

Contents lists available at ScienceDirect

# **Preventive Medicine Reports**



journal homepage: www.elsevier.com/locate/pmedr

# Are beliefs about the importance of genetics for cancer prevention and early detection associated with high risk cancer genetic testing in the U. S. Population?

Sukh Makhnoon<sup>a</sup>, Kristin G. Maki<sup>b</sup>, Robert Yu<sup>c</sup>, Susan K. Peterson<sup>a,1</sup>, Sanjay Shete<sup>d,e,1,\*</sup>

<sup>a</sup> Department of Behavioral Science, UT MD Anderson Cancer Center, Houston, TX, USA

<sup>b</sup> Department of Health Services Research, UT MD Anderson Cancer Center, Houston, TX, USA

<sup>c</sup> Department of Biostatistics, UT MD Anderson Cancer Center, Houston, TX, USA

<sup>d</sup> Department of Epidemiology, UT MD Anderson Cancer Center, Houston, TX, USA

<sup>e</sup> Division of Cancer Prevention and Population Sciences, UT MD Anderson Cancer Center, Houston, TX, USA

ARTICLE INFO

*Keywords:* Cancer prevention Beliefs Genetic testing Early detection

#### ABSTRACT

Public attitudes towards germline genetic testing for inherited cancers have been found to be generally positive. Past research demonstrated that diverse causal beliefs and contextual factors are associated with uptake of genetic testing. However, it is unclear how beliefs about genetically informed cancer prevention and early detection ultimately shape testing behaviors. We used data from the National Health Information National Trends Survey (HINTS 5 Cycle 4) to evaluate these beliefs and the relationship between beliefs related to cancer genetics and participation in cancer genetic testing. Overall, 5.24% of the total weighted sample underwent cancer genetic testing, of whom 70.5% (n = 141) had no personal history of cancer, whereas others had a personal diagnosis of breast, ovarian, or colorectal cancer (23.0%), or other cancers (6.5%). In adjusted multivariable analysis, testing was positively associated with personal history of breast, ovarian, or colorectal cancer (OR = 28.37, 95% CI: 10.19-79.04), female sex (OR = 2.97, 95% CI: 1.41-6.26), having high cancer worry (OR = 4.78, 95%: 2.19-10.45), and negatively associated with being Hispanic (OR = 0.37, 95%: 0.16-0.86) or non-Hispanic Asian (OR = 0.12, 95% CI: 0.04-0.33). Belief in the importance of genetics for early detection of cancer was associated with testing (OR = 18.03, 95% CI: 4.07–79.79), whereas belief in the importance of genetics for cancer prevention was not. The association between testing and belief about the importance of genetics for early detection of cancer, but not cancer prevention, is a surprising finding that warrants further research. Better understanding of these beliefs and their potential impact on test uptake may inform population genetic testing efforts.

# 1. Introduction

Advances in cancer genetics have opened the door to new possibilities for cancer prevention and early detection. Identifying carriers of pathogenic variants through genetic testing can inform preventive strategies such as prophylactic surgery and intensified screening for many hereditary cancers. Despite widespread availability and great progress in the clinical application of germline genetic testing for cancer susceptibility, their delivery and use for cancer prevention remain underutilized (Turnbull et al., 2018). This may, in part, be due to insufficient population awareness of the fact that germline genetic test results can inform cancer prevention and early detection of cancer.

Beliefs about disease causation contribute to engagement in relevant health behaviors (Leventhal et al., 2016) including undergoing cancer genetic testing (Allen et al., 2019). At the same time, beliefs about using genetics to inform cancer prevention and early detection oppose commonly held beliefs of genetic fatalism, which is the belief that we cannot avoid specific genetically predetermined outcomes, no matter what we do or what happens to us (Resnik and Vorhaus, 2006). This belief adversely affects motivation to engage in risk-reducing behavior (Alper and Beckwith, 1993) and is a likely barrier to genetically informed cancer prevention. Prior research has identified personal

 $^{1}\,$  co-senior authors.

https://doi.org/10.1016/j.pmedr.2022.101781

Received 4 October 2021; Received in revised form 18 March 2022; Accepted 26 March 2022 Available online 29 March 2022 2211-3355/© 2022 The Author(s). Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/bync-nd/4.0/).

<sup>\*</sup> Corresponding author at: Department of Cancer Prevention and Population Sciences, UT MD Anderson Cancer Center, 1155 Pressler St, CPB8.3080, Houston, TX 77030, USA.

E-mail address: sshete@mdanderson.org (S. Shete).

perceptions that genetic risk is less controllable (Senior et al., 1999; Haukkala et al., 2015) and less preventable (Senior et al., 2000) than other risk factors. Population awareness of the availability of genetic testing for cancer susceptibility is generally low (Mai et al., 2014) and its impact on test utilization is not well understood. In particular, awareness of the importance of genetics for two related yet distinct concepts cancer prevention (through chemoprevention and prophylactic surgery) and early detection (through intensive screening) - may also influence genetic test uptake, yet remains unknown. Understanding the degree to which perceptions about genetic susceptibility to cancer align with uptake of cancer genetic testing is an important research question with practical implications, particularly for population genetic screening and cancer prevention.

