Preventive Medicine Reports 37 (2024) 102564

Contents lists available at ScienceDirect

Preventive Medicine Reports

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

Racial and ethnic disparities in knowledge, attitudes, and invitation to participate in clinical trials among cancer survivors in the United States: An analysis of the 2020 U.S. HINTS

Sarah Commaroto [a,b], Marlene Camacho-Rivera [c], Yi Guo [d,e], Young-Rock Hong [e], Kea Turner [f,g], Imran K. Islam [h], Argelis Rivera [i], Jessica Y. Islam [a,g,*]

[a] Cancer Epidemiology Program, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL, 36635, USA
[b] University of South Florida Morsani College of Medicine, USA
[c] Department of Community Health, SUNY Downstate School of Public Health, Brooklyn, NY, USA
[d] Department of Health Outcomes and Biomedical Informatics, College of Medicine, University of Florida, Gainesville, FL, USA
[e] UF Health Cancer Center, Gainesville, FL, USA
[f] Department of Health Outcomes and Behavior, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL, 36635, USA
[g] Department of Oncologic Sciences, Morsani School of Medicine, University of South Florida, Tampa, FL, 33635, USA
[h] College of Letters and Science, University of Wisconsin Oshkosh, Oshkosh, WI, USA
[i] Department of Hospital Medicine, The Mount Sinai Hospital, New York, NY, USA

ARTICLE INFO

Keywords:
Diversity
Clinical trials
Cancer survivors
Knowledge
Attitudes
Motivation
Disparities
Inequities
Oncologists

ABSTRACT

Background: Despite the use of clinical trials to provide gold-standard evidence of cancer treatment and intervention effectiveness, racial/ethnic minorities are frequently underrepresented participants. Our objective was to evaluate racial/ethnic differences in knowledge and attitudes towards clinical trials among U.S. cancer survivors.
Methods: We leveraged the 2020 Health Informational National Trends Survey (HINTS) data (February-June 2020), which is a weighted, nationally representative survey of 3865 adults (≥18 years), including cancer survivors. We descriptively evaluated cancer survivor's (n = 553) knowledge of clinical trials, and trusted sources of information regarding clinical trials. Using Poisson regression, we estimated predictors of self-reported knowledge of clinical trials.
Results: Among cancer survivors, 82 % were NH-White and 60 % self-reported to at least have some knowledge about clinical trials. When asked about factors that would influence their decision to participate in clinical trials, participants across racial groups frequently chose "I would want to get better" and "If the standard care was not covered by my insurance." NH-White (76 %), NH-Black (78 %), and Hispanic/Latinx (77 %) cancer survivors reported their trusted source of information about clinical trials was their health care provider; NH-Asian cancer survivors reported their health care provider (51 %) as well as government health agencies (30 %) as trusted sources. Cancer survivors with only a high school degree were less likely to have any knowledge of clinical trials compared to those with a Baccalaureate degree or more (aPR:0.61;95 % CI:0.45–0.83).
Conclusion: Health care providers are a trusted source of clinical trial information.

1. Background

In the field of oncology, innovations developed through clinical trials play a crucial role in evaluating novel treatment options and improving cancer-related outcomes, such as survival. However, many of these clinical trials largely underrepresent individuals from minoritized groups and fail to create a study sample that reflects the racial and ethnic composition of the US population (Duma et al., 2018; Murthy et al., 2004; Niranjan et al., 2021; Oyer et al., 2022). In a systematic review analyzing the proportion of underrepresented minority participants in

Acronyms: CI, Confidence Intervals; HINTS, Health Information National Trends Survey; NCI, National Cancer Institute; NH, Non-Hispanic; PO, Post Office; U.S., United States.

