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# Genetic Testing for Cancer Risk and Perceived Importance of Genetic Information Among US Population by Race and Ethnicity: a Cross-sectional Study

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## Abstract

**Background** Genetic testing can help determine the risk of many cancers and guide cancer prevention and treatment plans. Despite increasing concern about disparities in precision cancer medicine, public knowledge and cancer genetic testing by race and ethnicity have not been well investigated.

**Methods** We analyzed data from the 2020 Health Information National Trends Survey in 2022. Self-reported cancer genetic testing (e.g., Lynch syndrome, BRCA1/2) knowledge and utilization were compared by race and ethnicity. Perceived importance of genetic information for cancer care (prevention, detection, and treatment) was also examined in relation to the uptake of cancer genetic testing. Multivariable logistic regression models were employed to examine factors associated with knowledge and genetic testing to calculate predicted probability of undergoing genetic testing by race and ethnicity.

**Results** Of 3551 study participants, 37.8% reported having heard of genetic testing for cancer risk and 3.9% stated that they underwent cancer genetic testing. Being non-Hispanic Black (OR=0.47, 95% CI=0.30–0.75) or Hispanic (OR=0.56, CI=0.35–0.90) was associated with lower odds of genetic testing knowledge. Although Hispanic or non-Hispanic Black respondents were more likely to perceive higher importance of genetic information versus non-Hispanic Whites, they had a lower predicted probability of cancer genetic testing.

**Conclusion** Non-Hispanic Black and Hispanic adults had lower knowledge and were less likely to undergo cancer genetic testing than non-Hispanic Whites. Further research is needed on sources of genetic testing information for racial and ethnic minorities and the barriers to accessing genetic testing to inform the development of effective cancer risk genetic testing promotion.

**Keywords** Cancer risk genetic testing · Public knowledge · Racial and ethnic disparities · Health Information National Trends Survey

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## Introduction

With the rapid advances in genomic technologies during the past decades, genetic testing has become widely used in clinical practice for identification of individuals at increased risk for inherited conditions [1]. Cancer is the most common genetic disease; and genetic testing allows identification of high-risk individuals who may benefit from interventions that mitigate risk and personalize care [2]. For example, genetic testing for hereditary breast and ovarian cancer syndrome (HBOC) and Lynch syndrome are listed in tier 1 genomic applications by the Office of Public Health Genomics at the Centers for Disease Control and Prevention (CDC), given their significant potential for reducing cancer morbidity and mortality through early detection [3].

Individual knowledge and awareness are well-established factors that increase the likelihood of initiating patient-provider discussion for shared decision-making regarding utilization of genetic testing [4–6]. Public knowledge of genetic testing for health has increased over time in the U.S. Data from a national survey show that between 2007 and 2017, the percentage of US adults who reported knowledge of health-related genetic testing increased from 31% to 57% [6, 7]. The current literature indicates that, despite increased media coverage and direct-to-consumer marketing for genetic tests in recent years, [6, 7] there is still a lack of empirical evidence about genetic testing among ethnic and racial minorities or those who are economically disadvantaged (e.g., low-income, rural residents) [8, 9]. A few studies have primarily focused on racial and ethnic disparities in the knowledge of genetic testing for cancer risk [10]. However, their estimates are outdated (2005 data), and they lack a comprehensive assessment of how knowledge/perception of cancer genetics interacts with the actual use of this testing across different races and ethnic groups. Existing differences in knowledge and awareness of genetic testing may have adversely affected genetic testing access and/or adoption, with negative implications for the use of personalized medicine [9]. For example, cancer patients from racial and ethnic minority backgrounds and those with publicly funded health insurance plans were less likely to undergo genetic testing than non-Hispanic White patients and those with private plans [11, 12].

Examining knowledge of cancer genetic testing and its association with the receipt of that testing would provide opportunities to optimize cancer care. Previous research on genetic literacy in the U.S. population assessed the public knowledge of genetic testing for general health purposes [8]. However, it is still unclear to what extent potential cancer patients are aware of and utilizing high-risk cancer testing, such as testing for BRCA1/2 or Lynch syndrome. Although prior evidence demonstrated no significant association between race and ethnicity and perception of cancer-related risk [13–15], it remains unknown whether racial and ethnic disparities exist in knowledge and perception of cancer genetic testing. To address this knowledge gap, we analyzed nationally representative data to [1] examine the prevalence of cancer genetic testing knowledge and its utilization by race and ethnicity, and [2] investigate the association between perceived importance of genetic testing for cancer care and receipt of cancer genetic testing. Lastly, we [3] explored whether racial and ethnic disparities exist in the association between perceived importance of genetic information and cancer genetic testing.

## Materials and Methods

### Data, Design, and Study Population

This was a cross-sectional analysis of the 2020 Health Information National Trends Survey (HINTS-5 Cycle 4), a nationally representative survey by the National Cancer Institute to assess and track public knowledge and use of health-related information among US adult population [16]. A total of 3551 respondents were included with complete information on knowledge and receipt of genetic testing in the HINTS Genetic Testing Module (314 were excluded from the total of 3865 who completed surveys) [17]. One hundred and ninety-two respondents were excluded due to missing information on key study variables (family cancer history, $n$=86; perceived importance of genetic testing, $n$=106). Those excluded were likely to be older, male, or have lower education and family income. No other difference was detected between those included and excluded. The final analytic sample included 3359 US adults ages 18 years or older (representing 226 million Americans). This study was exempted from review by the University of Florida Institutional Review board and followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines.

### Knowledge and Receipt of Cancer Genetic Testing

Knowledge and receipt of genetic testing for cancer risk were assessed from binary (yes/no) responses to survey questions. Respondents were asked if they had ever heard of high-risk cancer testing (for example, BRCA1/2 or Lynch syndrome) and if they had ever received cancer genetic testing. As we aimed to capture only clinically relevant or actionable

cancer genetic tests, we did not include direct-to-consumer or ancestry genetic tests (e.g., 23andMe).