Public attitudes towards germline genetic testing have been generally positive and research demonstrates that diverse causal beliefs and contextual factors are associated with test uptake (Hann et al., 2017). However, it is unclear how beliefs about genetically informed cancer prevention and early detection ultimately shape behaviors and whether cancer genetics-related beliefs are associated with undergoing cancer genetic testing. Cognitive and affective factors that likely motivate interest in testing include test awareness, perceived likelihood of developing cancer, cancer fatalistic belief, and self-efficacy (Wade et al., 2012; Sherman et al., 2014). Emotions such as worry, anxiety, and fear of cancer and genetic testing act as deterrents to genetic testing (Hann et al., 2017). However, beliefs evolve over time as awareness and understanding grows, possibly due to new public and private efforts to increase awareness (Genetic and Diagnostics, 2021; Institute, 2021). High-risk populations such as those with a cancer family history or clinical indications of cancer susceptibility, frequently express interest and positive attitudes towards genetic testing (Alvord et al., 2020). There is a lack of similar awareness in the general population (McKinney et al., 2020) due to skepticism for genetic testing based on a perceived lower need to learn about genetic risk for cancer, and uncertainty of the need for genetic testing.

Unlike diagnostic testing where cancer diagnosis, signs, or symptoms precedes genetic testing, genetically targeted primary prevention of cancer requires testing before cancer diagnosis (Murray et al., 2021). DNA based population screening to guide preventive care has long been discussed, is increasingly being considered in oncology, and has even seen some recent application in limited settings (Grzymski et al., 2020; Buchanan et al., 2020). In fact, given the clinical and economic effectiveness of testing for certain breast cancer variants, population risk profiling is arguably overdue in certain subpopulations. Thus, understanding factors associated with test uptake is critical for the anticipated DNA-based screening programs' success and contribution to cancer prevention.

Little is known about public beliefs regarding the importance of genetics for cancer prevention and early detection. In the present study, we evaluate these beliefs and explore the relationship between beliefs related to cancer genetics and participation in high-risk cancer genetic testing. We hypothesized that public awareness of the importance of genetics for cancer prevention and early detection will be low but positively associated with cancer genetic testing.

# 2. Materials and methods

# 2.1. Participants

Participants were respondents to the National Cancer Institute National Health Information National Trends Survey (HINTS 5 Cycle 4, fielded from February to June 2020, response rate 36.7%). HINTS is a mailed, nationally representative, cross sectional survey of the adult (age 18 or older) civilian non-institutionalized population of the United States. Its content centers on health-related knowledge, perceptions, and behaviors among members of the public; information accessibility, needs, and use of health-related information is also included. A detailed overview of the history and methodology used for HINTS data collection is available elsewhere (Finney Rutten et al., 2020; Finney Rutten et al., 2012). Sampling involved a two-stage design that drew a stratified sample of addresses, followed by the selection of one adult from each sampled household. Genetic testing was one of the topics of interest in this cycle of HINTS. Detailed methodological information is provided online (Survey, 2020). This study utilized data from a publicly available anonymized database and was thus exempt from ethical compliance and oversight from an institutional review board.

# 2.2. Measures

#### 2.2.1. Cancer genetic testing

We created a single yes/no variable indicating participants' cancer genetic testing status from the item, "Have you ever had any of the following types of genetic tests?" with yes indicating those who chose 'High-risk cancer testing (for example, *BRCA1/2* or Lynch Syndrome)' and no indicating those who chose 'None of the above'. In order to focus on clinical cancer genetic testing, we excluded participants from our analysis who only selected ancestry testing to determine the background or geographic/ethnic origin of an individual's ancestors, e.g., through Ancestry.com or 23 and Me (n = 368) or only selected genetic health risk testing to determine health risk for a variety of health conditions, e.g., through 23andMe (n = 72). Ancestry testing and direct-to-consumer health risk testing are inherently different from clinical cancer genetic testing used for medical decision making.

#### 2.2.2. Risk perceptions

Perceived genetic susceptibility to cancer was measured using one item that asked, "How much do you think genes that are inherited determine whether or not a person will develop [cancer]?" The role of genetics for cancer prevention and early detection were measured using two items, "How important is knowing a person's genetic information for: a) preventing cancer; and, b) detecting cancer early" For all risk perception questions, response options ranged from (Turnbull et al., 2018). A lot to (Resnik and Vorhaus, 2006) Not at all. Responses were dichotomized as Not at all/A little, and Very/Somewhat for analysis.

# 2.2.3. Cancer beliefs

Cancer worry was measured using the item, "How worried are you about getting cancer?" Response options ranged from (Turnbull et al., 2018). Not at all to (Alper and Beckwith, 1993) Extremely, and were trichotomized as: high cancer worry (extremely/moderately); moderate cancer worry (somewhat); and, low cancer worry (not at all/slightly). Additional potentially relevant beliefs were assessed using participants' agreement with two items, "There's not much you can do to lower your chances of getting cancer", "There are so many different recommendations about preventing cancer, it's hard to know which ones to follow", on a scale of (Turnbull et al., 2018) strongly agree to (Resnik and Vorhaus, 2006) strongly disagree. Cancer fatalism was assessed using the item, "It seems like everything causes cancer," with response options ranging from (Turnbull et al., 2018) strongly agree to (Resnik and Vorhaus, 2006) strongly disagree. Responses to the last three items were dichotomized (strongly agree/somewhat agree vs. somewhat disagree/ strongly disagree) for analysis.

# 2.2.4. Self-efficacy

Self-efficacy regarding the ability to engage in behavior change based on cancer genetic information was assessed using the item "If I found out from a genetic test that I was at high risk of cancer, I would change my behaviors such as diet, exercise and getting routine medical tests," with response options of (Turnbull et al., 2018) strongly agree to (Resnik and Vorhaus, 2006) strongly disagree. Desire to know about mutation status was measured using one item, "How much would you want to know if you have a genetic change that increases your chances of getting cancer?" with response options of (Resnik and Vorhaus, 2006)

#### S. Makhnoon et al.

Not at all to (Turnbull et al., 2018) A lot that. Both responses were dichotomized for analysis.

