Data Resource Profile

Data Resource Profile: The National Cancer Institute’s Health Information National Trends Survey (HINTS)

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Data resource basics

The National Cancer Institute’s (NCI) Health Information National Trends Survey (HINTS) was conceived in 1997 during a multidisciplinary conference focused on risk communication with attenders representing the fields of psychology, health behaviour and education, public health, clinical medicine and health journalism. The key recommendation born of this conference encouraged NCI to develop a communication-specific population survey to track trends in US adults’ access to, need for and use of health and cancer information. Heeding the call for development of a national communication survey, NCI developed a nationally representative survey to assess trends in cancer-related communication, health information-seeking and cancer-related knowledge, attitudes and behaviour.

HINTS is a cross-sectional, nationally representative survey of the US non-institutionalized adult population (aged 18 years and older) which collects data on health-related information and health-related knowledge, attitudes and behaviour.1,2 HINTS was first fielded in 2002–032 and the general population survey has been administered five times over a 15-year period, with HINTS 4 and 5 including multiple annual cross-sectional data collection cycles. The resulting data (n = 37 365) can be tracked for trends over time or, if there are no trends anticipated a priori, can be aggregated into a larger sample for further analysis. Table 1 summarizes survey design and implementation details for each completed survey administration, including survey field period, survey mode, total sample size, response rate, and number of cancer patients and survivors.

Data collected

HINTS 1 was administered in 2002–03 as a random digit dial (RDD) computer-assisted telephone interview to a representative sample of US households drawn from all telephone exchanges in the US. One adult aged 18 years or older within each household was selected for the extended interview during a household screening. Interviews were conducted in English or Spanish, depending on respondent preference. Further details about the sample and sampling design are published elsewhere.2

HINTS 2 was administered in 2005 as an RDD computer-assisted telephone interview to a representative sample of U.S. households drawn from all telephone exchanges in the U.S. One adult aged 18 years or older within each household was selected for interview, which was conducted in English or Spanish according to respondent preference. Further details about sampling design are published elsewhere.3

HINTS 3 was fielded in 2008 using a mixed-mode, dual-frame design. One sample frame was a list-assisted
RDD computer-assisted telephone interview, wherein one adult from each household was selected for an interview. Interviews were conducted in English or Spanish, depending on respondent preference. The second sample frame was a comprehensive national listing of addresses available from the United States Postal Service. These households were administered a mailed survey. In the mail sample, all adults in the household at each sampled address were asked to complete a questionnaire. Thus, the mail sample was a stratified cluster sample, in which the household was the cluster. Further details on the HINTS 3 survey design and operations are published elsewhere.4

The HINTS 4 administration included four cross-sectional mail-mode data collection cycles over 4 years starting in 2011 and concluding in 2014 (Table 1). HINTS 4 Cycles 1–4 were administered as mailed questionnaires using a sampling frame of addresses provided by Marketing Systems Group (MSG). The protocol for mailing the questionnaires involved an initial mailing of the questionnaire, followed by a reminder postcard, and up to two additional mailings of the questionnaire as needed for non-responding households. Most households received one survey per mailing (in English), whereas households that were potentially Spanish-speaking received two surveys per mailing (one in English and one in Spanish). In the second stage of sampling, one adult from each sampled household was selected for participation. Further details on the survey design and operations for the HINTS 4 data collection cycles have been previously described.5–8

HINTS 5 includes four cross-sectional data collection cycles over 4 years, starting in 2017 and scheduled to end in 2020. The first of the HINTS 5 data collection cycles (HINTS 5, Cycle 1) was conducted in 2017. HINTS 5, Cycle 1 was administered as a single-mode mailed survey using a sampling frame of addresses provided by MSG, following the same protocol as HINTS 4. Further details on the HINTS 5, Cycle 1 data collection have been previously published.9

Three additional topic-specific HINTS modules, not described in this data resource profile, were fielded in 2009 (HINTS Puerto Rico), 2015 (HINTS-FDA Cycle 1) and 2017 (HINTS-FDA Cycle 2).

**Data quality**

To ensure data quality before data collection, each HINTS administration has included cognitive testing for each HINTS instrument, with testing particularly focused on new questions. The goal of cognitive testing is to provide valid measures of the constructs of interest with a minimum of response error.10–12 Testing was conducted on both paper and RDD surveys.