* Corresponding author at: Cancer Epidemiology Program, H. Lee Moffitt Cancer Center and Research Institute, 12902 Magnolia Drive, Tampa, FL, 33612, USA.
E-mail address: Jessica.islam@moffitt.org (J.Y. Islam).

https://doi.org/10.1016/j.pmedr.2023.102564
Received 13 October 2023; Received in revised form 2 December 2023; Accepted 14 December 2023
Available online 19 December 2023

phase three cancer clinical trials conducted between 2001 and 2010, 82.9 % of participants were White, 6.2 % were African American or Black adults, 3.3 % were Asian, 2.2 % were Hispanic/Latinx/Latinx, and 0.1 % were Native American (Kwiatkowski et al., 2013). The lack of diversity in cancer clinical trials is a multifaceted problem stemming from various multi-level factors leading to barriers to clinical trials access, including individual-level socioeconomic factors (Unger et al., 2016), such as variability in insurance coverage (Hamel et al., 2016; Klabunde et al., 1999), as well as health systems-level factors such as trust in the healthcare system as well as shorter or less informative patient-provider discussions of clinical trials with non-white patients (Eggly et al., 2015), and macro-level systemic problems such as lack of access to transportation and childcare (Rivers et al., 2013). While the reasons are multifaceted, this pattern of underrepresentation impairs our ability to generalize the safety and effectiveness of new therapeutic options, and ultimately contributes to preventable disparities in treatment outcomes and survival rates.

To improve clinical trial enrollment of racial and ethnic minoritized cancer patient population, data regarding the racial and ethnic differences in knowledge of and attitudes towards clinical trials among cancer survivors among a nationally representative survey of U.S. adults would be valuable to inform future intervention development. Our objective was to evaluate racial/ethnic differences in knowledge and attitudes towards clinical trials among adults with a history of cancer in the U.S. using data from the nationally representative Health Information National Trends Survey (HINTS). We also explored determinants of receiving an invitation to participate in a clinical trial among cancer survivors.

2. Methods

2.1. Study population

To conduct this analysis, we used data from the 2020 HINTS. HINTS is a nationally representative, cross-sectional survey conducted by the National Cancer Institute (NCI) since 2003. HINTS provides a comprehensive assessment of the US public's access to and use of information about cancer across the cancer care continuum, including health information sources, risk perceptions, cancer-relevant health behaviors (e.g., smoking, diet, screening), and cancer communication. The content of each HINTS data collection cycle focuses on understanding the general US adult population's understanding of vital cancer prevention messages. In addition to the standard HINTS survey modules, HINTS 2020 (Cycle 4) included a module focused on clinical trials to assess knowledge and perceptions of clinical trials, as well as history of participation in clinical trials. Westat, Inc., a research organization that supports the NCI in carrying out the HINTS survey, provides a detailed description of the HINTS survey sampling and dissemination process (2020). Here, we briefly describe the methodology. Westat leverages a sampling frame based on a database of addresses used by Marketing Systems Group (MSG) to provide random samples of addresses. All non-vacant residential addresses in the US present on the MSG database, including post office (P.O.) boxes, throwbacks (i.e., street addresses for which mail is redirected by the USPS to a specified P.O. box), and seasonal address were subject to sampling. Data were collected from February 24th – June 15th, 2020, using a stratified, random sample selected from a national list of mailing addresses. A total of 3,865 completed surveys were collected with a response rate of 37 %. Further details regarding data collection and methodology used in this study can be found online at hints.cancer.gov. For this analysis, we restricted our sample to HINTS respondents who had reported receiving a diagnosis of cancer from a healthcare professional (n = 553). The present analysis uses publicly available anonymized data, and thus exempt from ethical compliance.

2.2. Primary outcomes

Knowledge and attitudes regarding clinical trials were evaluated using several questions. The first question assessed overall knowledge of clinical trials using the following: How would you describe your level of knowledge about clinical trials?; response options include: (1) I don't know anything about clinical trials, (2) I know a little about clinical trials, or (3) I know a lot about clinical trials. Respondents who chose response option two or three were categorized as having self-reported any knowledge of clinical trials.

Next, participants were asked: How much would each of the following influence your decision to participate in a clinical trial? Participants were asked to rate the following statements on their level of influence using the following response options: (1) a lot, (2) somewhat, (3) a little, or (4) not at all.

- I would be helping other people by participating.
- I would get paid to participate.
- I would get support to participate such as transportation, childcare, or paid time off from work.
- If my doctor encouraged me to participate.
- If my family and friends encouraged me to participate.
- I would want to get better.
- I would get the chance to try a new kind of care.
- If the standard care was not covered by my insurance.

