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# Advancing Cancer Control in San Francisco: Cancer Screening in Under-represented Populations

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## Abstract

**Introduction:** Cancer risk and screening data are limited in their ability to inform local interventions to reduce the burden of cancer in vulnerable populations. The San Francisco Health Information National Trends Survey was developed and administered to assess the use of cancer-related information among under-represented populations in San Francisco to provide baseline data for the San Francisco Cancer Initiative.

**Methods:** The survey instrument was developed through consultation with research and community partners and translated into four languages. Participants were recruited between May and September 2017 through community-based snowball sampling with quotas to ensure adequate numbers of under-represented populations. Chi-square tests and multivariate logistic regression were used between 2018 and 2019 to assess differences in screening rates across groups and factors associated with cancer screening.

**Results:** One thousand twenty-seven participants were recruited. Asians had lower rates of lifetime mammogram (p=0.02), Pap test (p<0.01), and prostate-specific antigen test (p=0.04) compared with non-Asians. Hispanics had higher rates of lifetime mammogram (p=0.02), lifetime Pap test (p=0.01), recent Pap test (p=0.03), and lifetime prostate-specific antigen test (p=0.04)

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compared with non-Hispanics. Being a woman at birth was the only factor that was independently associated with cancer screening participation (AOR=3.17, 95% CI=1.40, 7.19).

**Conclusions:** Screening adherence varied by race, ethnicity, and screening type. A collaborative, community-based approach led to a large, diverse sample and may serve as a model for recruiting diverse populations to add knowledge about cancer prevention preferences and behaviors. Results suggest targeted outreach efforts are needed to address disparate cancer screening behaviors within this diverse population.

### INTRODUCTION

Cancer is the second leading cause of death in the U.S.,<sup>1</sup> but the first in San Francisco.<sup>1</sup> In the most recent 5-year period for which data are available (2011–2015), San Francisco had an age-adjusted incident rate of 409 per 100,000 people compared with the statewide average of 404 cases per 100,000 people.<sup>2</sup> To address this cancer burden, in 2016, a collaboration between the University of California, San Francisco (UCSF), the San Francisco Department of Public Health, major regional health systems, and community coalitions launched the San Francisco Cancer Initiative (SF CAN) to reduce cancer-related morbidity and mortality in San Francisco.<sup>1</sup>

A large proportion of cancer burden is preventable: 50%–60% of cancers could be prevented if efforts were focused on eliminating individual behaviors known to increase the risk of cancer.<sup>3,4</sup> SF CAN, through efforts detailed in Hiatt et al.,<sup>1</sup> focuses on decreasing the burden of the five most common cancers for which there are effective evidence-based prevention practices (breast, lung and other tobacco-related, prostate, colorectal, and liver cancer), and of which are associated with health behaviors and disproportionately affect vulnerable populations.<sup>1</sup>

San Francisco is a diverse city and is a minority-majority city, with 53% of population being non-white, and 44% of residents speaking a language other than English at home.<sup>5</sup> An estimated 15.4% of San Franciscans identify as gay, lesbian, or bisexual.<sup>6</sup> San Francisco also has one of the highest household income inequality levels in the country, where the top 5% of earners make 16 times more than the lower 20% of earners.<sup>7</sup> Because risk behaviors vary by race/ethnicity, language, and SES,<sup>8–10</sup> addressing cancer disparities will require developing interventions that address cultural, literacy, and linguistic issues faced by these populations.<sup>11–13</sup>

Local data on cancer services and health communication needs for vulnerable populations, necessary to inform local public health efforts, are limited. To better define and describe the populations that National Cancer Institute–designated cancer centers serve, supplemental funding was awarded to 15 cancer centers throughout the country to focus on local health disparities and communication inequalities.<sup>14</sup>

The UCSF Helen Diller Family Comprehensive Cancer Center decided that efforts should focus on the diverse populations residing in San Francisco to further inform the efforts of SF CAN. A community-based survey was developed and administered—in English, Spanish, Cantonese, and Mandarin—to focus on region-specific needs and gather additional

behavioral data not available from administrative surveys, particularly access to and use of health information technology for health communication needs and cancer prevention. This paper describes the methods used to develop and conduct a multilingual community-based survey ("SF HINTS") targeted to a large underserved population and assesses cancer screening behaviors by vulnerable population group and factors associated with screening in the sample. Findings will inform SF CAN initiatives aimed at reducing the cancer burden in San Francisco.