After data collection, data quality efforts for the RDD surveys include direct data entry. The computer-assisted telephone interview (CATI) program ensures that proper skip patterns are followed and constrains data entry to valid values for each survey item. The CATI program also allows for range and edit checks on the entry of numerical responses to questions such as age, length of time since last search for health information, servings of fruits or vegetables consumed daily, height and weight and other numerical response questions.

For mailed surveys, post-data collection quality control checks are conducted on the scanned data and electronic images of the survey. Quality assurance staff compare the hard-copy questionnaire with the data captured in the database item-for-item and the images stored in the repository page-for-page, to ensure that all items are correctly captured. Scanned data are validated according to HINTS specifications. Violations of validation rules (such as marking more than one choice box in a mark-only-one question) are flagged and reviewed. Additionally, quality assurance staff closely review frequencies and cross tabulations of the HINTS raw data to identify outliers and to verify open-ended items.

**Survey constructs and measures**

Each HINTS administration includes a core set of items. Table 2 summarizes the key constructs represented in the survey core of HINTS and describes the nature of the associated survey items. Core constructs include health information-seeking, cancer prevention and screening, cancer-related knowledge and behaviour; cancer risk perceptions;

### Table 1. Health Information National Trends Survey (HINTS) survey design and implementation characteristics (2003–17)

|                      | HINTS 1 | HINTS 2 | HINTS 3 | HINTS 4 | HINTS 5 |
|----------------------|---------|---------|---------|---------|---------|
|                      | Cycle 1 | Cycle 2 | Cycle 3 | Cycle 4 | Cycle 1 |
| Field period initiated | 2002    | 2005    | 2008    | 2011    | 2017    |
| Mode                 | RDD     | RDD     | Mail & RDD | Mail | Mail |
| Total no. of respondents | 6369   | 5586    | Mail: 3582 RDD: 4092 | 3999    | 3630    |
|                      | 3185    | 3285    | 3185    | 3677    | 3285    |
| Response rate        | 33.0%   | 24.0%   | Mail: 40.0% RDD: 24.2% | 36.7%   | 40.0%   |
|                      | 35.2%   | 34.4%   | 34.4%   | 32.4%   | 32.4%   |
| No. cancer patients/survivors | 763   | 873     | 1001    | 563     | 542     |
|                      | 464     | 459     | 542     | 304     | 304     |
health care use and access; and technology utilization and access. Additional constructs or items have been included in specific HINTS administrations to capture timely or emerging phenomena or to glean greater detail on core constructs. Table 3 summarizes the sociodemographic characteristics of the total sample and weighted estimates for each of the survey administrations. Estimates are weighted to correct for non-response bias and to be representative of the US population; population distributions therefore reflect those of the US population with regard to age, sex, race and ethnicity.

Regulatory and ethical considerations
Each HINTS administration has been approved through expedited review by the Westat Institutional Review Board, and subsequently deemed exempt by the U.S. National Institutes of Health Office of Human Subjects Research Protections.

Data resource use
HINTS data are used by researchers to explore use of different communication channels to obtain health information among the US adult population; these data are also used to assess public knowledge and attitudes about health-relevant topics. HINTS data are used by programme planners to identify health information and communication facilitators and barriers within and across populations, and to inform the development of effective health communication strategies. Social scientists use HINTS data to test and refine their theories of health communication in the information age and to guide recommendations for theory-driven interventions aimed at improving population health.

HINTS data have been used to pursue a wide variety of research questions. To date, there have been more than 400 peer-reviewed articles, published in more than 160 journals, which have used HINTS data, and an edited dedicated book comprising the HINTS knowledge base.13 As an illustrative example, two special issues of the Journal of Health Communication have featured HINTS articles, following from HINTS research presented at the national HINTS Data Users Conferences. The first special issue, The Health Information National Trends Survey (HINTS): Research from the Baseline, was published in 2006, featuring data from the inaugural HINTS data collection.1 Studies published in this special issue covered a range of topics including cancer knowledge,14,15 cancer cognition and risk perceptions,16–20 and cancer information-seeking and communication.21–25 The second special issue, Partners in Progress: Informing the Practice of Health Communication through National Surveillance, was published in 2010.26 This special issue featured analysis of data from the first three administrations of HINTS and included studies on the following topics: health communication surveillance methodology,27,28 health communication and information-related disparities,29–37 patient-provider communication,38–40 and use of the internet and health communication technology.33,41–43