Participants were also asked about primary sources of information and most trusted sources of information about clinical trials using the following questions: "Imagine you had a need to get information about clinical trials. Which of the following would you (i) go to first (ii) most trust as a source of information about clinical trials?" The following answer options were provided for both questions: (1) my health care provider, (2) my family and friends, (3) government health agencies, (4) health organizations or groups (for example, the American Cancer Society), (5) disease-specific patient support groups, (6) drug companies, or (7) internet search. Participants were also asked "Have you ever heard of the website clinicaltrials.gov?" and "Have you ever been invited to participate in a clinical trial?" Respondents who responded "Yes" to the latter question were categorized as previously invited to participate in a clinical trial. Finally, participants were asked "Did you participate in a clinical trial?"*Demographic Factors*.

Self-reported sociodemographic characteristics such as age group, sex (male/female), education (high school and below, some college, and college graduate and more), income level (<US $19,999/US $20,000-US $49,999/US $50,000-US $99,999/≥US $100,000), race and ethnicity [non-Hispanic (NH) White, NH-Black, NH-Asian, Hispanic/Latinx, NH-Other), census region (Northeast/Midwest/South/West), political views (liberal/moderate/conservative), body mass index (underweight/normal/overweight/obese), and smoking status were recorded. Participants self-reported whether they were ever diagnosed with a number of chronic conditions including diabetes, high blood pressure, heart disease, lung disease, and depression. Participants self-reported the cancer type they were diagnosed with and reported the date of diagnosis.

2.3. Statistical anaslyses

Descriptive statistics were displayed in weighted frequencies were calculated to describe the survey participants by self-reported racial/ethnic group. Chi-squared (χ 2) tests were used for bivariate comparisons of sociodemographic data and outcomes of interest by race/ethnicity among adults with a history of cancer. All analyses were adjusted using appropriate weighting variables, including Jackknife replicate weights, provided by HINTS to calculate standard errors and nationally representative estimates after controlling for group differences in data collection methods. To identify determinants of any knowledge of clinical trials and an invitation to participate in a clinical

trial, we computed prevalence ratios with Poisson regression using robust estimation of standard errors (Barros and Hirakata, 2003; Behrens et al., 2004). Potential variables for inclusion in the model were assessed using available sociodemographic variables and bivariate Poisson regression analysis. Due to the exploratory nature of this analysis using a predictive framework, a p-value of < 0.25 was used as criteria to include the variable in the multivariable Poisson regression model. For multivariable Poisson regression models, adjusted prevalence ratios (aPR), and 95 % confidence intervals (CIs) for each independent variable were calculated. Additionally, p-value < 0.05 was used as the level of significance. Based on the exploratory nature of this analysis, we did not include an adjustment for multiple comparisons (Rothman, 1990). Due to limited missing data (<10 %), we conducted a complete case analysis approach. All statistical analyses were conducted in Stata 15 (College Station, TX).

3. Results

Sociodemographic characteristics of cancer survivors included in our sample of US adults are summarized in Table 1, as well as differences in demographic characteristics by race and ethnicity. Women comprised 56 % of the overall sample and 74 % of Hispanic/Latinx respondents. Turning to cancer risk factors, 39 % of respondents were smokers and 8 % were current smokers at the time of the survey. Smoking was less common among racial and ethnic minorities, with 67 % of NH-Black, 81 % of Hispanic/Latinx, and 72 % of NH-Asian participants reporting as never smokers compared to NH-White participants (49 %). Approximately, 29 % of participants were of healthy or normal weight, 33 % were considered overweight, and 35 % were considered obese. Among non-Hispanic Black participants, 28 % were considered overweight and 58 % were considered obese. The most common primary malignancies within the overall sample were non-melanoma skin cancer (31 %), breast cancer (18 %), melanoma (12 %), and prostate cancer (11 %). Overall, 34 % of participants reported knowing nothing about clinical trials, with 31 % of NH-Whites, 53 % of NH-Blacks, 46 % of Hispanic/Latinxs and 17 % of NH-Asians reporting no knowledge. Fifty-six percent of respondents overall reported knowing a little bit about clinical trials, with NH-Asian participants more frequently reporting within this category (83 %) compared to participants from other groups. Overall, 10 % of participants reported knowing a lot about clinical trials, with NH-Whites more frequently reporting within this category (11 %), compared to NH-Black (5 %), Hispanic/Latinx (5 %), and NH-Asian (0 %) participants.