# 2.2.5. Covariates

Based on prior research examining predictors of cancer genetic test uptake, age, sex, education, race/ethnicity, income, personal history of cancer, and family history of cancer were included in the analysis as covariates.

# 2.3. Statistical analysis

We incorporated survey sampling weights specified for HINTS 5 cycle 4 into our analyses to account for the complex sampling framework used in the HINTS survey and to provide nationally representative estimates of the US population. The computation of full-sample weights included calculating the household-level base weights for each household in the sample; adjustments for non-response; initial person-level weight for adult in responding household; and finally, calibration of survey weights to the American Community Survey 2018. Additional details about specific weighting methodology can be found in the Methodology Report (Survey, 2020). Weighted prevalence of cancer genetic testing was calculated for the overall study sample as well as after stratifying the study population by risk perceptions, cancer related beliefs, and socio-demographic factors. We used weighted multivariable survey logistic regression to identify factors associated with genetic testing. All pre-selected covariates were included in the multivariable model. Statistical significance was determined using a two-sided P value < 0.05. Statistical analyses were conducted using survey analysis procedures SAS/STAT (Version 9.4).

#### 3. Results

Weighted percentages of sociodemographic characteristics stratified by high-risk cancer genetic test status are shown in Table 1. Of the 3,865 total survey respondents, 2,265, representing 158,364,845 of the U.S. population were included in the analyses. According to weighted analysis, the participants were 50.8% female, predominantly non-Hispanic (NH) White (64.9%), well-educated with 73.7% having some college education or higher, and of high socioeconomic status with 45.7% having an annual income of \$75,000 or more. Nearly equal proportions were within the age categories of 18 to <35 years (28.3%), 35 to <50years (27.7%), and 50 to <65 years (28.5%). Overall, 5.24% (n = 142, weighted n = 8,368,022) of the total sample underwent cancer genetic testing. Of those who underwent high-risk cancer genetic testing, 70.5% had no personal history of cancer, whereas others had a personal diagnosis of breast, ovarian, or colorectal cancer (23.0%), or other cancers (6.5%); 93% believed that genetics was a lot or somewhat important for cancer prevention, and 98.3% believed genetics was a lot or somewhat important for early detection of cancer. (Table 1).

Table 2 summarizes the univariate and multivariate analyses of factors associated with undergoing high-risk genetic testing. In multivariable regression, participants who reported moderate (OR = 2.37, 95%: 1.12-5.01) and high cancer worry (OR = 4.78, 95%: 2.19-10.45) were more likely to undergo testing compared to those with lower cancer worry. Belief in the importance of genetics for early detection of cancer was also significantly associated with testing (OR = 18.03, 95%CI: 4.07–79.79) whereas belief in the importance of genetics for cancer prevention was not significantly associated with testing. Undergoing cancer genetic testing was not significantly associated with comparative risk perceptions, the belief that "everything causes cancer" or that there are "too many recommendations" about cancer prevention strategies, desire to know about mutation status, or self-efficacy regarding behavior change based on a cancer genetic test result (all P-values > 0.05). Of the sociodemographic and clinical covariates, females were more likely to report having undergone cancer genetic tests (OR = 2.97, 95% CI: 1.41-6.26), whereas Hispanics and NH Asians were less likely to have

Table 1

Descriptive statistics ( $N = 2,265$ ) of survey respondents stratified by high-risk	
cancer genetic testing status.	

Variable	Categories	Underwent high-risk cancer genetic testing		No genetic testing	
		N	Wtd %	N	Wtd %
Sex	Male	30	20.0	880	50.9
Age Group	Female 18 to less than 35	111 10	80.0 8.9	1208 317	49.1 29.4
nge droup	35 to less than 50	32	34.3	426	27.4
	50 to less than 65	54	41.8	663	27.8
	65 to less than 75	30	10.8	448	10.6
Race/Ethnicity	75 or older NH White	11 91	4.2 79.4	191 1263	4.9 64.1
Race/ Edimenty	NH Black	12	9.2	277	11.9
	Hispanic	17	7.8	288	16.4
	NH Asian	2	0.7	79	4.5
Education	NH Others Less than high	7 12	2.9 7.1	70 98	3.0 5.4
Education	school 12 years or	20	21.0	98 344	20.7
	completed high school				
	Some college College graduate or higher	42 64	43.3 28.6	640 989	42.3 31.5
Income	Less than 20,000	20	13.5	302	13.5
	20,000 to less than 35,000	11	3.3	246	10.1
	35,000 to less than 50,000 50,000 to less	16 24	10.0 26.5	248 352	11.6 19.2
	than 75,000 75,000 or more	60	46.7	791	45.7
Cancer Worry <sup>1</sup>	Not at all or Slightly Somewhat	29 40	14.6 29.2	940 581	41.7 30.8
	Extremely or Moderately	70	56.2	578	27.5
Perceived Genetic Susceptibility <sup>2</sup>	A lot or Somewhat A little or Not at	128 10	95.3 4.7	1737 334	84.2 15.8
Importance of Genetics for	all Very or	126	93.0	1646	82.3
cancer prevention <sup>3</sup>	Somewhat A little or Not at	13	7.0	425	17.7
Importance of genetics for early detection of cancer <sup>3</sup>	all Very or Somewhat	136	98.3	1772	87.6
	A little or Not at all	4	1.7	301	12.4
Fatalistic belief <sup>4</sup>	Strongly/ Somewhat agree Strongly/	97 42	68.3 31.7	1433 654	72.2 27.8
	Somewhat disagree		51.7	034	27.0
Prevention not possible <sup>5</sup>	Strongly/ Somewhat agree	31	22.6 77.4	562 1529	30.0 70.0
	Strongly/ Somewhat disagree	108	//.4	1329	70.0
Too many recommendations <sup>6</sup>	Strongly/ Somewhat agree	94	74.7	1526	75.1
	Strongly/ Somewhat disagree	44	25.3	562	24.9
Self-efficacy <sup>7</sup>	Strongly/ Somewhat agree	124	86.7	1861	90.4
	Strongly/ Somewhat disagree	15	13.3	224	9.6
Desire to know about mutation status <sup>8</sup>	A lot or Somewhat	127	89.6	1621	78.5