Highly cited articles from these special issues offer examples of the specific research topics pursued through use of HINTS data. Viswanath and colleagues examined the relationship between publicity and knowledge gaps using two cancer topics with varied levels of publicity: knowledge about tobacco and sun exposure.14 Results indicated that education and income were associated with awareness of the smoking and cancer link despite heavy media attention, and having at least a high school

Table 2. Core constructs measured in the Health Information National Trends Survey (HINTS)

| Construct | Measures |
|-----------|----------|
| Sociodemographics | Age, sex, race, ethnicity, income, home ownership status, financial strain, health insurance coverage, education, marital status, employment status, country of origin (US vs other), health status, cancer history |
| Health information-seeking | Ever sought health information, health information sources, trust in health information sources, confidence in health information-seeking, information-seeking experiences, internet use for health information |
| Cancer prevention and screening knowledge and behaviour | Colorectal, breast, and cervical cancer screening, HPV vaccination |
| Cancer-related behaviour | Tobacco use, sun safety, physical activity, diet |
| Cancer risk perceptions | Confusion, fatalism, health beliefs, perceived risk of developing cancer |
| Health care use and access | Usual source of care, cost barrier to care, patient-provider communication |
| Technology use and access | Internet access through dial-up, broadband, cellular network, wireless network; use of internet for health-related reasons; ownership of tablet computers, smartphones, basic cellphones; use of health-related apps; use of social media for health-related reasons |
|        | HINTS 1 | HINTS 2 | HINTS 3 | HINTS 4 | HINTS 5 | Combined |
|--------|---------|---------|---------|---------|---------|----------|
|        | 2003 N | 2005 N | 2008 N | Cycle 1 (2011) N | Cycle 2 (2012) N | Cycle 3 (2013) N | Cycle 4 (2014) N | Cycle 1 (2017) N | Total N |
| Total  | 6369 | 5586 | 7674 | 3959 | 3630 | 3185 | 3677 | 3285 | 37365 |
| Sex    |        |        |        |        |        |        |        |        |        |
| Female | 3848 | 3657 | 4696 | 2304 | 2172 | 1906 | 2184 | 1914 | 22681 |
| Male   | 2521 | 1929 | 2969 | 1552 | 1390 | 1197 | 1424 | 1303 | 14285 |
| Age    |        |        |        |        |        |        |        |        |        |
| 18-34  | 1656 | 1037 | 1113 | 582  | 529  | 426  | 467  | 367  | 6177  |
| 35-49  | 1961 | 1494 | 1831 | 932  | 845  | 712  | 743  | 655  | 9173  |
| 50-64  | 1492 | 1522 | 2451 | 1399 | 1168 | 1070 | 1220 | 1063 | 11325 |
| 65-74  | 694  | 812  | 1189 | 583  | 555  | 514  | 637  | 676  | 5660  |
| >=75   | 548  | 707  | 1010 | 455  | 414  | 360  | 428  | 385  | 4307  |
| Race/ethnicity |        |        |        |        |        |        |        |        |        |
| Hispanic | 764  | 496  | 683  | 461  | 511  | 511  | 540  | 427  | 4332  |
| NH White | 4276 | 4103 | 5445 | 2431 | 2043 | 1584 | 1960 | 1868 | 23710 |
| NH Black | 716  | 438  | 687  | 576  | 496  | 421  | 534  | 409  | 4277  |
| NH Other | 312  | 299  | 424  | 271  | 208  | 209  | 239  | 249  | 2211  |
| Education |        |        |        |        |        |        |        |        |        |
| Less than high school | 747  | 687  | 683  | 391  | 329  | 297  | 308  | 217  | 3659  |
| High school graduate | 1828 | 1447 | 1804 | 785  | 775  | 699  | 670  | 616  | 8624  |
| Some college | 1637 | 1545 | 2192 | 1167 | 1057 | 933  | 1090 | 942  | 10563 |
| College graduate | 1927 | 1696 | 2637 | 1331 | 1380 | 1167 | 1438 | 1406 | 13202 |
| Income |        |        |        |        |        |        |        |        |        |
| <$20,000 | 1111 | 899  | 1142 | 829  | 740  | 680  | 774  | 559  | 6734  |
| $20,000 to <$35,000 | 1295 | 868  | 1056 | 584  | 501  | 418  | 489  | 423  | 5634  |
| $35,000 to <$50,000 | 958  | 652  | 873  | 520  | 459  | 394  | 482  | 386  | 4724  |
| $50,000 to <$75,000 | 955  | 924  | 1203 | 594  | 524  | 446  | 530  | 530  | 5726  |
| $75,000+ | 1214 | 1150 | 2041 | 1031 | 926  | 801  | 979  | 1064 | 9206  |
| Metro/non-metro county |        |        |        |        |        |        |        |        |        |
| Metro | 5174 | 4352 | 6192 | 3231 | 3087 | 3079 | 3157 | 2812 | 30804 |
| Non-metro | 1195 | 1234 | 1482 | 638  | 543  | 476  | 520  | 473  | 6561  |
education was associated with knowledge of the sun exposure and cancer link. Dillard and colleagues assessed whether perceived risk of developing lung cancer was associated with acceptance of smoking-related myths and beliefs. Those whose perceived risk was less than their objective risk (unrealistic optimists) were more likely to report that there is no risk of developing lung cancer among those who smoke only a few years; and that developing lung cancer is determined by genetic factors. Unrealistic optimists were less likely to report an intention to quit smoking. Koch-Weser and colleagues examined patients reporting at least 2 years since diagnosis. These data from U.S. national collection of the Health Information National Trends Survey (HINTS); and (ii) the study focused on cancer survivors/patients or compared cancer survivors or patients with other populations. Studies that used HINTS items or a HINTS instrument to collect data in a special (non-national) population were excluded, and studies that used cancer history as a control variable (i.e. not a variable of specific interest) were also excluded. A total of 35 articles met the inclusion criteria and were reviewed. The following themes emerged in the focus of the articles reviewed: information seeking trends, experiences and sources; patient-centred communication and clinical care; use of internet and mobile technology in health; health-related behaviour; cancer cognition; and health status and health outcomes.