Table 2 describes sources of and trust in knowledge of clinical trials across various sources of information among participants who reported having some knowledge of clinical trials. Overall, health care providers were most frequently reported as the first source of information about clinical trials, with 74 % of participants overall mentioning health care providers, 72 % of NH-White, 98 % of NH-Black, 78 % of Hispanic/Latinx, and 70 % of NH-Asian participants. Internet search was the second most frequented source of clinical trial information at 18 % overall, with 20 % of NH-White participants, 2 % of NH-Black, 0 % of Hispanic/Latinx, and 30 % of NH-Asian participants. Interestingly, Hispanic/Latinx participants also frequently reported health organizations or groups, such as the American Cancer Society, with 18 % of Hispanic/Latinx participants reporting this source as their first source of clinical trial information. Overall, awareness of the clinicaltrials.gov website was low, with only 11 % of respondents having heard of the resource. NH-Black participants (18 %) were more likely to have heard about the clinicaltrials.gov website compared to NH-White (11 %) or Hispanic/Latinx participants (9 %). Invitation to participate in clinical trials varied by race/ethnicity, with 24 % of NH-White participants compared to 48 % of NH-Black participants, 12 % of Hispanic/Latinx participants, and 0 % of NH-Asian participants having been invited to participate. Actual participation in clinical trials also varied with 10 % of NH-White participants, 7 % of NH-Black participants, and 3 % of Hispanic/Latinx participants reporting having ever participated in a clinical trial.We did not observe any statistically significant differences by race/ethnicity as summarized in Table 2.

Fig. 1 illustrates racial and ethnic differences in the importance of factors influencing participation in clinical trials among a subset of cancer survivors with at least some knowledge of clinical trials (n = 402). Hispanic/Latinx participants were more likely to report payment as an influential factor to participate in a clinical trial compared to other racial and ethnic groups. Hispanic/Latinx participants were least likely to report participating in a clinical trial if the standard of care was not covered by insurance compared to other groups. NH-Asian participants were significantly more likely to report wanting to get better as strongly influencing their decision to participate in a clinical trial. NH-Black participants were also more likely to report getting a chance to try a new form of care as a factor that would motivate them a lot to participate in a clinical trial. NH-Black participants were also more likely to report the encouragement of family and friends as a factor that would influence their decision to participate in a clinical trial a lot or somewhat compared to other groups.

Table 3 summarizes sociodemographic characteristics associated with (1) self-reported knowledge of clinical trials and (2) prior invitation to participate in a clinical trial. Cancer survivors with lower educational attainment were less likely to have any self-reported knowledge of clinical trials compared to those with a Baccalaureate degree or above. For example, cancer survivors with a high school degree were less likely to have any knowledge of clinical trials compared to those with a Baccalaureate degree or more (aPR: 0.61; 95 % CI: 0.45–0.83). We did not observe any sociodemographic characteristics significantly associated with a prior invitation to participate in a clinical trial.

4. Discussion

In our analysis of the nationally representative 2020 HINTS data, we shed light on numerous factors that may influence cancer clinical trial participation and the trusted sources of information among different racial and ethnic groups. The influence of physician recommendation on participation was evident across all populations, emphasizing the pivotal role of healthcare providers in shaping patient perceptions and decisions, as observed in prior work (Walker et al., 2023). Healthcare providers were pointed to as the first place patients would go to for information on clinical trials and were also identified as the most trusted source of information, above health organizations, government health agencies, drug companies, and family and friends (Camacho-Rivera et al., 2020; Fareed et al., 2021). While healthcare providers are the most trusted source of clinical trial information for all groups, variations in secondary trusted sources were evident, with non-Hispanic Asian participants showing a greater tendency to trust government health agencies compared to other racial/ethnic groups. Therefore, diversifying the platforms for conveying clinical trial information could enhance engagement among different racial and ethnic groups and be a pointed step towards more targeted interventions.