(continued on next page)

#### Table 1 (continued)

Variable	Categories	Underwent high-risk cancer genetic testing		No genetic testing	
		N	Wtd %	N	Wtd %
	A little or Not at all	13	10.4	460	21.5
Personal history of cancer	No cancer history	91	70.5	1806	92.9
	Breast/ovarian/ rectal/colon cancer	32	23.0	30	0.6
	Other cancers	18	6.5	258	6.6
Family history of cancer	Yes	122	89.9	1539	71.3
	No/Not sure	16	10.1	532	28.7

NH: Non-Hispanic; <sup>1</sup>How worried are you about getting cancer?; <sup>2</sup>How much do you think genes that are inherited determine whether or not a person will develop [cancer]?; <sup>3</sup>How important is knowing a person's genetic information for: a) preventing cancer; and, b) detecting cancer early; <sup>4</sup>It seems like everything causes cancer; <sup>5</sup>There's not much you can do to lower your chances of getting cancer; <sup>6</sup>There are so many different recommendations about preventing cancer, it's hard to know which ones to follow; <sup>7</sup>If I found out from a genetic test that I was at high risk of cancer, I would change my behaviors such as diet, exercise and getting routine medical tests; <sup>8</sup>How much would you want to know if you have a genetic change that increases your chances of getting cancer?

undergone tests compared to NH Whites (OR = 0.37, 95% CI: 0.16–0.86 and OR = 0.12, 95% CI: 0.04–0.33 respectively). Compared to those without personal history of cancer, having a personal history of breast, ovarian, or colorectal cancer was associated with higher odds of undergoing testing (OR = 28.38, 95% CI: 10.19–79.04). Neither family history of cancer, age, education, nor income was associated with cancer genetic testing.

Separate multivariable logistic regressions for individuals with and without personal history of cancer (Supplementary Table S1) shows that beliefs about the importance of genetics for early detection of cancer, cancer worry, older age, and female sex was positively associated with genetic testing among those without personal history of cancer. Among those with personal history of any cancer, significant predictors of testing include female sex, older age, and education.

# 4. Discussion

Our findings show that beliefs about the importance of genetics for both cancer prevention and for early detection of cancer was high in the U.S. population, however only the latter belief was associated with having had cancer genetic testing. Of the small proportion of survey respondents who underwent cancer genetic testing, the majority had a family history, but not a personal diagnosis of cancer. This suggests that the opportunity to learn results from testing that may inform cancer prevention and early detection potentially motivated testing decisions. Adjusting for a number of relevant covariates, results from the present study confirm previous reports of cancer genetic testing being associated with female sex, higher cancer worry, and personal history of cancer; and adds empirical data on underutilization of testing among Hispanic and non-Hispanic Asian individuals. These findings confirm most previous studies where psychosocial and demographic characteristics (e.g., knowledge of cancer genetics, risk perceptions, fatalistic beliefs) were important for engagement with testing (Agurs-Collins et al., 2015; Wade et al., 2012; Sherman et al., 2014), though it contradicts one where attitudinal and psychosocial variables (e.g., risk perceptions, cancer beliefs) were not associated with uptake of tests for BRCA1/2 or Lynch Syndrome (Roberts et al., 2019). It is important to note that survey items on belief in importance of genetics for cancer prevention and early detection included in our analyses were unavailable in previous population based surveys. These findings also offer new insights regarding the relationship between cancer genetic testing and beliefs about cancer prevention and early detection in the U.S. population, given the nationally representative sample for the HINTS survey.

It is unclear why belief about the importance of genetics for early detection of cancer, but not cancer prevention, was associated with cancer genetic testing. Genetic fatalism may partly explain why belief about the importance of genetics for cancer prevention was not associated with genetic testing, but whether and how respondents distinguish between cancer prevention and early detection remains inconclusive. There are few genetically-informed strategies that can prevent cancer with a complete degree of certainty - in vitro fertilization coupled with prenatal genetic diagnosis is perhaps one such strategy. Other strategies reduce cancer risk to varying degrees. For example, there remains a 1-2% residual level of cancer risk from any inadvertently missed breast tissue following risk-reducing mastectomy for BRCA1 mutation carriers (Domchek et al., 2010). It is possible that the general public may understand that 'cancer prevention' generally comprises approaches to reduce cancer risk rather than completely eliminating risk of cancer occurrence. The public's views and opinions may be shaped by how information about cancer prevention and early detection is presented in various information sources, including the mainstream media, Web and social media (Johnson et al., 2021). Trustworthy sources such as Centers for Disease Control and Prevention and National Cancer Institute do not appear to distinguish between the meaning of the terms 'cancer prevention' and 'early detection' in their public-facing information on cancer genetic testing; and there is limited data on laypersons' use of these information sources. The heuristics people use to think about the role of genetics in cancer prevention and early detection need to be better explored using qualitative methodology.