Table 4 summarizes the sociodemographic, cancer diagnosis and treatment status characteristics of the cross-sectional cohorts of cancer patients and survivors for each relevant HINTS administration. The table summarizes the total number of cancer patients per each survey administration, describes the sociodemographic characteristics thereof and indicates counts and percentages for specific cancer types. Across the survey years, the most frequent cancer types were breast, colon, cervical, skin, prostate, melanoma and endometrial cancer. In each survey year, most cancer patients reported receiving treatment for their cancer (range: 81.5–91.8%), with the majority of respondents reporting at least 2 years since diagnosis. These data offer a rich resource for examination of cancer patients’ and survivors’ cancer-related knowledge, attitudes and behaviours, as well as their information-seeking experiences and needs.

Cancer patients and survivors

HINTS data have been extensively used to characterize the experiences of cancer patients and survivors. We conducted a review of the literature to identify published studies using HINTS data focused on cancer patients and survivors. We searched MEDLINE and EMBASE from 1 January 2003 to 15 May 15 2018, using the following search terms: health information national trend* or HINTS as text phrases, AND survivor* or cancer* OR explode neoplasms [MeSH]. This search returned 229 abstracts. All abstracts were reviewed to identify those meeting the following conditions: (i) the study used data

Strengths and weaknesses

HINTS is unique among national data resources in its focus on health communication and health information. The HINTS programme offers a resource for investigators from diverse disciplines and gives access to data that speak to population use of information and communication resources during a time of unprecedented change in the information and communication landscape. As described above and in Table 4, HINTS also provides a rich cohort of cancer patient and survivor data for secondary analysis.

Since its inception, the HINTS programme has invested heavily in efforts to ensure that the data are readily and easily accessible and usable for data users and results users. The HINTS website is rich with tools to enable data access and to support data use (see Data resource access section). A variety of materials have also been developed for results users, including an online data display tool, and HINTS Briefs, which summarize key results from HINTS.
### Table 4. Sample size and weighted estimates for HINTS respondents with a personal history of cancer by sociodemographic characteristics and cancer-related characteristics