#### **METHODS**

A pool of potential survey questions was generated using a catalogue prepared by a National Cancer Institute Working Group, a subgroup of investigators from supplemental funding grantee sites that identified survey domains and questions that were used across the 15 sites for data harmonization purposes. An internal working group composed of investigators from the UCSF Helen Diller Family Comprehensive Cancer Center who were members of SF CAN was formed to develop the framework for the selection of survey topics. A focus on two main areas guided the selection of survey questions: (1) specific barriers to digital health communication and (2) high-priority areas identified by the SF CAN initiative.

Most survey domains were taken from the National Cancer Institute Measures Working Group catalogue that provided guidelines for survey development (Appendix 1, available online). The Working Group specified demographic and behavior core measures required to be collected by all participating sites. These questions were previously assessed for readability, brevity, and clarity for the general public.<sup>15</sup> It also issued a set of recommended measures from which each site could select relevant survey items for their survey based on specific population needs.

Site-specific survey domains that were of interest owing to their relevance to SF CAN priorities included gender and sexual identity, smartphone usage, and participation in clinical trials. Questions on gender and sexual identity were developed using the San Francisco Department of Public Health's guidelines on Sex and Gender Identity Reporting.<sup>16</sup> Questions measuring smartphone access and usage were adapted from the Pew Research Center American Trends Panel Survey.<sup>17</sup> Participation in clinical trials questions were obtained from a survey developed by collaborators at Duke University.<sup>18</sup>

The final domains included in the fielded survey were: health communication, beliefs about cancer, cancer family history, screening behaviors, cancer risk behaviors, prior participation in medical research, health status, healthcare access, and demographic characteristics. The full survey is available in Appendix 2 (available online).

Forty-four percent of San Francisco residents speak a language other than English at home,<sup>5</sup> and 21% have limited English proficiency.<sup>19</sup> It was thus critical that the survey also be available in Spanish and Chinese (Cantonese and Mandarin), the most widely spoken languages in San Francisco after English. For the development of the Spanish version of the survey, a staff member took existing questions from the Spanish version of HINTS 4 and translated additional questions from the original source. For the Chinese versions, a native

Cantonese and Mandarin–speaking staff member directly translated questions from the English version of the SF HINTS instrument. All items were translated and back-translated and final items were based on team reconciliation, according to standard practices.<sup>19–20</sup>

Project staff worked with community members to ensure appropriate translation and cultural adaptation of survey items. Initial feedback on the survey instrument highlighted instances where the English survey included items that were not relevant to a targeted community. For example, the English version of the physical activity questions included forms of physical activity not popular among the Chinese community in San Francisco. Examples were modified to be relevant to the Chinese-speaking community (e.g., tai chi, badminton). Non-English surveys were circulated among culturally concordant researchers and community-based organization leaders with longstanding partnerships with the Helen Diller Family Comprehensive Cancer Center for a review of the language translation and their cultural appropriateness.

#### **Study Population**

A community-based sampling strategy was used to optimize survey recruitment from populations that are often missed in probability sampling schemes.<sup>22</sup> The subgroups of interest were: African Americans, Hispanics, Asians, low income, housing unstable, and sexual and gender minorities. Collaborating with SF CAN and several community-based organizations in the city working with the targeted groups, community events and common gathering places were identified for target populations. For each target population, participants were recruited from popular community establishments (e.g., restaurants, churches, salons, and community centers) and community events (health and wellness fairs, street fairs, and support groups). In addition, participants were enrolled at small businesses and street locations in neighborhoods where the target populations resided. Inclusion criteria for participation were residence in San Francisco, age 18–75 years, and able to take the survey verbally in either English, Spanish, Cantonese, or Mandarin. Recruiters were bilingual and bicultural staff members and volunteers with experience in community outreach and clinical research coordination. Recruitment took place between May and September 2017.