Our findings highlight the need for interventions to improve clinical trial enrollment to incorporate patient values into clinical decision-making, as demonstrated in prior work in the context of general cancer care (Noteboom et al., 2021; Seidman et al., 2019). Across all racial and ethnic populations, the desire to improve one's health emerged as the strongest motivator, followed by if the standard of care was not covered by the patient's insurance. Similarly, the majority of participants among all racial and ethnic groups expressed a willingness to participate in a trial if it benefited others, and if the trial gave them the chance to try a new kind of care. Future studies should explore how appealing to patient's altruistic side might encourage trial participation and should emphasize the ability to try new treatment methods. Our data stresses the need to understand patient personal motivators when deciding whether to participate in a clinical trial, and indicates interventions aimed at increasing underrepresented groups in trials should

Table 1
Sociodemographic data of Cancer Survivors in the United States, 2020 Health Information National Trends Survey, February - June 2020.

	Total (%)*	NH-White (%)	NH-Black (%)	Hispanic (%)	NH-Asian (%)	NH-Other (%)†	P-Value
Unweighted Population, n	553	421	55	53	12	12	
Weighted Population, n	20, 599, 942	16, 908, 951	1,705,262	1, 457, 596	317, 739	210, 393	
Sex							0.45
Male	44.1	45.0	48.7	26.4	48.8	49.8	
Female	55.9	55.0	51.3	73.6	51.2	50.2	
Age Groups (years)							
Mean (SD)	58.9 (1.12)	59.9 (1.08)	52.5 (7.2)	54.7 (3.3)	68.3 (11.9)	50.5 (5.6)	0.01
18–34	3.5	1.9	13.7	6.2	21.5	0.0	
35–49	17.2	17.6	3.9	28.2	0.0	56.1	
50–64	34.0	33.7	33.3	44.7	19.8	8.2	
65+	45.2	46.8	49.1	20.9	58.7	35.7	
Income level							0.002
0-<$20,000	18.1	15.9	39.9	17.5	0.0	45.0	
$20,000-<$50,000	25.9	24.0	35.7	35.6	34.4	20.9	
$50,000-<$100,000	32.3	33.3	22.5	38.7	14.4	10.0	
$100,000 or more	23.8	26.8	1.8	8.1	51.2	24.1	
Educational Categories							0.004
Less than High School	5.4	4.5	5.9	17.0	0.0	0.0	
High School Graduate	26.5	24.0	49.3	30.8	19.4	20.9	