| Have you ever been diagnosed as having cancer? | HINTS 1 | HINTS 2 | HINTS 3 | HINTS 4 | HINTS 5 | Combined |
|-----------------------------------------------|--------|--------|--------|--------|--------|----------|
| **N** | **%** | **N** | **%** | **N** | **%** | **N** | **%** | **N** | **%** | **N** | **%** | **N** | **%** |
| **Yes** | | | | | | | | | | | | | |
| 763 | 10.77 | 873 | 11.31 | 1,001 | 7.25 | 563 | 8.19 | 459 | 8.08 | 542 | 8.52 | 504 | 8.64 |
| **Sex** | | | | | | | | | | | | | |
| Female | 532 | 64.57 | 596 | 56.09 | 590 | 56.65 | 317 | 57.83 | 258 | 54.77 | 280 | 59.96 | 139 | 59.08 |
| Male | 231 | 35.43 | 277 | 43.91 | 411 | 43.35 | 229 | 42.17 | 200 | 45.23 | 168 | 40.04 | 165 | 40.92 |
| **Age** | | | | | | | | | | | | | |
| 18-34 | 57 | 8.78 | 29 | 5.09 | 18 | 2.54 | 14 | 3.08 | 15 | 5.80 | 12 | 4.66 | 9 | 3.78 |
| 35-49 | 139 | 19.71 | 117 | 17.55 | 101 | 14.89 | 46 | 10.08 | 45 | 11.78 | 40 | 15.37 | 48 | 15.07 |
| 50-64 | 229 | 30.44 | 246 | 32.18 | 323 | 40.10 | 202 | 35.00 | 138 | 31.95 | 137 | 29.64 | 164 | 34.82 |
| 65-74 | 164 | 21.29 | 233 | 22.78 | 278 | 22.36 | 144 | 24.98 | 126 | 24.59 | 141 | 25.85 | 146 | 22.30 |
| >75 | 173 | 19.78 | 246 | 22.40 | 270 | 26.12 | 145 | 26.86 | 135 | 25.87 | 120 | 24.49 | 146 | 24.03 |
| **Race/ethnicity** | | | | | | | | | | | | | |
| Hispanic | 38 | 4.69 | 33 | 5.12 | 40 | 5.28 | 27 | 4.72 | 42 | 8.92 | 37 | 5.77 | 51 | 11.24 |
| NH White | 613 | 82.70 | 730 | 84.58 | 844 | 84.37 | 411 | 82.61 | 320 | 80.42 | 285 | 84.43 | 337 | 80.38 |
| NH Black | 51 | 7.51 | 37 | 5.03 | 54 | 6.18 | 51 | 6.36 | 39 | 6.32 | 36 | 7.08 | 50 | 6.23 |
| NH Other | 31 | 5.09 | 38 | 5.27 | 35 | 2.50 | 32 | 6.30 | 18 | 4.13 | 16 | 2.72 | 22 | 2.15 |
| **Education** | | | | | | | | | | | | | |
| Less than high school | 86 | 17.07 | 105 | 14.19 | 100 | 15.97 | 56 | 13.81 | 42 | 16.11 | 46 | 11.54 | 48 | 15.70 |
| High school graduate | 246 | 37.02 | 233 | 31.48 | 242 | 26.70 | 140 | 26.38 | 106 | 19.02 | 106 | 25.12 | 94 | 16.00 |
| Some college | 185 | 22.85 | 266 | 30.73 | 268 | 28.77 | 161 | 26.90 | 151 | 29.75 | 132 | 30.24 | 164 | 31.95 |
| College graduate | 228 | 23.06 | 239 | 23.60 | 384 | 28.55 | 193 | 32.91 | 160 | 25.12 | 162 | 33.10 | 209 | 36.36 |
| **Income** | | | | | | | | | | | | | |
| <$20,000 | 150 | 22.12 | 172 | 22.02 | 160 | 21.11 | 128 | 24.53 | 84 | 18.84 | 96 | 17.55 | 114 | 18.52 |
| $20,000 to <$35,000 | 177 | 25.63 | 143 | 20.58 | 161 | 21.86 | 68 | 19.91 | 64 | 15.50 | 46 | 11.82 | 79 | 13.95 |
| $35,000 to <$50,000 | 106 | 16.87 | 95 | 14.29 | 134 | 17.31 | 81 | 18.00 | 59 | 15.67 | 61 | 14.22 | 70 | 14.98 |
| $50,000 to <$75,000 | 100 | 14.39 | 127 | 19.89 | 146 | 16.61 | 74 | 14.69 | 64 | 18.46 | 73 | 20.79 | 73 | 13.68 |
| $75,000+ | 117 | 19.07 | 141 | 23.22 | 241 | 26.21 | 131 | 25.87 | 111 | 31.54 | 109 | 36.37 | 137 | 38.88 |
| **Metro/non-metro county** | | | | | | | | | | | | | |
| Metro | 613 | 79.54 | 676 | 78.30 | 798 | 79.33 | 459 | 82.23 | 376 | 74.03 | 389 | 83.75 | 461 | 80.16 |
| Non-metro | 150 | 20.46 | 197 | 21.70 | 203 | 20.67 | 104 | 25.97 | 70 | 16.25 | 81 | 19.84 | 78 | 18.01 |
| **Derived variable to categorize responses on cancer type** | | | | | | | | | | | | | |
| Bladder cancer only | 10 | 1.38 | 13 | 1.78 | 17 | 1.54 | 4 | 0.74 | 8 | 1.46 | 6 | 1.52 | 11 | 1.30 |
| Bone cancer only | 1 | 0.23 | 2 | 0.19 | 5 | 0.79 | 1 | 0.09 | 0 | 0.00 | 0 | 0.00 | 2 | 0.12 |
| Breast cancer only | 108 | 13.11 | 164 | 14.25 | 139 | 13.02 | 77 | 10.93 | 65 | 12.54 | 72 | 15.13 | 87 | 14.72 |