#### Measures

Trained staff using computer tablets (iPads) carried out the survey in the field. Staff obtained informed consent using IRB-approved verbal consent language. All pertinent study information was communicated in the preferred language of the participant and sufficient time was given for participants to ask questions. Participants were compensated USD \$25 for survey completion. Data were captured with REDCap, a secure web-based tool for collecting and storing data hosted at UCSF.<sup>23</sup> With REDCap, the amount of missing data was reduced by restricting the data format and type, setting ranges for numeric fields, and using the platform's internal data quality tools to identify discrepancies. Staff reviewed the survey after a participant completed the survey to ensure completion of questions and reduce missing data.

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Collected demographic data collected included age, race/ethnicity, income, education, nativity status, health insurance status, sexual identity, gender identity, and location of usual source of health care. Low income was defined has having a household annual income < \$20,000, approximately equal to bottom 20th percentile of household income in San Francisco. Housing instability was assessed by asking if the participant had slept outdoors or in shelters, stayed with family or friends, or lived in a single-room occupancy hotel within the last year.<sup>24,25</sup> Sexual and gender minorities were defined as anyone who identified as bisexual, gay/lesbian/same-gender loving, transgender, questioning, gender queer, or gender or sexual identity category other than male or female.<sup>26</sup> Location of usual source of health care was categorized as: no or unknown place of care/county-run clinics and hospitals/ community safety net clinics/private practice/non-profit healthcare systems.

Data were collected for the following cancer screening examinations: mammogram, Pap test, prostate-specific antigen (PSA) test, blood stool test, and colonoscopy or sigmoidoscopy. Gender at birth was used for gender-specific cancer screening behaviors.

The definition of adherence to screening recommendations are defined by both age and sex at birth. For female at birth, adherence for each type of cancer screening examination was defined as: (1) having had a mammogram within the past year if aged 45–54 years or having had a mammogram in the past 2 years if aged 55 years, (2) aged 21 years and had a Pap test within the last 3 years, and (3) aged 50 years and had blood stool test within the last year or had a sigmoidoscopy or colonoscopy in the past 10 years. For male at birth, adherence for each type of cancer screening examination was defined as: (1) PSA test if aged 40 years and (2) PSA test and done blood stool test within the last year or had a sigmoidoscopy or colonoscopy in the past 10 years.

Cancer screening participation was defined as having completed the aforementioned procedures for sex at birth and age at least once (yes or no). For example, a 54-year-old female at birth who reported having a Pap test, mammogram, and a colorectal cancer screening was considered to have participated in cancer screening. Cancer screening participation is considered an indicator of screening awareness and acceptability<sup>27</sup> and also indicates some level of healthcare access, such as availability of providers offering screening.<sup>28</sup> Although PSA screening is not widely recommended as other evidence-based screenings,<sup>29</sup> it was included in the analysis given the oversampling of African American men, who are disproportionately affected by prostate cancer, and at a younger age.<sup>30</sup>

#### **Statistical Analysis**

Data analysis took place between 2018 and 2019. Descriptive statistics were used to characterize the sample. Chi-square tests were performed to compare cancer screening rates by type of examination and population group, comparing each subgroup with the rest of the sample combined.

A weighted multivariate logistic regression was used to model the log odds of cancer screening participation. Predictors used in the logistic regression models included gender, race/ethnicity, education, income group (<\$20,000, \$20,000–\$50,000, >\$50,000) and place of health care. Weights were computed using iterative proportional fitting (raking), a

technique used for non-probability samples that involves raking over a set of variables (age, gender, and education) iteratively to reweight the cohort population to match the distribution of the reference population (San Francisco).<sup>31</sup> Responses to education and income that were *don't know* or *refused* were considered missing. The fully efficient fractional imputation method was used to address missing income and education data.<sup>30,31</sup> All statistical analyses were performed using SAS, version 9.4.

## RESULTS

One thousand twenty-seven participants, composed of 514 English dominant–speaking, 256 Spanish dominant–speaking, and 257 Chinese dominant–speaking participants, were recruited. Demographic characteristics of both the sample and City and County of San Francisco are in Table 1. The sample was racially and ethnically diverse (96% non-white), was predominantly Hispanic (36%), and female (52%). Half of sample reported household income <\$20,000 per year. Medicare is the main source of health insurance coverage for the largest share of the sample (38%). Thirteen percent identified as sexual or gender minority. Twenty-seven percent reported housing instability and homelessness within the last year (Table 1). Compared with the San Francisco population, this sample appeared less educated, more likely to be foreign-born, and uninsured.