### Perceived Importance of Genetic Information for Cancer Care

Respondents were asked about the perceived importance of knowing a person's genetic information for cancer care. The questions were as follows: *"How important is knowing a person's genetic information for … (1) preventing cancer? (2) detecting cancer? and (3) treating cancer?"*. Three components of cancer care (prevention, detection, and treatment) were assessed using a 4-point Likert scale ranging from 1 "Very important" and 4 "Not at all."

### Covariates

Covariates were selected a priori based on previous research on genetic testing knowledge and use; [4–10] we also considered and included individual characteristics associated with cancer risk and access to health services in previous research [18, 19]. HINTS data included self-reported sociodemographic and health-related information; and we used these characteristics for bivariate and multivariable analysis. Sociodemographic variables included race and ethnicity (Hispanic, non-Hispanic Black, non-Hispanic White, and Other; due to small cell sizes, we decided to combine Alaska Native, American Indian, Asian, Pacific Islander, and multiple races into Other group), age (18–34, 35–49, 50–64, 65–74, and 75+), sex, education (high school or less, some college, and college graduate or higher), marital status, family income (less than $20,000, $20,000–$49,999, $50,000–$99,999, and $100,000 or higher), census region, and health insurance type (private, public, and uninsured). Health-related variables included self-reported cancer type (no cancer history, melanoma/skin, breast/lung/colorectal, and other cancer types), family history of cancer (first- and second-degree biological relatives), obesity (defined as BMI>29.9 kg/m$^2$), current smoking, and the number of comorbidities except cancer (i.e., hypertension, diabetes, heart disease, lung disease, and depression). Given the association of increasing patient knowledge with frequent visits to health care or using the Internet for health-related information [19, 20], we also included the number of visits to health care providers in the past 12 months and online health information–seeking behavior (measured as whether using a computer or smart device to look for health or medical information in the past 12 months) as covariates.

### Statistical Analysis

We employed survey-design methods weighted to provide nationally representative estimates. We applied HINTS complex survey methodology and jackknife replicate weights to estimate accurate standard errors [17]. Descriptive statistics were used to summarize sample characteristics. Separate multivariable logistic regression models were fitted to identify factors associated with knowledge and receipt of genetic testing for cancer risk, including all patient sociodemographic and health-related characteristics listed above. We used general linear regression models to compare the perceived importance of genetic information by race and ethnicity. We then used the logistic regression model to calculate and compare the predicted probability of receiving cancer genetic testing across varying levels of perceived importance of genetic information (Not at all/A little, Somewhat, and Very important) stratified by race and ethnicity—these estimates can be interpreted as the expected probability that each race/ethnic group will undergo genetic testing for cancer risk after adjustment for covariates [21]. Finally, we conducted additional exploratory subgroup analyses using the same logistic models to further examine potential racial and ethnic disparities in the utilization of cancer genetic testing among high-risk groups [9, 22]. We restricted the analytic sample to 3 different subsets of participants with any cancer diagnosis, breast/lung/colorectal cancer types, and family cancer history. Statistical significance was defined as 2-sided $P$ value <.01 for multiple comparisons. All analyses were performed using SAS 9.4 (SAS Institute, Cary, NC) between March and July in 2022.

### Data Availability

Data were obtained from the National Cancer Institute, Division of Cancer Control and Population Sciences Health Communication and Informatics Research Branch and available online at https://hints.cancer.gov/.

## Results

### Knowledge of Genetic Testing for Cancer Risk

A total of 3359 respondents (mean age [SE], 47.3 [0.3]; 50.5% women; 61.0% non-Hispanic White; 10.5% non-Hispanic Black; 15.4% Hispanic, 13.1% other races) were included in this study. Overall, 37.8% (95% CI, 35.1%–40.5%) of individuals reported having ever heard of genetic testing for cancer risk (Table 1). In the multivariable model, individual factors associated with higher odds of cancer genetic testing knowledge were being female (OR=1.93, [95% CI, 1.40–2.65]) compared with male and having family history of cancer (OR=1.68, [95% CI, 1.30–2.18]) compared with no family history. Non-Hispanic Black (OR=0.47, [95%

**Table 1** Characteristics of study participants by Cancer Genetic Testing Awareness and Receipt of the Testing, HINTS 2020