(Continued)
Table 4. Continued

| Cancer Type | HINTS 1 | HINTS 2 | HINTS 3 | HINTS 4 | HINTS 5 | Combined |
|-------------|---------|---------|---------|---------|---------|----------|
|             | 2003    | 2005    | 2008    | Cycle 1 (2011) | Cycle 2 (2012) | Cycle 3 (2013) | Cycle 4 (2014) | Cycle 1 (2017) | Total |
| N          | %       | N       | %       | N       | %       | N       | %       | N       | %       |
| Cervical cancer only | 90 | 11.32 | 60 | 7.74 | 66 | 8.98 | 37 | 7.46 | 33 | 8.39 | 30 | 5.46 | 30 | 7.10 | 29 | 8.67 | 375 | 8.18 |
| Colon cancer only | 41 | 5.54 | 37 | 4.44 | 50 | 5.02 | 30 | 5.10 | 15 | 2.61 | 17 | 3.42 | 20 | 3.31 | 23 | 5.08 | 233 | 4.35 |
| Endometrial cancer only | 36 | 4.88 | 35 | 2.79 | 31 | 2.64 | 13 | 3.26 | 10 | 2.87 | 11 | 1.92 | 15 | 4.11 | 10 | 1.58 | 161 | 3.04 |
| Head/neck cancer only | 8 | 0.81 | 5 | 0.77 | 5 | 0.75 | 7 | 1.35 | 3 | 0.72 | 4 | 0.92 | 10 | 1.85 | 6 | 1.47 | 48 | 1.08 |
| Hodgkin's only | 6 | 1.03 | 4 | 0.34 | 8 | 0.57 | 8 | 4.17 | 2 | 0.42 | 7 | 1.13 | 4 | 3.16 | 35 | 1.36 |
| Renal cancer only | 11 | 1.69 | 12 | 1.29 | 10 | 0.71 | 5 | 0.78 | 5 | 1.21 | 10 | 2.03 | 9 | 2.13 | 4 | 0.51 | 66 | 1.30 |
| Leukaemia only | 4 | 0.51 | 3 | 0.49 | 13 | 1.36 | 8 | 1.23 | 3 | 0.59 | 5 | 0.72 | 7 | 2.49 | 7 | 1.44 | 50 | 1.08 |
| Liver cancer only | 2 | 0.22 | 1 | 0.30 | 2 | 0.08 | 0 | 0. | 3 | 0.78 | 1 | 0.49 | 9 | 0.23 |
| Lung cancer only | 13 | 1.92 | 9 | 1.77 | 16 | 1.85 | 6 | 1.15 | 10 | 2.66 | 6 | 1.74 | 8 | 1.10 | 8 | 2.07 | 76 | 1.78 |
| Melanoma only | 52 | 7.66 | 68 | 8.78 | 67 | 7.75 | 26 | 5.21 | 19 | 4.39 | 20 | 5.97 | 27 | 4.99 | 23 | 4.58 | 302 | 6.22 |
| Non-Hodgkin only | 9 | 1.42 | 8 | 1.07 | 6 | 1.22 | 7 | 1.30 | 6 | 1.95 | 4 | 0.35 | 9 | 2.08 | 49 | 1.17 |
| Oral cancer only | 6 | 0.88 | 2 | 0.25 | 3 | 0.20 | 3 | 0.70 | 4 | 0.95 | 1 | 0.13 | 1 | 0.17 | 1 | 0.12 | 19 | 0.42 |
| Ovarian cancer only | 21 | 2.69 | 21 | 3.46 | 16 | 1.46 | 13 | 2.64 | 6 | 0.63 | 4 | 0.60 | 4 | 0.52 | 2 | 0.05 | 87 | 1.59 |
| Pancreatic cancer only | 2 | 0.23 | 1 | 0.07 | 3 | 0.24 | 0 | 0. | 1 | 0.04 | 3 | 0.17 | 0 | 0. | 2 | 0.35 | 12 | 0.14 |
| Pharyngeal cancer only | 5 | 0.60 | 6 | 1.60 | 6 | 1.35 | 1 | 0.05 | 1 | 0.09 | 1 | 0.11 | 2 | 0.67 | 0 | 0. | 22 | 0.57 |
| Prostate cancer only | 61 | 9.62 | 71 | 9.72 | 87 | 8.48 | 53 | 9.97 | 51 | 10.76 | 54 | 9.47 | 59 | 8.33 | 42 | 6.20 | 478 | 9.08 |
| Rectal cancer only | 2 | 0.13 | 2 | 0.09 | 2 | 0.15 | 3 | 0.18 | 0 | 0. | 0 | 0. | 2 | 0.21 | 4 | 0.78 | 15 | 0.20 |
| Skin cancer only | 138 | 16.30 | 162 | 17.88 | 239 | 22.44 | 116 | 23.08 | 92 | 20.05 | 107 | 25.40 | 117 | 25.02 | 124 | 24.95 | 1095 | 21.67 |
| Stomach cancer only | 5 | 1.45 | 9 | 1.65 | 3 | 0.35 | 0 | 0. | 3 | 0.50 | 2 | 0.17 | 1 | 0.01 | 2 | 0.71 | 25 | 0.66 |
| More than one cancer checked | 60 | 7.54 | 115 | 10.95 | 140 | 11.32 | 107 | 18.44 | 82 | 18.21 | 66 | 14.17 | 65 | 13.93 | 70 | 13.63 | 705 | 13.72 |
| Other cancer only | 62 | 8.71 | 57 | 7.01 | 50 | 4.99 | 32 | 5.76 | 26 | 5.86 | 24 | 6.57 | 28 | 5.01 | 34 | 6.72 | 313 | 6.42 |
| Lymphoma only (HINTS 1) | 19 | 2.81 | | | | | | | | | | | | | | | | |