Cancer screening rates are presented in Table 2. Of all cancer screenings that were measured, ever having a sigmoidoscopy or colonoscopy had the lowest overall rate (47%). Asians had significantly lower rates of ever having had a mammogram (p=0.02), a Pap test (p<0.01), and PSA test (p=0.04) compared with non-Asians. Hispanics had significantly higher rates of ever having had a mammogram (p=0.02), ever having had Pap test (p=0.01), having a recent Pap test (p=0.03), and ever having had a PSA test (p=0.04) compared with non-Hispanics.

Logistic regression models of the odds of cancer screening participation are presented in Table 3. The odds of cancer screening participation among people who identified as female at birth were three times higher than those who identified as male at birth (OR=3.17, 95% 0=1.40, 7.19). No other factors were significantly and independently associated with cancer screening participation.

#### DISCUSSION

This paper aimed to describe cancer screening behaviors among under-represented and vulnerable populations in San Francisco from a purposive sample. Though not representative of the general population, these results are intended to shed light on trends in high-risk populations. Cancer screening rates and screening adherence vary by race, ethnicity, income, housing status, and sexual and gender minority identification in this sample. Generally, vulnerable populations fare worse in following guidelines for cancer prevention behaviors. The subpopulations in this sample have higher screening rates than reported general population estimates. Though not statistically significant, odds of cancer screening participation among African Americans and Hispanics are higher compared with whites (OR=1.08 and 2.69, respectively). The rate of African Americans receiving guideline-

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concordant screening with mammography and colonoscopy or sigmoidoscopy screening are higher in the SF HINTS sample compared with national rates (81% vs 74%<sup>34</sup> and 80% vs 59%,<sup>35</sup> respectively). These detailed behavioral data on vulnerable populations, unavailable before, will be used to update and refine SF CAN interventions.

Cancer control efforts in San Francisco may well have the greatest impact with a focus on the Asian population, which makes up more than a third of the city's population. Asians in SF HINTS report the lowest rate of cancer screenings (Table 2) and lower odds of cancer screening participation compared with whites (Table 3), though these differences were not statistically significant. Cultural tailoring and education about cancer screening in multiple languages may address this disparity.

An advantage of this study is the large sample size of minority populations that are typically under-represented in health studies. This is in large part due to community outreach and inperson field administration of the survey. Traditional survey types, such as mail, randomdigit dialing, and online surveys, may not be accessible to vulnerable populations. Recent studies that examine health information seeking behavior among these populations mainly focused on the role of the Internet.<sup>36–39</sup> In San Francisco, 30% of African American residents and 16% of Hispanic residents do not have access to the Internet at home.<sup>40</sup> There is quick turnover of mobile phones and of phone numbers among homeless adults,<sup>41</sup> which may make it more difficult for this population to take part in telephone surveys. Homelessness and housing instability, a growing issue in San Francisco,<sup>42</sup> can prevent individuals from receiving and sending mailed survey materials. Traditional survey types have been failing to collect critical data from these target populations. It was therefore most productive to employ a field survey to collect data that SF CAN will be able to use to target interventions with adapted evidence-based interventions that fit the needs of these underrepresented populations.

#### Limitations

Despite its strengths in reaching a low-income, diverse population, this study does have limitations. The snowball sampling strategy, which enabled oversampling of vulnerable groups, did not allow for response rates calculation, as staff directly approached and enrolled participants. This sampling method is also not designed to provide population estimates and is subject to selection bias. However, the advantage of using snowball sampling with quotas is that it is both cost and time effective for reaching vulnerable populations.<sup>43</sup> This is advantageous for local public health jurisdictions and community-based organizations, which generally do not have the budget to support the collection of local data. Finally, cancer screening was ascertained through self-report, which is subject to recall bias.

#### CONCLUSIONS

The SF HINTS study is one of the first efforts that SF CAN supported in its mission to use a multilevel, interdisciplinary approach that integrates cancer research, prevention activities, improvements in cancer health care and health systems, community voices, and political leaders. SF HINTS focuses on the need to collect data across population subgroups and to use these data to ensure that vulnerable subgroups have equal access to culturally

appropriate cancer information, treatment, and opportunities to participate in cancer research, including cancer clinical trials. SF HINTS data have been used to assess health information–seeking behaviors<sup>44</sup> and factors associated with biomedical research participation.<sup>45</sup> The overall project data set will be available to all investigators, providers, and community engagement workers in SF CAN. Data will also be available to other investigators upon approval by lead investigators and steering committee of a submitted proposal. As the diversity of the nation increases, such efforts will become critical to maintain the health of the whole population and reduce healthcare costs.