Some College	38.3	39.3	32.4	41.3	0.0	49.2	
College Graduate or More	29.8	32.2	12.5	10.9	80.6	29.9	
Census Region							<0.001
Northeast	13.9	15.7	5.0	2.2	13.3	20.8	
Midwest	19.0	21.4	4.3	11.3	0.0	22.7	
South	39.4	34.9	80.5	46.2	26.2	39.5	
West	27.7	28.0	10.1	40.2	60.5	17.0	
Political Views							0.04
Liberal	24.1	22.5	25.4	36.4	42.6	16.1	
Moderate	28.2	25.4	48.0	30.2	52.2	38.3	
Conservative	47.8	52.1	26.6	33.3	5.2	45.6	
Body Mass Index							0.007
Underweight	3.5	2.3	7.1	10.6	2.9	20.8	
Normal or Healthy weight	28.7	30.7	7.0	23.9	80.0	3.9	
Overweight	33.0	34.3	28.4	28.3	13.9	25.9	
Obese	34.8	32.7	57.6	37.2	3.1	49.5	
Smoking Status							0.02
Never smoker	53.0	49.0	66.8	81.4	71.7	37.6	
Ever smoker	39.0	42.4	28.4	15.0	21.8	41.5	
Current smoker	8.0	8.6	4.8	3.6	6.4	20.9	
Comorbid Conditions							
Diabetes	24.5	21.9	36.4	36.4	37.2	33.8	0.2
High blood pressure	51.6	52.6	60	34.3	38.5	38.6	0.29
Heart disease	11.3	11.5	10.2	10.2	22.5	0.9	0.687
Lung disease	18.4	18.1	23.6	5.4	39.7	59	0.029
Depression	24.5	26.1	16.2	19.6	6.6	24.9	0.44
Has Regular Provider	85.6	86.7	78.4	81.7	75.5	100.0	0.5
Self-Rated Quality of health care you received in the past 12 months							0.19
Excellent	32.4	35.2	13.6	21.1	31.4	51.0	
Very Good	44.1	41.4	59.4	56.9	50.4	31.9	
Good	18.2	17.4	27.0	20.6	3.3	16.2	
Fair	3.7	4.5	0.0	0.0	0.0	0.9	
Poor	1.5	1.4	0.0	1.4	14.9	0.0	
Insurance Status							0.12
Uninsured	5.7	3.7	19.8	13.4	0.0	0.0	
Insured	94.3	96.3	80.2	86.6	100.0	100.0	
Cancer Type							–
Breast Cancer	18.1	18.1	27.6	9.8	15.4	3.2	
Non-Melanoma Skin Cancer	30.6	36.2	1.4	3.8	14.2	24.9	
Melanoma	11.6	13.9	0.0	2.5	0.0	4.9	
Prostate Cancer	10.5	9.9	15.0	14.5	1.8	5.1	
Lymphomas/Blood Cancer	8.2	9.0	0.5	7.2	7.9	20.8	
Cervical Cancer	7.4	6.3	8.9	17.1	0.0	22.7	
Colon Cancer	3.7	2.8	4.0	11.5	14.3	0.0	
Bladder Cancer	2.4	1.8	7.5	0.0	12.5	12.0	
Bone Cancer	2.2	1.9	6.9	1.1	0.0	0.0	
Endometrial Cancer	1.9	1.3	3.6	7.2	2.7	0.0	
Head and Neck Cancer	2.0	1.8	4.4	0.8	6.4	0.0	
Lung cancer	2.2	2.0	1.0	5.9	0.0	0.0	
Other	9.1	9.2	7.4	11.7	7.5	8.0	
Time Since Cancer Diagnosis							0.028
Less than 1 year	14.2	12.4	11.8	34.5	11.0	48.0	