Another possible explanation is that clinicians and genetic counselors preferentially use one term over another, and thus survey respondents favorably endorse early detection over prevention. There is generally low population awareness of cancer susceptibility genetic testing (Krakow et al., 2017), which suggests that most people don't have a priori exposure to these concepts. However, genetic counselors likely use these terms interchangeably to facilitate communication, and in fact may even favor the more technically accurate term of riskreduction over prevention or early detection (personal communication). The seeming disconnect between attitude and behavior in cancer genetic testing and cancer prevention beliefs aligns with results from a prior population survey from our group. Specifically, respondents who believed that inherited predispositions cause cancer were less likely to discuss genetic testing with a healthcare provider compared to those who did not believe that inherited cancer predispositions cause cancer (Makhnoon et al., 2021). This may indicate an interaction between fatalism and limited knowledge of the potential preventive benefits of genetic testing, however additional research to better understand the general public's beliefs about the role of genetics in cancer prevention is warranted.

The rate of high-risk cancer genetic testing from data collected in 2020 and reported here (5.24%) is greater than a previous report from 2015 (1.64%), which included all types of genetic tests in addition to tests for high-risk cancer susceptibility (Allen et al., 2019). This increase is likely a combined product of increased awareness of genetic testing among laypersons, patients, and healthcare providers; more inclusive genetic testing guidelines, and improved access to genetic testing services. Particularly encouraging is the cancer genetic testing among unaffected individuals with family history of cancer, which is critical for cancer prevention. The higher odds of testing among breast/ovarian/ colorectal cancer patients suggests that most individuals are undergoing guideline concordant testing. Notably, family history of cancer was not associated with testing - even though significant family history of cancer is a key indication for testing – and may be explained by the way family history was measured within HINTS. The survey measured family history of any cancer, regardless of age of inset, cancer type, or degree of

#### Table 2

Factors associated with high risk cancer genetic testing (N = 2265, representing 158,364,845 in weighted).

Variable	Categories	Unadjusted model			Adjusted model		
		OR	95% CI	Р	OR	95% CI	Р
Cancer worry <sup>1</sup>	Not at all or Slightly	ref					
	Somewhat	2.72	1.47-5.01	0.002	2.37	1.12-5.01	0.025
	Extremely or Moderately	5.84	2.87 - 11.86	less than0.001	4.78	2.19-10.43	less than0.001
Perceived genetic susceptibility <sup>2</sup>	A little or Not at all	ref					
с <u>г</u>	A lot or Somewhat	3.81	0.86-16.80	0.076	2.38	0.55-10.24	0.239
Importance of genetics for cancer prevention <sup>3</sup>	A little or Not at all	ref					
	Very or Somewhat	2.86	0.82-9.98	0.097	0.78	0.19-3.29	0.735
Importance of genetics for early detection of	A little or Not at all	ref					
cancer <sup>3</sup>	Very or Somewhat	8.26	1.65-41.25	0.011	18.03	4.07-79.79	less than0.001
Fatalistic belief <sup>4</sup>	Strongly/Somewhat disagree	ref					
	Strongly/Somewhat agree	0.83	0.43-1.59	0.572	0.82	0.41-1.63	0.564
Prevention not possible <sup>5</sup>	Strongly/Somewhat disagree	ref					
1	Strongly/Somewhat agree	0.68	0.35-1.35	0.265	0.68	0.27 - 1.72	0.403
Too many recommendations <sup>6</sup>	Strongly/Somewhat disagree	ref					
	Strongly/Somewhat agree	0.98	0.52-1.86	0.943	0.82	0.36-1.89	0.639
Self-efficacy <sup>7</sup>	Strongly/Somewhat disagree	ref					
	Strongly/Somewhat agree	0.69	0.29-1.67	0.405	0.45	0.17-1.18	0.102
Desire to know about mutation status <sup>8</sup>	A little or Not at all	ref					
	A lot or Somewhat	2.36	0.89-6.30	0.084	1.85	0.77-4.43	0.165
Personal history of cancer	No	ref					
	Breast/ovarian/Colorectal	52.20	24.16-112.80	less than0.001	28.38	10.19-79.04	less than0.001
	cancer						
	Other cancer	1.30	0.63-2.68	0.469	0.69	0.31 - 1.52	0.346
Family history of cancer	No/Not sure	ref					
	Yes	3.59	1.46-8.81	0.006	2.43	0.77-7.64	0.127
Age	Age	1.02	1.01-1.03	0.002	1.02	1.00-1.03	0.085
Sex	Male	ref					
	Female	4.14	2.23-7.70	less than0.001	2.97	1.41-6.26	0.005
Race/Ethnicity	NH White	ref		1000 (110101001	,	1111 0120	01000
Tacco, Dunnerty	NH Black	0.63	0.25-1.54	0.302	0.75	0.19-3.02	0.679
	Hispanic	0.39	0.18-0.82	0.014	0.37	0.16-0.86	0.022
	NH Asian	0.12	0.01-2.43	0.162	0.12	0.04-0.33	less than 0.001
	NH Other	0.79	0.22-2.81	0.705	1.30	0.21-8.17	0.775
Education	Less than high school	ref	0.22 2.01	0.700	1.00	0.21 0.17	0.770
Education	12 years or completed high	0.78	0.22-2.76	0.688	0.38	0.08 - 1.80	0.218
	school	0.70	0.22 2.70	0.000	0.00	0.00 1.00	0.210
	Some college	0.78	0.25-2.49	0.674	0.33	0.08-1.42	0.133
	College graduate or higher	0.70	0.28-1.76	0.436	0.33	0.09-1.23	0.098
Income	Less than 20,000	017 0		0.100	0.00		0.090
	20,000 to less than 35,000	0.33	0.11-0.98	0.046	0.31	0.07-1.37	0.120
	35,000 to less than 50,000	0.86	0.26-2.83	0.799	0.83	0.18-3.82	0.809
	50,000 to less than 75,000	1.38	0.51-3.73	0.524	1.76	0.60-5.21	0.300
	75,000 or more	1.02	0.46-2.24	0.962	1.70	0.41-3.88	0.673
	, 3,000 01 more	1.02	0.40-2.24	0.902	1.2/	0.0.0-11-3.00	0.073