| | Heard of genetic testing for cancer risk | | | | Had genetic testing for cancer risk | | | |
|---|---|---|---|---|---|---|---|---|
| | No | Yes | Adjusted odds ratio[a] | | No | Yes | Adjusted odds ratio[a] | |
| | | | | | No | Yes | | |
| Unweighted population | 2057 | 1302 | | | 3212 | 147 | | |
| Weighted population | 140,856,515 | 85,598,557 | | | 77,790,636 | 7,808,197 | | |
| Characteristics | % (95% CI)[b] | % (95% CI) [b] | OR (95% CI) | P-value | % (95% CI) [b] | % (95% CI) [b] | OR (95% CI) | *P*-value |
| Race/ethnicity | | | | | | | | |
| Hispanic | 73.8 (66.8–80.8) | 26.2 (19.2–33.2) | 0.57 (0.35–0.91) | 0.020 | 98.2 (97.1–99.3) | 1.8 (0.7–2.9) | 0.62 (0.29–1.31) | 0.206 |
| Non-Hispanic Black | 77.0 (70.9–83.2) | 23.0 (16.8–29.1) | 0.47 (0.30–0.74) | 0.002 | 97.1 (94.7–99.5) | 2.9 (0.5–5.3) | 0.83 (0.27–2.60) | 0.750 |
| Non-Hispanic White | 55.7 (52.1–59.3) | 44.3 (40.7–47.9) | Reference | | 95.4 (93.9–96.9) | 4.6 (3.1–6.1) | Reference | |
| Other[c] | 67.0 (58.0–76.1) | 33.0 (23.9–42.0) | 0.74 (0.46–1.20) | 0.217 | 96.2 (93.3–99.0) | 3.8 (1.0–6.7) | 1.36 (0.48–3.87) | 0.561 |
| Age group | | | | | | | | |
| 18–34 | 63.7 (55.5–71.9) | 36.3 (28.1–44.5) | 1.43 (0.73–2.78) | 0.286 | 98.8 (97.8–99.8) | 1.2 (0.2–2.2) | 1.00 (0.13–7.58) | 0.998 |
| 35–49 | 55.4 (50.1–60.7) | 44.6 (39.3–49.9) | 2.03 (1.23–3.35) | 0.007 | 95.0 (92.5–97.6) | 5.0 (2.4–7.5) | 3.09 (0.62–15.31) | 0.164 |
| 50–64 | 61.7 (57.6–65.8) | 38.3 (34.2–42.4) | 1.59 (0.95–2.66) | 0.079 | 93.9 (91.5–96.3) | 6.1 (3.7–8.5) | 3.41 (0.85–13.63) | 0.081 |
| 65–74 | 65.4 (60.5–70.2) | 34.6 (29.8–39.5) | 1.49 (0.93–2.39) | 0.097 | 96.4 (94.6–98.2) | 3.6 (1.8–5.4) | 1.20 (0.32–4.51) | 0.780 |
| 75+ | 76.7 (70.3–83.1) | 23.3 (16.9–29.7) | Reference | | 96.7 (94.0–99.3) | 3.3 (0.7–6.0) | Reference | |
| Sex | | | | | | | | |
| Male | 69.4 (64.4–74.4) | 30.6 (25.6–35.6) | Reference | | 98.1 (97.1–99.2) | 1.9 (0.8–2.9) | Reference | |
| Female | 55.0 (52.2–57.9) | 45.0 (42.1–47.8) | 1.93 (1.40–2.65) | <.001 | 94.0 (92.2–95.8) | 6.0 (4.2–7.8) | 2.39 (1.29–4.44) | 0.007 |
| Education | | | | | | | | |
| High school graduate or less | 76.7 (70.5–82.9) | 23.3 (17.1–29.5) | Reference | | 95.7 (93.3–98.0) | 4.3 (2.0–6.7) | Reference | |
| Some college | 62.0 (57.4–66.5) | 38.0 (33.5–42.6) | 1.59 (0.98–2.6) | 0.062 | 96.0 (94.0–97.9) | 4.0 (2.1–6.0) | 0.67 (0.28–1.61) | 0.361 |
| College graduate or higher | 49.4 (45.6–53.1) | 50.6 (46.9–54.4) | 2.11 (1.23–3.6) | 0.008 | 96.5 (95.3–97.7) | 3.5 (2.3–4.7) | 0.48 (0.19–1.20) | 0.114 |
| Marital status | | | | | | | | |
| Married | 58.7 (55.5–61.9) | 41.3 (38.1–44.5) | Reference | | 95.2 (93.7–96.8) | 4.8 (3.2–6.3) | Reference | |
| Divorced/widowed/separated | 68.2 (64.0–72.4) | 31.8 (27.6–36.0) | 0.85 (0.62–1.17) | 0.319 | 94.0 (91.2–96.8) | 6.0 (3.2–8.8) | 1.52 (0.79–2.90) | 0.205 |
| Single | 64.5 (58.6–70.4) | 35.5 (29.6–41.4) | 1.11 (0.81–1.53) | 0.517 | 98.0 (96.6–99.4) | 2.0 (0.6–3.4) | 1.00 (0.38–2.63) | 0.994 |
| Family income | | | | | | | | |
| Less than $20,000 | 76.1 (70.8–81.4) | 23.9 (18.6–29.2) | Reference | | 96.5 (94.4–98.6) | 3.5 (1.4–5.6) | Reference | |
| $20,000 to < $50,000 | 69.9 (64.8–75.0) | 30.1 (25.0–35.2) | 1.17 (0.74–1.84) | 0.492 | 97.7 (96.5–99.0) | 2.3 (1.0–3.5) | 0.49 (0.16–1.56) | 0.223 |