(*continued on next page*)

Table 1 (*continued*)

	Total (%)*	NH-White (%)	NH-Black (%)	Hispanic (%)	NH-Asian (%)	NH-Other (%)†	P-Value
2–5 Years	16.8	15.1	26.4	32.1	0.0	14.2	
6–10 Years	19.8	21	15.5	6.7	24.4	29.8	
11 + years	49.2	51.4	46.3	26.8	64.6	8.0	
How would you describe your level of knowledge about clinical trials?							0.18
I don't know anything about clinical trials	33.8	31.0	53.0	46.2	17.3	44.0	
I know a little bit about clinical trials	56.3	58.0	42.2	49.3	82.7	47.7	
I know a lot about clinical trials	9.9	11.1	4.8	4.6	0.0	8.3	

*Study population was limited to cancer survivors with race and ethnicity data; excluding n = 73 or 10 %
† Other = American Indian/Alaskan Native, Native Hawaiian, Pacific Islander, Mixed Race

Table 2
Sources of Clinical Trial Information and Self-Reported Participation in Clinical Trials among Cancer Survivors who have heard of clinical trials in the United States, Health Information National Trends Survey, February - June 2020*.

	Total (%)	NH-White (%)	NH-Black (%)	Hispanic (%)	NH-Asian (%)	NH-Other (%)	P-Value
Unweighted Population, n	384	306	28	25	7	8	
Weighted Population, n	13, 762, 327	11, 457, 503	784, 235	784, 860	229, 822	113, 902	
Imagine you had a need to get information about clinical trials. Which of the following **would you go to first** to get information about clinical trials?							0.2
My health care provider	73.5	71.7	97.5	78.4	70.3	57.8	
My family and friends	0.6	0.5	0.0	2.8	0.0	0.0	
Government health agencies	2.1	2.4	0.0	0.7	0.0	0.0	
Health organizations or groups (for example, the American Cancer Society)	4.9	4.5	0.0	18.1	0.0	2.9	
Disease-specific patient support groups	1.1	1.0	0.0	0.0	0.0	39.3	
Drug companies		0.4	0.0	0.0	0.0	0.0	
Internet search	17.5	19.5	2.5	0.0	29.7	0.0	
Imagine you had a need to get information about clinical trials. Which of the following **would you most trust** as a source of information about clinical trials?							0.42
My health care provider	75.7	76.0	78.1	77.4	50.7	76.2	
My family and friends	0.4	0.5	0.0	0.0	0.0	0.0	
Government health agencies	3.1	2.9	0.0	1.3	29.7	0.0	
Health organizations or groups (for example, the American Cancer Society)	15.1	14.4	20.9	21.3	19.6	1.6	
Disease-specific patient support groups	5.2	5.7	1.1	0.0	0.0	22.2	
Drug companies	0.5	0.5	0.0	0.0	0.0	0.0	
Have you ever heard of the website clinictrials.gov?							0.89
No	88.9	89.0	82.1	91.2	89.0	100.0	
Yes	11.1	11.0	17.9	8.8	11.0	0.0	
Have you ever been invited to participate in a clinical trial?							0.41
No	76.1	76.4	51.7	87.6	100.0	76.5	
Yes	23.9	23.6	48.3	12.4	0.0	23.5	
Did you participate in the clinical trial?							0.84
No	90.8	89.9	92.8	97.3	100.0	100.0	
Yes	9.2	10.1	7.2	2.7	0.0	0.0	

*Total sample includes participants who responded either I know a little bit about clinical trials or I know a lot about clinical trials to the following question: "Clinical trials are research studies that involve people. They are designed to compare new kinds of health care with the standard health care people currently get. For example, a new drug or a new way for patients to track their diets. How would you describe your level of knowledge about clinical trials."
**Other = American Indian/Alaskan Native, Native Hawaiian, Pacific Islander, Mixed Race

focus on the pivotal role physicians play in dispersing and discussing this information.

Although physician recommendation strongly influences willingness to enroll in a clinical trial among cancer survivors, it is necessary to question what makes doctors recommend clinical trials in the first place, to who they are recommending these trials, and how this influences the awareness of clinical trials among different population groups. Our findings highlight existing disparities in clinical trial knowledge, with non-Hispanic White participants reporting higher levels of awareness compared to minority groups. Previous studies have also highlighted the discordance between provider and patient knowledge and attitudes towards cancer clinical trial participation (Hillyer et al., 2020; Salman et al., 2016). This knowledge gap is particularly pronounced among non-Hispanic Black participants and Hispanic/Latinx participants, where a substantial proportion reported minimal familiarity with clinical trials. We also found patients' education level plays a role in the awareness of clinical trials, as those with lower educational attainment reported less knowledge of clinical trials when compared to those with a Baccalaureate degree. This suggests lack of education may impair an individual's ability to ask their physician about clinical trials or may point to clinicians avoiding these discussions with patients of lower educational levels. To bridge this gap, targeted interventions should strive to enhance awareness and understanding of clinical trials, especially among poorly educated and minority populations that traditionally have limited access to such information.

The lack of awareness may also stem from inadequacies within healthcare systems and hospitals in supporting clinical trials coupled with the financial constraints of these organizations (Hamel et al., 2016). This may in turn have a disproportionate effect on minority participation as these individuals are more likely to receive care at an underserved hospital system where few clinical trials are available. Clinicians themselves also often have limited awareness about the