OR: Odds ratio; NH: Non-Hispanic; <sup>1</sup>How worried are you about getting cancer?; <sup>2</sup>How much do you think genes that are inherited determine whether or not a person will develop [cancer]?; <sup>3</sup>How important is knowing a person's genetic information for: a) preventing cancer; and, b) detecting cancer early; <sup>4</sup>It seems like everything causes cancer; <sup>5</sup>There's not much you can do to lower your chances of getting cancer; <sup>6</sup>There are so many different recommendations about preventing cancer, it's hard to know which ones to follow; <sup>7</sup>If I found out from a genetic test that I was at high risk of cancer, I would change my behaviors such as diet, exercise and getting routine medical tests; <sup>8</sup>How much would you want to know if you have a genetic change that increases your chances of getting cancer?

relatedness, thus not everyone with family history had a significant family history of cancer. The increased odds of testing among females found in this study confirms previous reports (Roberts et al., 2019) and is unsurprising as a large proportion of all cancer genetic testing occurs within breast and ovarian cancers, which are more common among females. In addition, the well-established gender differences in perceptions of cancer – particularly the fact that men are more likely to identify behavioral factors as important in cancer whereas women are more likely to rate heredity as important (Murray and McMillan, 1993), may also partly explain the higher odds of cancer genetic testing among females.

It is important to note that the population prevalence of cancer genetic testing and related health beliefs reported in this study do not support or oppose ongoing population genetic screening efforts, but rather may be useful in shaping health messaging for these efforts. If associations between belief and testing from this cross-sectional study are confirmed and found to be predictive in future longitudinal studies, the results could inform health messaging for population screening. In particular, motivations for undergoing genetic testing between those with and without personal history of cancer may be different (as shown in <u>Supplementary Table S1</u>) suggesting the need to target different mechanisms to improve test uptake in these populations. Comprehensive genetic counseling will still be necessary to communicate the clinical implications and limitations of clinical cancer genetic testing.

Hispanic and NH Asian participants were less likely to undergo highrisk cancer genetic testing than NH White participants in this study which aligns well with existing literature on racial/ethnic disparity in use of genetic testing for hereditary cancers (Childers et al., 2018; Hall et al., 2009; Manrriquez et al., 2017). This disparity in testing persisted even after adjustment for relevant psychosocial and attitudinal covariates that are known to vary among racial/ethnic groups (Canedo et al., 2019) and impact test uptake. In contrast to previous reports that demonstrated lower use of genetic services among Blacks (Armstrong et al., 2005; Lerman et al., 1999), we found no significant difference in test uptake between NH Blacks and NH Whites. Racism, a critical driver for racial health inequity, may potentially underlie these observed differences. The mechanism by which it may be operating in this situation include unmeasured structural barriers that limit access to genetic testing among racial/ethnic minorities, e.g., lack of testing recommendation from physicians, insurance (Modell et al., 2021) and high genetic testing cost (Cragun et al., 2019). Awareness of genetic testing or acculturation that have been previously shown to influence test uptake among Latino participants (Vadaparampil et al., 2006; Hamilton et al., 2016) may also explain some of the observed differences. However, these interpersonal and institutional factors were not measured in this version of the HINTS survey and thus not included in our analyses. The specific underlying reason notwithstanding, this persistent racial/ethnic disparity in genetic testing use is a barrier to realizing the promise of precision cancer prevention and multilevel targeted interventions are needed to ensure equitable access to genetic services among minority populations. Future studies should explore the impact of rural/urban residency as potential surrogates for geographic barrier to access, potential language and cultural barriers to testing, and attempt to identify the form by which racism may be operating in genetic testing.

The present study benefits from the use of data from a large nationally representative survey to estimate the prevalence of high-risk cancer genetic testing and beliefs regarding the importance of genetics for cancer prevention and early detection. Our analytic strategy focused on high-risk cancer genetic testing and removed other types of direct-toconsumer and ancestry genetic testing; this enabled us to accurately define the study outcome and focus on clinically relevant genetic testing for cancer. The unique cross-sectional data along with large sample size provided the ability to identify factors associated with high-risk cancer genetic testing. Despite these strengths, this study is not without its limitations. Self-reported data is subject to individual interpretation and response bias but we used weights to make the survey responses population representative. As with any cross-sectional study, this study cannot determine temporality. Nuanced examination of these cancer genetic beliefs in future research could shed light on why they are differently associated with genetic testing.

In conclusion, this study showed that over 5% of the US population has undergone high-risk cancer genetic testing and cancer prevention is the likely motivation behind many of these tests. However racial and ethnic disparities in use of genetic testing persists. Belief about the importance of genetics for early detection of cancer, but not cancer prevention, is associated with testing, which is a surprising finding that warrants further research. Better understanding of these beliefs and their potential impact on test uptake may inform population genetic testing efforts.