**Table 1** (continued)

| | Heard of genetic testing for cancer risk | | | | Had genetic testing for cancer risk | | | |
|---|---|---|---|---|---|---|---|---|
| | No | Yes | Adjusted odds ratio[a] | | No | Yes | Adjusted odds ratio[a] | |
| | | | | | No | Yes | | |
| Unweighted population | 2057 | 1302 | | | 3212 | 147 | | |
| Weighted population | 140,856,515 | 85,598,557 | | | 77,790,636 | 7,808,197 | | |
| Characteristics | % (95% CI)[b] | % (95% CI) [b] | OR (95% CI) | P-value | % (95% CI) [b] | % (95% CI) [b] | OR (95% CI) | *P*-value |
| $50,000 to < $100,000 | 59.6 (54.2–65.1) | 40.4 (34.9–45.8) | 1.47 (0.95–2.26) | 0.081 | 95.5 (93.3–97.6) | 4.5 (2.4–6.7) | 1.35 (0.57–3.18) | 0.484 |
| $100,000 or More | 52.7 (46.8–58.6) | 47.3 (41.4–53.2) | 1.61 (0.92–2.79) | 0.092 | 95.3 (93.2–97.3) | 4.7 (2.7–6.8) | 1.19 (0.50–2.88) | 0.688 |
| Census region | | | | | | | | |
| Northeast | 62.8 (55.7–69.9) | 37.2 (30.1–44.3) | Reference | | 97.1 (95.1–99.1) | 2.9 (0.9–4.9) | Reference | |
| Midwest | 55.4 (48.5–62.4) | 44.6 (37.6–51.5) | 1.30 (0.89–1.88) | 0.170 | 95.1 (92.6–97.6) | 4.9 (2.4–7.4) | 1.71 (0.70–4.13) | 0.231 |
| South | 64.3 (59.8–68.7) | 35.7 (31.3–40.2) | 1.00 (0.68–1.48) | 0.989 | 96.3 (94.8–97.8) | 3.7 (2.2–5.2) | 1.19 (0.45–3.18) | 0.719 |
| West | 64.2 (57.9–70.5) | 35.8 (29.5–42.1) | 0.95 (0.60–1.51) | 0.833 | 95.9 (93.6–98.1) | 4.1 (1.9–6.4) | 1.30 (0.44–3.84) | 0.630 |
| Health insurance | | | | | | | | |
| Private | 57.9 (54.6–61.3) | 42.1 (38.7–45.4) | Reference | | 95.3 (93.9–96.8) | 4.7 (3.2–6.1) | Reference | |
| Public | 71.9 (66.4–77.4) | 28.1 (22.6–33.6) | 0.90 (0.60–1.35) | 0.607 | 96.7 (95.3–98.2) | 3.3 (1.8–4.7) | 0.88 (0.45–1.73) | 0.710 |
| Uninsured | 64.9 (51.8–78.1) | 35.1 (21.9–48.2) | 1.19 (0.55–2.57) | 0.649 | 99.9 (99.8–100) | 0.1 (0.0–0.2) | 0.02 (0.01–0.05) | <.001 |
| Cancer diagnosis | | | | | | | | |
| No | 62.5 (59.4–65.6) | 37.5 (34.4–40.5) | Reference | | 97.0 (96.0–97.9) | 3.0 (2.1–4.0) | Reference | |
| Melanoma/skin | 54.7 (46.4–63.0) | 45.3 (37.0–53.6) | 1.20 (0.80–1.81) | 0.369 | 96.7 (93.7–99.7) | 3.3 (0.3–6.3) | 0.94 (0.30–2.89) | 0.905 |
| Breast/lung/CRC | 37.3 (21.2–53.5) | 62.7 (46.5–78.8) | 2.52 (1.27–5) | 0.009 | 49.8 (33.3–66.3) | 50.2 (33.7–66.7) | 27.60 (12.16–62.62) | <.001 |
| Other types | 73.0 (65.2–80.8) | 27.0 (19.2–34.8) | 0.80 (0.49–1.28) | 0.341 | 95.0 (91.0–99.1) | 5.0 (0.9–9.0) | 1.96 (0.73–5.28) | 0.180 |
| Family history of cancer | | | | | | | | |
| No | 73.0 (68.6–77.5) | 27.0 (22.5–31.4) | Reference | | 98.6 (97.8–99.5) | 1.4 (0.5–2.2) | Reference | |
| Yes | 57.6 (54.6–60.5) | 42.4 (39.5–45.4) | 1.68 (1.30–2.18) | <.001 | 95.0 (93.5–96.5) | 5.0 (3.5–6.5) | 2.72 (1.12–6.65) | 0.029 |
| Number of comorbidities | | | | | | | | |
| 0 | 59.4 (55.4–63.3) | 40.6 (36.7–44.6) | Reference | | 96.0 (94.8–97.3) | 4.0 (2.7–5.2) | Reference | |
| 1 | 60.6 (55.7–65.5) | 39.4 (34.5–44.3) | 1.05 (0.78–1.41) | 0.740 | 96.4 (94.4–98.3) | 3.6 (1.7–5.6) | 0.78 (0.35–1.75) | 0.539 |
| 2+ | 73.6 (68.7–78.5) | 26.4 (21.5–31.3) | 0.68 (0.45–1.01) | 0.057 | 95.8 (93.7–97.9) | 4.2 (2.1–6.3) | 1.13 (0.45–2.79) | 0.795 |
| Obesity | | | | | | | | |
| No | 59.8 (56.7–63.0) | 40.2 (37.0–43.3) | Reference | | 95.2 (93.7–96.7) | 4.8 (3.3–6.3) | Reference | |
| Yes | 66.9 (61.8–72.0) | 33.1 (28.0–38.2) | 0.86 (0.62–1.18) | 0.343 | 97.9 (97.0–98.8) | 2.1 (1.2–3.0) | 0.33 (0.16–0.66) | 0.003 |