The development and administration of this survey was a cooperative effort between researchers and community leaders. This study highlights how community engagement is key in reaching underserved multicultural, multilingual, and multiethnic populations for medical research. It also highlights that field surveys can yield detailed data from these populations and cancer screening trends masked in other types of surveys. The results of the survey will provide an important foundation for eliminating cancer disparities in San Francisco.

#### Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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The IRB at the University of California, San Francisco approved of this study (IRB #: 16-20707).

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#### Table 1.

#### Sociodemographic Characteristics of Study Participants

Variable	SF HINTS sample, N=1,027 (%)	San Francisco, N=805,235 (%)
Median age, years	48	38
Sex		
Female	537 (52)	396,773 (49)
Race/ethnicity		
White, alone	44 (4)	353,000 (44)
Black/African American	243 (24)	45,654 (6)
Asian	317 (31)	295,347 (37)
Hispanic/Latino	365 (36)	131,949 (16)
Other	58 (6)	114,996 (14)
Education		
No high school degree	236 (23)	82,618 (10)
High school degree or equivalent	305 (30)	84,072 (10)
Some college or completed vocational/technical training	284 (28)	135,318 (17)
College degree or higher	186 (18)	381,066 (47)
Don't know/refused	16 (2)	-
Household income		а
<\$20,000	511 (50)	63,861 (18) <sup>b</sup>
\$20,000 to <\$50,000	221 (22)	44,847 (13) <sup>b</sup>
\$50,000	158 (15)	249,347 (70)
Don't know/refused	137 (13)	-
Foreign born	528 (51)	300,542 (37)
Sexual/gender minority	133 (13)	N/A
Housing unstable	276 (27)	N/A
Primary healthcare coverage		
No or unknown coverage	300 (29)	58,719 (7)
Commercial	236 (23)	619,665 (67)
Medicare	318 (31)	239,641 (26) <sup>C</sup>
Medicaid	167 (16)	
Other public coverage	6 (1)	

<sup>a</sup>Household n=358,772.

<sup>b</sup>Census has structured income ranges has less than \$10,000; \$10,000-\$14,999; \$15,000-\$24,999; \$25,000-\$34,999; \$35,000-\$49,999. For this table, <\$10,000; \$10,000-\$14,999; \$15,000-\$24,999 was categorized as <\$20,000 and \$25,000 to \$34,999; \$35,000 to \$49,999 categorized as \$20,000 to <\$50,000.

 $^{\it C}$  U.S. Census Bureau reports aggregated public insurance coverage.

SF HINTS, San Francisco Health Information National Trends Survey; N/A, not collected by U.S. Census Bureau.

#### Table 2.

#### Cancer Screening Behavior Rates in SF HINTS Sample

Measure	Frequency, % (n/N)	χ <sup>2</sup>	<i>p</i> -value
Ever had a mammogram (female at birth, 45 years)			
Total	92 (306/332)	-	-
African American	93 (78/84)	0.03	0.85
Hispanic	99 (85/86)	5.73	0.02
Asian	89 (118/132)	5.37	0.02
Low income	92 (193/207)	0.19	0.66
Housing unstable	91 (50/55)	0.60	0.44
SGM	100 (12/12)	0.90	0.34
Following mammography guidelines (female at birth, 45 years)			
Total	77 (236/306)	-	-
African American	81 (63/78)	0.79	0.37
Hispanic	72 (61/85)	1.92	0.17
Asian	80 (94/118)	0.70	0.4
Low income	76 (146/193)	0.06	0.8
Housing unstable	82 (41/50)	0.81	0.37
SGM	83 (10/12)	0.27	0.6
Ever had Pap test (female at birth)			
Total	78 (417/536)	-	-
African American	89 (119/134)	6.27	0.01
Hispanic	88 (156/178)	6.63	0.01
Asian	67 (102/153)	32.46	<0.01
Low income	75 (219/279)	10.77	<0.01
Housing unstable	80 (86/107)	0.14	0.71
SGM	80 (32/40)	0.07	0.79
Following Pap test guideline (female at birth)			
Total	85 (356/417)	-	-
African American	84 (100/119)	0.24	0.63
Hispanic	90 (141/156)	5.02	0.03
Asian	80 (82/102)	2.68	0.10
Low income	81 (178/219)	6.45	0.01
Housing unstable	88 (76/86)	0.78	0.38
SGM	84 (27/32)	0.03	0.87
Ever had PSA (male at birth, 45 years)			
Total	50 (122/245)	-	-
African American	54 (35/65)	0.58	0.45
Hispanic	60 (57/95)	4.02	0.04
Asian	38 (21/56)	4.39	0.04
Low income	44 (63/142)	4.88	0.03
Housing unstable	50 (45/91)	0.01	0.93