#### Funding

This work was supported in part by the National Cancer Institute through Cancer Center Support Grant (5P30CA016672 to S.S.); a National Cancer Institute Career Development Award (1K99CA256216 to SM); a Cancer Prevention Fellowship supported by the Cancer Prevention and Research Institute of Texas (RP170259 to K.G.M.); the Duncan Family Institute for Cancer Prevention and Risk Assessment (to S.S.); and the Betty B. Marcus Chair in Cancer Prevention (to S.S.).

Notes:

Role of the funder: The funders had no role in the design of the study; the collection, analysis, or interpretation of the data; the writing of the manuscript; or the decision to submit the manuscript for publication.

Prior presentation: N/A.

**Data availability:** The data are publicly available through the National Health Information National Trends Survey website.

#### CRediT authorship contribution statement

Sukh Makhnoon: Conceptualization, Writing – original draft, Writing – review & editing. Kristin G. Maki: Conceptualization, Writing – review & editing. Robert Yu: Formal analysis, Writing – review & editing. Susan K. Peterson: Writing – review & editing. Sanjay Shete: Resources, Supervision, Writing – review & editing.

# **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

#### Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pmedr.2022.101781.

#### References

- Turnbull, C., Sud, A., Houlston, R.S., 2018. Cancer genetics, precision prevention and a call to action. Nat Genet. 50 (9), 1212–1218.
- Leventhal, H., Phillips, L.A., Burns, E., 2016. The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management. J. Behav. Med. 39 (6), 935–946.
- Allen, C.G., Roberts, M., Guan, Y., 2019. Exploring predictors of genetic counseling and testing for hereditary breast and ovarian cancer: findings from the 2015 U.S. National Health Interview Survey. J. Pers. Med. 9 (2).
- Resnik, D.B., Vorhaus, D.B., 2006. Genetic modification and genetic determinism. Philos Ethics Humanit Med. 1 (1), E9.
- Alper, J.S., Beckwith, J., 1993. Genetic fatalism and social policy: the implications of behavior genetics research. Yale J. Biol. Med. 66 (6), 511–524.
- Senior, V., Marteau, T.M., Peters, T.J., 1999. Will genetic testing for predisposition for disease result in fatalism? A qualitative study of parents responses to neonatal screening for familial hypercholesterolaemia. Soc. Sci. Med. 48 (12), 1857–1860.
- Haukkala, A., Konttinen, H., Hankonen, N., Perola, M., Kääriäinen, H., Salomaa, V., 2015. Genetic causal beliefs about morbidity: associations with health behaviors and health outcome beliefs about behavior changes between 1982–2002 in the Finnish population. BMC Public Health. 15, 389.
- Senior, V., Marteau, T.M., Weinman, J., 2000. Impact of genetic testing on causal models of heart disease and arthritis: An analogue study. Psychol Health. 14 (6), 1077–1088.
- Mai, P.L., Vadaparampil, S.T., Breen, N., McNeel, T.S., Wideroff, L., Graubard, B.I., 2014. Awareness of cancer susceptibility genetic testing: the 2000, 2005, and 2010 National Health Interview Surveys. Am. J. Prev. Med. 46 (5), 440–448.
- Hann, K.E.J., Freeman, M., Fraser, L., et al., 2017. Awareness, knowledge, perceptions, and attitudes towards genetic testing for cancer risk among ethnic minority groups: a systematic review. BMC Public Health. 17 (1), 503.
- Wade, C.H., Shiloh, S., Woolford, S.W., et al., 2012. Modelling decisions to undergo genetic testing for susceptibility to common health conditions: an ancillary study of the Multiplex Initiative. Psychol Health. 27 (4), 430–444.
- Sherman, K.A., Miller, S.M., Shaw, L.K., Cavanagh, K., Sheinfeld, G.S., 2014. Psychosocial approaches to participation in BRCA1/2 genetic risk assessment among African American women: a systematic review. J. Community Genet. 5 (2), 89–98.
- Eurofins EGL Genetic Diagnostics EN, Invitae, LabCorp and Myriad Genetics. CancerIQ Officially Launches Lab Network to Increase Awareness and Accelerate Adoption of Genetic Testing. https://www.labcorp.com/canceriq-officially-launches-lab-netwo rk-increase-awareness-and-accelerate-adoption-genetic-testing. Accessed July 27, 2021.
- Institute NHGR. Promoting Safe and Effective Genetic Testing in the United States. http s://www.genome.gov/10002396/genetic-testing-reportchapter-4. Accessed July 27, 2021.
- Alvord, T.W., Marriott, L.K., Nguyen, P.T., et al., 2020. Public perception of predictive cancer genetic testing and research in Oregon. J. Genet. Couns. 29 (2), 259–281.
- McKinney, L.P., Gerbi, G.B., Caplan, L.S., Claridy, M.D., Rivers, B.M., 2020. Predictors of genetic beliefs toward cancer risk perceptions among adults in the United States: Implications for prevention or early detection. J. Genet. Couns. 29 (4), 494–504.
- Murray, M.F., Giovanni, M.A., Doyle, D.L., et al., 2021. DNA-based screening and population health: a points to consider statement for programs and sponsoring organizations from the American College of Medical Genetics and Genomics (ACMG). Genet. Med.
- Grzymski, J.J., Elhanan, G., Morales Rosado, J.A., et al., 2020. Population genetic screening efficiently identifies carriers of autosomal dominant diseases. Nat. Med. 26 (8), 1235–1239.
- Buchanan, A.H., Lester Kirchner, H., Schwartz, M.L.B., et al., 2020. Clinical outcomes of a genomic screening program for actionable genetic conditions. Genet. Med. 22 (11), 1874–1882.
- Finney Rutten, L.J., Blake, K.D., Skolnick, V.G., Davis, T., Moser, R.P., Hesse, B.W., 2020. Data Resource Profile: The National Cancer Institute's Health Information National Trends Survey (HINTS). Int. J. Epidemiol. 49 (1), 17.
- Finney Rutten, L.J., Davis, T., Beckjord, E.B., Blake, K., Moser, R.P., Hesse, B.W., 2012. Picking up the pace: changes in method and frame for the health information national trends survey (2011–2014). J. Health Commun. 17 (8), 979–989.
- Health Information National Trends Survey 5 (HINTS 5) Cycle 4. Methodology Report. Rockville, MD: Westat, 2020. Available from https://hints.cancer.gov/docs/metho dologyreports/HINTS5 Cycle4 MethodologyReport.pdf.
- Agurs-Collins, T., Ferrer, R., Ottenbacher, A., Waters, E.A., O'Connell, M.E., Hamilton, J. G., 2015. Public Awareness of Direct-to-Consumer Genetic Tests: Findings from the 2013 U.S. Health Information National Trends Survey. J. Cancer Educ. 30 (4), 799–807.