**Table 1** (continued)

| | Heard of genetic testing for cancer risk | | | | Had genetic testing for cancer risk | | | |
|---|---|---|---|---|---|---|---|---|
| | No | Yes | Adjusted odds ratio[a] | | No | Yes | Adjusted odds ratio[a] | |
| | | | | | No | Yes | | |
| Unweighted population | 2057 | 1302 | | | 3212 | 147 | | |
| Weighted population | 140,856,515 | 85,598,557 | | | 77,790,636 | 7,808,197 | | |
| Characteristics | % (95% CI)[b] | % (95% CI) [b] | OR (95% CI) | P-value | % (95% CI) [b] | % (95% CI) [b] | OR (95% CI) | *P*-value |
| Current smoking | | | | | | | | |
| No | 62.2 (59.3–65.2) | 37.8 (34.8–40.7) | Reference | | 96.3 (95.2–97.3) | 3.7 (2.7–4.8) | Reference | |
| Yes | 61.9 (54.5–69.3) | 38.1 (30.7–45.5) | 1.19 (0.74–1.93) | 0.465 | 94.9 (91.3–98.6) | 5.1 (1.4–8.7) | 1.05 (0.38–2.85) | 0.929 |
| Online health information-seeking | | | | | | | | |
| No | 76.6 (71.2–82.0) | 23.4 (18.0–28.8) | Reference | | 97.4 (95.9–98.8) | 2.6 (1.2–4.1) | Reference | |
| Yes | 57.3 (54.2–60.4) | 42.7 (39.6–45.8) | 1.43 (0.94–2.19) | 0.097 | 95.7 (94.3–97.0) | 4.3 (3.0–5.7) | 1.07 (0.47–2.47) | 0.865 |
| Number of visits to health care provider[d] | | | | | | | | |
| 0 | 69.2 (61.7–76.7) | 30.8 (23.3–38.3) | Reference | | 97.5 (95.6–99.5) | 2.5 (0.5–4.4) | Reference | |
| 1–2 | 62.1 (57.4–66.9) | 37.9 (33.1–42.6) | 1.11 (0.73–1.68) | 0.637 | 96.8 (95.2–98.4) | 3.2 (1.6–4.8) | 0.86 (0.27–2.72) | 0.793 |
| 3–4 | 59.5 (54.2–64.9) | 40.5 (35.1–45.8) | 1.23 (0.81–1.89) | 0.329 | 94.8 (92.6–97.0) | 5.2 (3.0–7.4) | 1.20 (0.36–3.94) | 0.762 |
| 5+ | 59.6 (54.3–64.9) | 40.4 (35.1–45.7) | 1.29 (0.79–2.11) | 0.296 | 95.2 (93.1–97.3) | 4.8 (2.7–6.9) | 0.90 (0.31–2.60) | 0.838 |
| Knowledge of cancer genetic testing | | | | | | | | |
| No | – | – | – | – | 99.3 (98.6–99.9) | 0.7 (0.1–1.4) | Reference | |
| Yes | – | – | – | – | 90.9 (88.4–93.4) | 9.1 (6.6–11.6) | 13.72 (5.75–32.8) | <.001 |

*HINTS*, Health Information National Trends Survey; *CI*, confidence interval; *OR*, odds ratio

[a]Adjusted for all variables listed in the table

[b]Percentages were weighted to be representative of the US population

[c]Includes Asians, Pacific Islanders, American Indians, Alaskan Natives, Multiracial, and other races

[d]In the past 12 months

CI, 0.30–0.75]) or Hispanic participants (OR=0.56, [95% CI, 0.35–0.90]) had a lower likelihood of cancer genetic testing knowledge compared with non-Hispanic White participants.

### Receipt of Genetic Testing for Cancer Risk

A percentage of 3.9% (95% CI, 2.8%–5.0%) reported receiving genetic testing for cancer risk (Table 1). Similar to the results of genetic testing knowledge, being female (OR=2.39, [95% CI, 1.29–4.44]) or having family cancer history (OR=2.72, [95% CI, 1.12–6.65]) were associated with increased odds of receiving the genetic testing. Individuals with diagnosis of breast/lung/CRC were also more likely (OR=27.6, [95% CI, 12.16–62.62)) to have cancer genetic testing than those without cancer. Having obesity (OR=0.33, [95% CI=0.16–0.66]) or being uninsured (OR=0.02, [95% CI, 0.01–0.05]) were associated with decreased likelihood of having genetic testing for cancer risk.

### Perceived Importance of Genetic Information for Cancer Care

Overall, more than half of respondents perceived genetic information as "very important" for preventing cancer (52%), detecting cancer (61%), and treating cancer (51%) (Fig. 1). When compared by race and ethnicity, non-Hispanic Black and Hispanic than non-Hispanic participants were more likely to report affirmatively ("very important" and "somewhat important" combined) to the importance of genetic information for cancer prevention ($P$=0.013) and treatment ($P$<.001; data not shown).

### Association Between Perceived Importance of Genetic Information and Cancer Genetic Testing

There was a statistically significant association between the perceived importance of genetic information and the likelihood of receiving cancer genetic testing ($P$<.01 for all) (Fig. 2). With all racial and ethnic groups combined, the predicted probability of cancer genetic testing appeared to increase as the degree of perceived importance of genetic information to cancer prevention, detection, and treatment increased. To ease the interpretation of the results by each cancer care domain, we combined four levels of perceived importance into two levels (very or somewhat important vs. a little or not at all). For example, respondents who perceived genetic information as "very or somewhat important" for preventing cancer had a higher predicted probability of receiving the test (4.6%, [95% CI, 4.0%–5.2%]) than those responding "a little or not at all" (1.7%, [95% CI, 1.3%–2.2%]) (2.9% probability difference; data not shown). Similar associations were observed when stratified by race and ethnicity (Fig. 2). In analyses of those who considered genetic testing to be very or somewhat important for preventing cancer (Fig. 2 [A]), the predicted probability of cancer genetic testing was lower for non-Hispanic Black and Hispanic respondents (3.2%, [95% CI, 2.4%–4.1%], 2.1%, [95% CI, 1.4%–2.8%], respectively) than non-Hispanic White respondents (5.5%, [95% CI, 4.6%–6.4%]).

### Subgroup Analysis

In analyses of selected population subgroups (Table 2), no significance difference was observed among those with any cancer diagnosis. However, when restricted to those with breast/lung/CRC cancer, non-Hispanic Black (31.7%, [95% CI, 11.6%–51.9%]) and other race group (31.4%, 95% CI, [17.1%–45.6%]) had lower predicted probability of cancer genetic testing than non-Hispanic White group (56.5%, [95% CI, 41.8%–71.2%]). Among those with family cancer history, Hispanic respondents had 2.8% (95% CI, −3.9% to −1.7%) lower predicted probabilities of receiving cancer genetic testing compared with non-Hispanic Whites.