Did you ever receive any treatment for your cancer?

| Did you ever receive any treatment for your cancer? | HINTS 1 | HINTS 2 | HINTS 3 | HINTS 4 | HINTS 5 | Combined |
|--------------------------------------------------|---------|---------|---------|---------|---------|----------|
| Yes                                              | 721 | 81.45 | 862 | 86.92 | 417 | 91.01 | 477 | 89.13 | 457 | 91.76 | 2934 | 87.83 |
| No                                               | 151 | 18.55 | 120 | 13.08 | 44 | 8.99 | 55 | 10.87 | 40 | 8.24 | 410 | 12.17 |

How long ago were you diagnosed with cancer? (derived)

| How long ago were you diagnosed with cancer? | HINTS 1 | HINTS 2 | HINTS 3 | HINTS 4 | HINTS 5 | Combined |
|--------------------------------------------|---------|---------|---------|---------|---------|----------|
| Less than 1 year since diagnosis           | 115 | 16.62 | 119 | 15.95 | 99 | 10.90 | 58 | 9.88 | 56 | 10.00 | 58 | 14.49 | 57 | 12.43 | 61 | 15.22 | 623 | 13.43 |
| 2-5 years                                  | 171 | 20.32 | 231 | 31.11 | 241 | 26.61 | 127 | 23.42 | 111 | 28.42 | 117 | 31.10 | 113 | 19.92 | 96 | 17.66 | 1207 | 24.82 |
| 6-10 years                                 | 164 | 23.43 | 160 | 16.06 | 184 | 17.95 | 101 | 20.24 | 84 | 20.31 | 88 | 17.73 | 94 | 21.14 | 95 | 20.73 | 970 | 19.71 |
| 11+ years                                  | 305 | 39.64 | 351 | 36.88 | 442 | 44.54 | 247 | 46.46 | 190 | 41.27 | 170 | 36.69 | 221 | 46.51 | 212 | 46.39 | 2138 | 42.04 |

