaskan Native                 |         | 2.0   | 1.9   | 2.7   | 2.2   | 2.3    |
| Asian, Native Hawaiian, or other Pacific Islander |         | 2.8   | 2.4   | 3.6   | 3.5   | 4.1    |
| Black or African American                         |         | 12.9  | 14.2  | 17.7  | 15.4  | 13.9   |
| White   |         | 81.1  | 80.2  | 73.9  | 77.3  | 77.8   |
| Multiracial                                       |         | 1.2   | 1.2   | 2.1   | 1.6   | 1.8    |
| Education   |         |       |       |       |       |        |
| Grade School                                      |         | 2.1   | 2.0   | 2.4   | 2.3   | 2.3    |
| Some High School                                  |         | 7.0   | 7.1   | 8.2   | 7.9   | 7.7    |
| High School Graduate                              |         | 26.5  | 26.1  | 26.3  | 24.5  | 26.1   |
| Some College                                      |         | 29.9  | 30.8  | 31.8  | 31.8  | 30.3   |
| College Graduate                                  |         | 22.7  | 21.6  | 20.6  | 21.8  | 22.1   |
| Postgraduate Training                             |         | 11.8  | 12.4  | 10.5  | 11.7  | 11.6   |
| <i>Total</i>                                      |         |       |       |       |       | 11.8   |

*Note.* CIS = Cancer Information Service. Demographic information is collected on a random sample of CIS users each year. These data are restricted to general public users of CIS who were sampled for demographic information each year. Sample sizes vary across years due to variability in random sampling for demographic information.