## Discussion

Our analysis of nationally representative data indicates that more than one-third (38%) of US adults report having heard of genetic testing for cancer risk and only 3.9% of the population reported receiving cancer genetic testing. Our estimates appear to be lower than previous estimates in 2017 (57.1% had heard of genetic testing for health risk; and 5.4% underwent at least one test for cancer risk) [8]. Being non-Hispanic Black, Hispanic individuals, male, and having no family history of cancer were associated with lower odds of cancer genetic testing knowledge. Females and those with private insurance, personal cancer history of breast/lung/CRC, and family history of cancer were more likely to report having genetic testing for cancer risk. Overall, this study found a low public knowledge of cancer genetic testing and receipt of testing among the US adults, although the perceived importance of genetic information for cancer screening and treatment was relatively high.

Consistent with previous studies on public knowledge about direct-to-consumer genetic testing [6, 9] and genetic literacy [8, 23], our findings revealed racial and ethnic disparities in the knowledge of cancer genetic testing, suggesting the need for more targeted public health messaging and culturally tailored patient educational interventions for racial and ethnic minority populations [8–10]. Intriguingly, we found that genetic information was perceived as more important for cancer screening, detection, and treatment among non-Hispanic Black and Hispanic individuals than among non-Hispanic White individuals. However, non-Hispanic Black and Hispanic respondents had lower prevalence

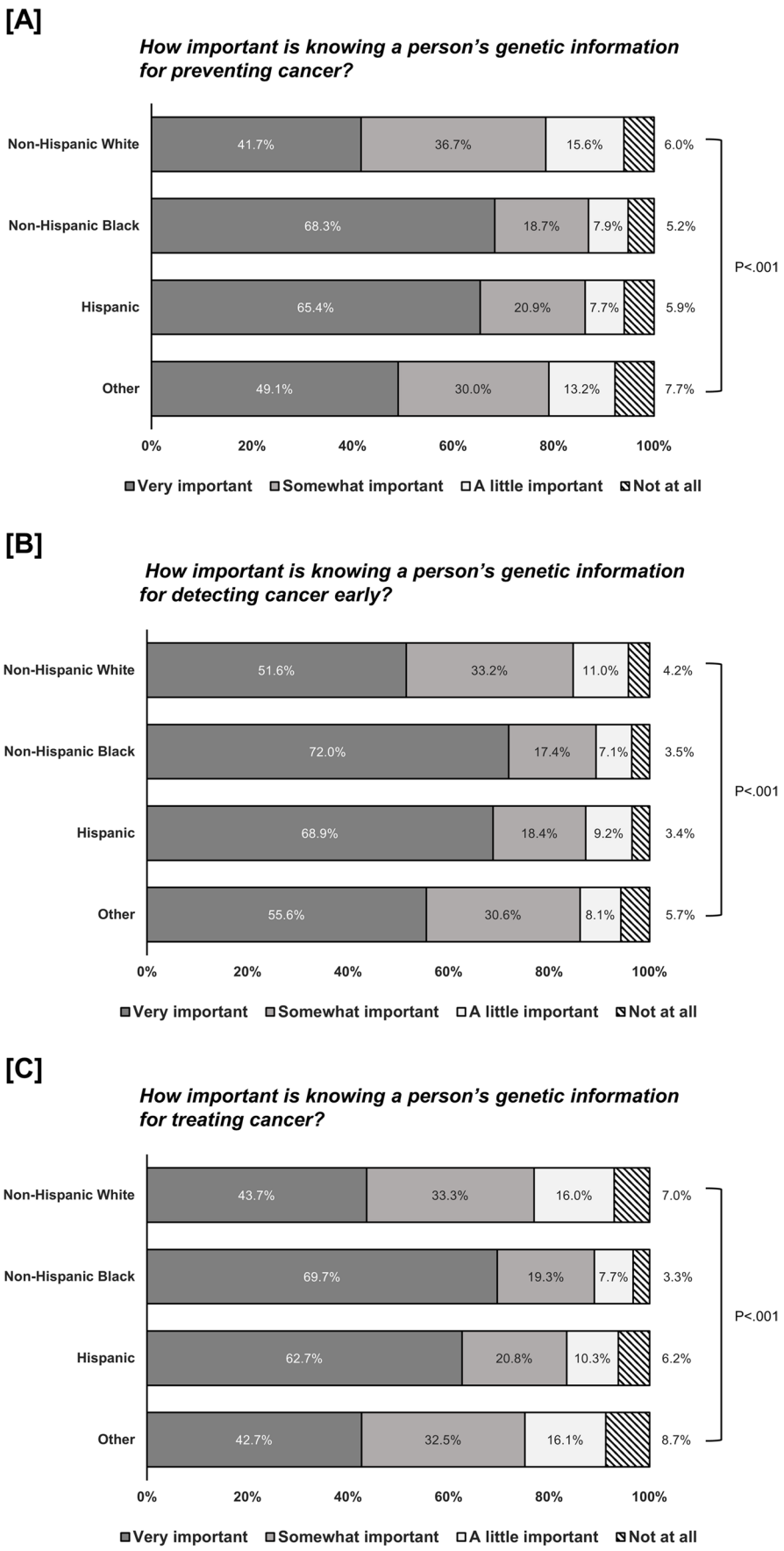


**Fig. 1** Perceived importance of genetic information for cancer care by race and ethnicity. Panel [**A**] for cancer prevention; panel [**B**] for cancer detection; and panel [**C**] for cancer treatment