aHINTS 1 had different response options that did not have liver, Hodgkin and non-Hodgkin cancers. Hodgkin and non-Hodgkin cancers were probably combined under lymphoma.
estimates, and supplemental funding has been granted. The HINTS programme have been employed to calculate regional geographical level, innovative geographical information system strategies have been employed to reduce potential for bias through sampling and weighting procedures. Additionally, methodological research suggests that the negative impact of declining response rates on data quality may not be as dramatic as previously assumed. The HINTS programme team recently conducted a rigorous non-response bias analysis of data from HINTS 4 (Cycles 1 and 3) to characterize the potential impact of non-response. Findings from this study revealed that many of the demographic influences on non-response (e.g. age, socioeconomic status) can be compensated for through application of standard weighting procedures. More specific results of this non-response analysis involving comparison of response rates among population subgroups, comparison with national benchmarks, and level-of-effort analysis have been previously published.

National surveys are usually constrained to measuring constructs with only one or two survey items, to reduce respondent burden. Therefore, the number of items available for measuring complex attitudinal and behavioural constructs is often limited. Although use of single items for measurement of social and behavioural constructs is not ideal, this approach is common in large-scale and national survey research. When compared with validated multi-item scales, single-item measures can have similar test–retest reliability and construct validity; however, single items are less reliable than scales and may attenuate observed associations. Constraints on survey length may also lead to changes in the survey content over time, thereby limiting the temporal trends and comparisons that may be tracked over time.

While the relatively small sample size for HINTS does not support the calculation of reliable estimates at the state level, innovative geographical information system strategies have been employed to calculate regional geographical estimates, and supplemental funding has been granted to certain NCI-designated comprehensive cancer centres to support collection of HINTS data at the local level.

**Data resource access**

The HINTS programme has striven from the beginning to enable users to use the HINTS data as easily as possible. HINTS data are in the public domain, and public use datasets are available for download as SAS, STATA and SPSS files from [https://hints.cancer.gov](https://hints.cancer.gov). Each dataset is bundled with supporting documents including analytics recommendations (including example statistical software code), history document, codebook, methodology report (including details about sampling and the creation of survey weights) and annotated survey instruments. Codebooks for each dataset are also available online, and all of the instruments included in the data download bundle are annotated with variable names and allowable codes. Additionally, several resources been published describing how to use HINTS data: [https://hints.cancer.gov/meetings-trainings/how-to-hints-webinar.aspx](https://hints.cancer.gov/meetings-trainings/how-to-hints-webinar.aspx). Where possible, HINTS adheres to the F.A.I.R. (Findable, Accessible, Interoperable, and Reusable) principles.

**Profile in a nutshell**

- **HINTS** is as a cross-sectional national survey of non-institutionalized adults, developed to track trends in cancer-related communication, health information-seeking and cancer-related knowledge, attitudes and behaviour in the US population. It is the only national population-based survey that collects information on the US public’s need for, access to and experience with cancer-related information.
- **HINTS** was first fielded in 2002–03, and has been administered five times over approximately a 15-year period, with HINTS 4 and 5 including multiple data collection cycles ($n = 37,365$).
- **HINTS** was initially administered as a random digit dial (RDD) computer-assisted telephone interview to a representative sample of households drawn from all telephone exchanges in the US. In 2008, HINTS was fielded using a mixed-mode (RDD telephone interview and mailed questionnaire), dual-frame (all telephone exchanges in the US and a comprehensive national listing of United States Postal Service addresses) format. Each HINTS administration since 2008 has been conducted as a mailed survey using an address-based sampling frame.
- **Each HINTS** instrument includes a core set of items to assess: communication technology access and use, health and cancer information-seeking, cancer-related knowledge and behaviour, cancer risk perceptions and health care access.
- **HINTS** public use datasets are available for download: [https://hints.cancer.gov](https://hints.cancer.gov).
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