Measure	Frequency, % (n/N)	<b>x</b> <sup>2</sup>	<i>p</i> -value
SGM	49 (23/47)	0.02	0.90
Ever had blood stool test ( 50 years)			
Total	59 (286/485)	-	-
African American	51 (67/115)	2.97	0.09
Hispanic	61 (82/135)	1.44	0.23
Asian	72 (113/157)	5.42	0.02
Low income	66 (187/285)	0	0.97
Housing unstable	59 (64/109)	2.39	0.12
SGM	68 (27/40)	0.14	0.71
Ever had sigmoidoscopy or colonoscopy ( 50 years)			
Total	47 (229/450)	-	-
African American	37 (50/116)	3.79	0.05
Hispanic	59 (83/141)	5.23	0.02
Asian	49 (77/158)	0.45	0.50
Low income	48 (138/288)	4.87	0.03
Housing unstable	39 (44/114)	9.23	<0.01
SGM	65 (26/40)	3.50	0.06
Following CRC screening guidelines ( 50 year)			
Total	82 (295/358)	-	_
African American	80 (59/73)	2.00	0.16
Hispanic	71 (67/94)	0.79	0.37
Asian	75 (81/108)	0.02	0.90
Low income	76 (142/187)	0.90	0.34
Housing unstable	75 (46/61)	0.03	0.87
SGM	66 (19/29)	1.39	0.24

*Note:* Boldface indicates statistical significance (p<0.05).

SF HINTS, San Francisco Health Information National Trends Survey; SGM, sexual and gender minority; PSA, prostate specific antigen; CRC, colorectal cancer.

#### Table 3.

Weighted Logistic Regression Model of Cancer Screening Participation<sup>a</sup>

Variable	OR (95% CI)	<i>p</i> -value
Preferred language		
English	ref	-
Chinese	0.83 (0.31, 2.18)	0.70
Spanish	0.43 (0.05, 3.32)	0.40
Race/ethnicity		
White	ref	-
Asian	0.50 (0.14, 1.76)	0.28
Black	1.08 (0.41, 2.87)	0.88
Hispanic	2.69 (0.46, 15.79)	0.27
Other	1.19 (0.26, 5.46)	0.82
Gender at birth		
Male	ref	-
Female	3.17 (1.40, 7.19)	0.01
Location of care		
Private	ref	-
Nonprofit healthcare system	1.22 (0.31, 4.72)	0.77
County operated hospitals and clinics	0.45 (0.13,1.55)	0.20
Integrated healthcare system	0.67 (0.16, 2.88)	0.59
No or unknown place of care	0.41 (0.09,1.81)	0.24
Community clinic	0.91 (0.24, 3.42)	0.89
Education		
No high school degree	ref	-
High school degree or equivalent	0.66 (0.36, 1.24)	0.20
Some college/vocational or technical training	0.66 (0.31, 1.40)	0.27
College degree or higher	1.00 (0.39, 2.62)	0.99
Income		
\$50,000	ref	-
<\$20,000	0.45 (0.17, 1.18)	0.11
\$20,000 to <\$50,000	1.22 (0.46, 3.23)	0.69
Age	1.00 (0.97, 1.03)	0.94

*Note*: Boldface indicates statistical significance (*p*<0.05).

<sup>a</sup>Cancer screening participation defined as completing all recommended cancer screenings for gender at birth and age at least once.