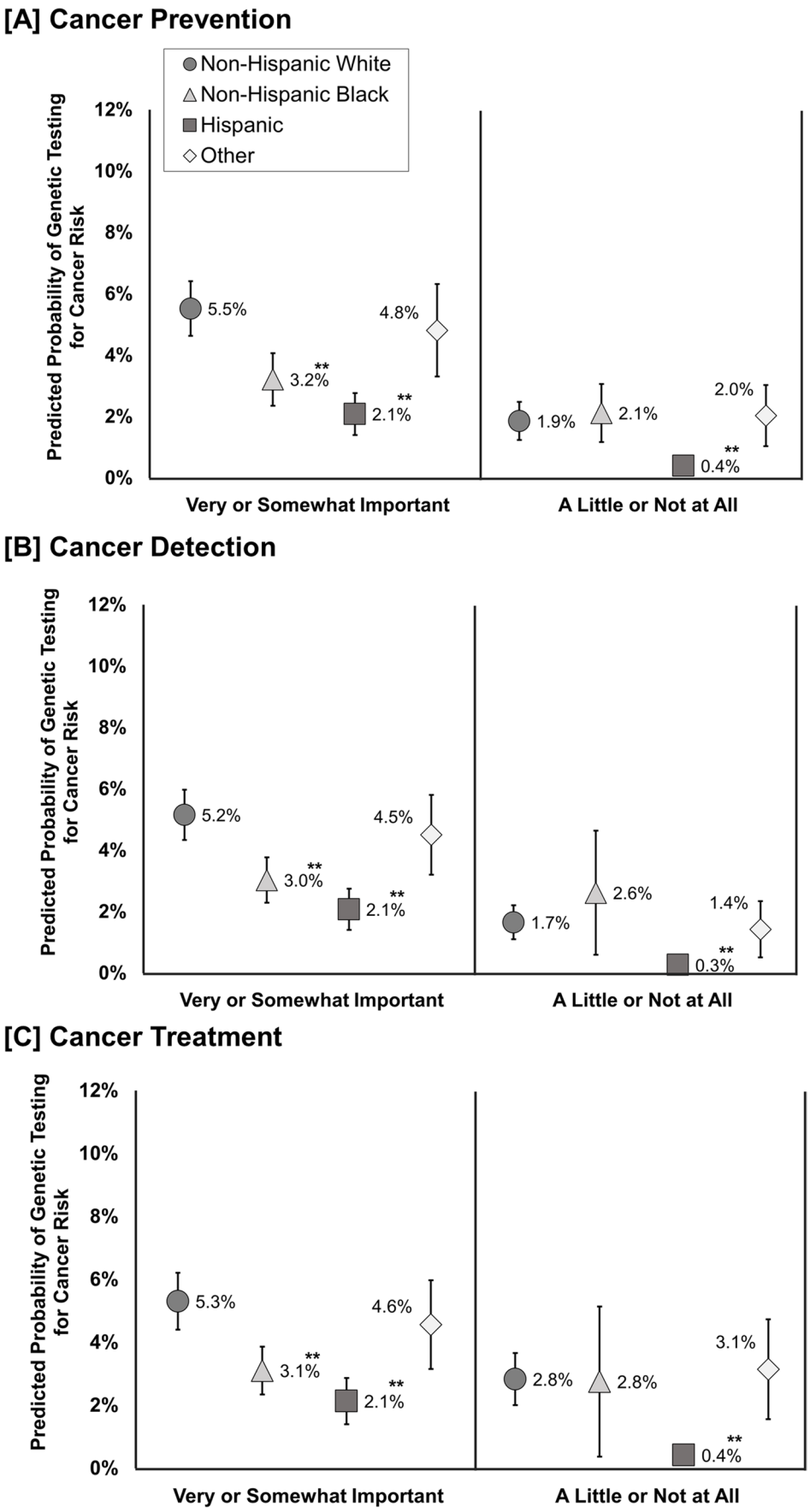


**Fig. 2** Predicted probability of receiving genetic testing for cancer risk by perceived importance of genetic information items, stratified by race and ethnicity. Separate logistic regression models were estimated for each level of perceived importance of genetic information. All models were adjusted for age, sex, education, marital status, family income, census region, insurance type, the number of comorbidities, obesity, current smoking, online health information-seeking behavior, and the number of visits to providers in the past 12 months. *Statistically significant at <0.01; **statistically significant at <0.001

**Table 2** Predicted probability of receiving genetic testing for cancer risk by cancer type and familiar risk, stratified by race/ethnicity

| | Probability of receiving cancer genetic testing, % (95% CI)[a] | | | | | |
|---|---|---|---|---|---|---|
| | Subgroup population[b] | | | | | |
| | Any cancer diagnosis | Difference | Breast/lung/CRC | Difference | Family cancer history | Difference |
| Race/ethnicity | | | | | | |
| Hispanic | 13.1 (4.6–21.7) | −0.4 (−10.5 to 9.6) | 37.6 (9.4 to 65.7) | −18.5 (−65.7 to 28.8) | 2.8 (1.9 to 3.6) | −2.8** (-3.9 to -1.7) |
| Non-Hispanic Black | 12.0 (4.4–19.5) | −1.7 (−10.7 to 7.3) | 31.7 (11.6 to 51.9) | −24.8** (−47.4 to -2.3) | 3.8 (2.8 to 4.9) | −1.7* (−3.3 to -0.2) |
| Non-Hispanic White | 13.6 (7.9–19.4) | Reference | 56.5 (41.8 to 71.2) | Reference | 5.6 (4.7 to 6.4) | Reference |
| Other[c] | 9.0 (4.8–13.3) | −4.6 (−11.7 to 2.5) | 31.4 (17.1 to 45.6) | -25.2** (−45.9 to −4.4) | 5.4 (4.1 to 6.7) | −0.2 (−1.7 to 1.4) |

*CI*, confidence interval; *CRC*, colorectal cancer

*Statistically significant at <0.01 ** Statistically significant at <0.001

[a]Adjusted for age, sex, education, marital status, family income, census region, insurance type, the number of comorbidities, obesity, current smoking, online health information seeking behavior, the number of visits to provider in the past 12 months

[b]Each model was estimated separately with the same set of covariates above

[c]Includes Asians, Pacific Islanders, American Indians, Alaskan Natives, Multiracial, and other races

of cancer genetic testing knowledge than non-Hispanic Whites. They also had lower uptake rate of cancer genetic testing. These findings should be applied to the development of interventions, such as cancer patient navigation programs that are intended to facilitate effective communication regarding genetic testing in racial and ethnic minority groups.