#### S. Makhnoon et al.

#### Preventive Medicine Reports 27 (2022) 101781

Roberts, M.C., Turbitt, E., Klein, W.M.P., 2019. Psychosocial, attitudinal, and demographic correlates of cancer-related germline genetic testing in the 2017 Health Information National Trends Survey. J. Community Genet. 10 (4), 453–459.

- Domchek, S.M., Friebel, T.M., Singer, C.F., et al., 2010. Association of risk-reducing surgery in BRCA1 or BRCA2 mutation carriers with cancer risk and mortality. JAMA 304 (9), 967–975.
- Johnson, S.B., Parsons, M., Dorff, T., et al., 2021. Cancer Misinformation and Harmful Information on Facebook and Other Social Media: A Brief Report. JNCI: J. Nat. Cancer Inst.
- Krakow, M., Ratcliff, C.L., Hesse, B.W., Greenberg-Worisek, A.J., 2017. Assessing Genetic Literacy Awareness and Knowledge Gaps in the US Population: Results from the Health Information National Trends Survey. Public Health Genomics. 20 (6), 343–348.
- Makhnoon, S., Yu, R., Cunningham, S.A., Peterson, S.K., Shete, S., 2021. Factors Influencing Discussion of Cancer Genetic Testing with Health-Care Providers in a Population-Based Survey. Public Health Genomics. 1–11.
- Murray, M., McMillan, C.L., 1993. Gender differences in perceptions of cancer. J. Cancer Educ. 8 (1), 53–62.
- Childers, K.K., Maggard-Gibbons, M., Macinko, J., Childers, C.P., 2018. National distribution of cancer genetic testing in the United States: evidence for a gender disparity in hereditary breast and ovarian cancer. JAMA Oncology. 4 (6), 876–879.
- Hall, M.J., Reid, J.E., Burbidge, L.A., et al., 2009. BRCA1 and BRCA2 mutations in women of different ethnicities undergoing testing for hereditary breast-ovarian cancer. Cancer 115 (10), 2222–2233.

- Manrriquez, E., Chapman, J.S., Mak, J., Blanco, A., Chen, L., 2017. Disparities in genetics assessment for women with ovarian cancer. Gynecol. Oncol. 147 (1), 216–217.
- Canedo, J.R., Miller, S.T., Myers, H.F., Sanderson, M., 2019. Racial and ethnic differences in knowledge and attitudes about genetic testing in the US: Systematic review. J. Genet. Couns. 28 (3), 587–601.
- Armstrong, K., Micco, E., Carney, A., Stopfer, J., Putt, M., 2005. Racial Differences in the Use of BRCA1/2 Testing Among Women With a Family History of Breast or Ovarian Cancer. JAMA 293 (14), 1729–1736.
- Lerman, C., Hughes, C., Benkendorf, J.L., et al., 1999. Racial differences in testing motivation and psychological distress following pretest education for BRCA1 gene testing. Cancer Epidemiol Biomarkers Prev. 8 (4 Pt 2), 361–367.

Modell, S.M., Allen, C.G., Ponte, A., Marcus, G., 2021. Cancer genetic testing in marginalized groups during an era of evolving healthcare reform. J. Cancer Policy. 28.

- Cragun, D., Weidner, A., Kechik, J., Pal, T., 2019. Genetic Testing Across Young Hispanic and Non-Hispanic White Breast Cancer Survivors: Facilitators, Barriers, and Awareness of the Genetic Information Nondiscrimination Act. Genet. Test Mol. Biomarkers. 23 (2), 75–83.
- Vadaparampil, S.T., Wideroff, L., Breen, N., Trapido, E., 2006. The impact of acculturation on awareness of genetic testing for increased cancer risk among Hispanics in the year 2000 National Health Interview Survey. Cancer Epidemiol. Biomarkers Prev. 15 (4), 618–623.
- Hamilton, J.G., Shuk, E., Arniella, G., et al., 2016. Genetic testing awareness and attitudes among latinos: exploring shared perceptions and gender-based differences. Public Health Genomics. 19 (1), 34–46.