As precision medicine disseminates further into the practice and includes aspects of medicine beyond cancer (e.g., cardiovascular, neurodegenerative, pharmacologic), it is essential to develop practical genetic risk communication tools [24–26]. Individual perceptions and attitudes about cancer genetic information play an important role in cancer risk assessment, cancer screening, and personalized cancer care [23, 27]. In this study, more than half of the study participants selected the most affirmative response regarding the importance of genetic information for cancer care. Specifically, racial and ethnic minority groups perceive genetic information for cancer differently from non-Hispanic White groups. Although we were unable to identify specific reasons for these differences in this analysis, it is possible that these differences are at least partially explained by higher perceptions of general cancer risk among racial and ethnic minorities [28, 29]. Studies have shown that a high perception of disease risk is associated with limited ability to obtain information and lack of preventive behavior, which results in fear and anxiety about the disease [30]. Therefore, those who perceive that they are at higher risk of cancer than their peers are more likely to require health education, counseling, and risk communication services [31]. Further investigation is needed on potential links between perceived cancer risks and the use of preventive care services (e.g., cancer screenings, genetic testing) among different racial and ethnic groups.

Our findings also demonstrated an association between increased likelihood of testing and the higher perceived importance of genetic information for cancer care. Notably, greater proportion of non-Hispanic Black and Hispanic respondents perceived the importance of genetic information; however, their likelihood of genetic testing was significantly lower non-Hispanic Whites. This difference was also observed in our subgroup analyses. While there was no significant difference in the subgroup with any cancer diagnosis, we observed that predicted probability of cancer genetic testing was lower for racial and ethnic minorities (18%–25% differences) among the subgroup with breast/lung/cancer diagnosis. This is concerning given that genetic variants may contribute to a substantial portion (5%–10%) of those types of cancer [18, 32]. Moreover, despite the increased risk among individuals with a family history of caner [18, 32], non-Hispanic Black and Hispanic respondents with family cancer history were less likely to undergo cancer genetic testing than their non-Hispanic White counterparts. Cancer risk perception by hereditary risk may not be a decisive factor that drives genetic testing and other preventive care uptakes. Prior studies on cancer risk perception and screening adherence also found no significant association among racial and ethnic minorities [33, 34]. It is also possible that racial and ethnic minority groups may face greater difficulty accessing cancer genetic testing despite higher cancer risk perception (e.g., testing cost burden, distrust in health provider) [35–37]. In particular, Hispanic individuals often

cited language problems, poor communication with providers, and low patient satisfaction, all of which are likely to pose additional barriers to cancer genetic testing [37–39]. Taken together, these findings suggest different pathways and barriers that may influence perceptions of health-related risk, adoption of preventive health behaviors, and use of related health services. Implementing health needs assessment for medical genetic services [26] or patient navigation programs for hereditary cancer risk [40] may be an effective strategy to target at-risk patients and provide information on the benefits of cancer genetic testing in clinical settings [26]. Further studies are necessary to better understand these pathways of cancer risk perception, the perceived importance of genetic information, and what motivates cancer genetic testing behavior across different racial and ethnic groups.

### Limitations

To our knowledge, this is the first study to provide a snapshot of the national prevalence and racial and ethnic disparities in knowledge and utilization of cancer-specific genetic testing. Nevertheless, this study has several limitations. Our analysis relied on self-reported information, and secondary data analysis limits our ability to measure other potential confounder (e.g., occupation, environmental factors) or other aspects of genetic testing for cancer risk and the perceived importance of genetic information (e.g., in-dept knowledge, other health services use). Furthermore, we were not able to confirm receipt of genetic testing nor determine whether cancer genetic testing was patient-or provider-initiated. Unlike direct-to-consumer genetic testing services (primarily based on personal interest), clinical genetic testing is ordered by clinicians based on a patient's medical conditions (e.g., testing for genes associated with a disease when symptoms are present) or hereditary risk (e.g., family history). Looking at provider or health system factors associated with cancer genetic testing would be an interesting avenue for future research. Communication challenges for providers and patients about cancer genetic risk assessment and counseling have been identified [41]. Additional research is needed to examine how and what aspects of patient-provider communication are associated with cancer genetic testing behaviors and subsequent medical procedures and cancer screenings. It is important to note that perception of genetic information importance was assessed using a single instrument. Further validation of this item is necessary, and future studies with a more in-depth inquiry of knowledge and perception of genetic information for cancer risk are warranted. Lastly, HINTS-5 Cycle 4 data was collected during the early COVID-19 pandemic (February and June 2020), which may influence willingness and completeness of responses. Despite this, concern about the representation of the US general population should be minimal as the weighted estimates are calculated to account for non-respondent bias and to match the distribution of the US population by age, sex, race, and ethnicity [17, 42].

## Conclusions

Public knowledge of cancer genetic testing and its receipt were low among the general US population. Our findings also highlight disparities in cancer genetic testing by race and ethnicity. Despite the higher perceived importance of genetic information, cancer genetic testing seemed not to be received uniformly across race and ethnicity groups. These findings could inform future interventions targeted at improving access to cancer genetic testing among potential cancer patients from racial and ethnic minority backgrounds.

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### Declarations

**Ethical Approval** This article used the de-identified public use data and did not contain any studies with human participants or animals performed by any of the authors.

**Conflict of Interest** TJG has received consulting fees from Tempus Labs, Inc. Other authors had nothing to disclose.

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