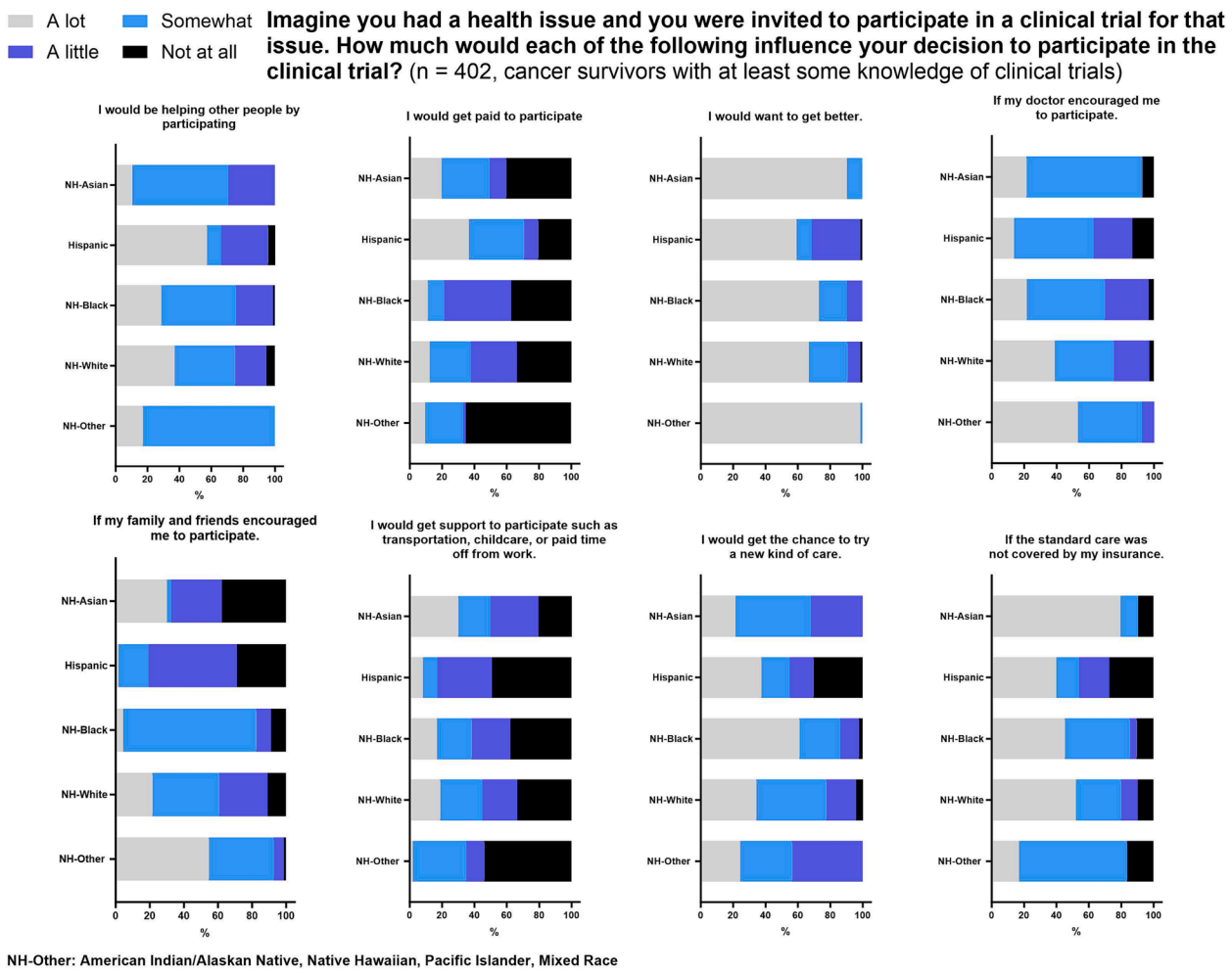

Fig. 1. Racial and ethnic differences in factors that would influence the decision to participate in a clinical trial among cancer survivors (n = 402).

opportunity to participate in trials, (Ford et al., 2005) and their biases may influence with which patients they choose to discuss clinical trials. Niranjan et al. (Niranjan et al., 2020) analyzed the bias and stereotyping among research and clinical professionals in recruiting minority groups for cancer clinical trials. Findings indicated some healthcare professionals view racial and ethnic minorities as less promising participants, with some withholding trial opportunities from minorities based on these perceptions (Niranjan et al., 2020). Additionally, some physicians hesitate to discuss clinical trials due fears of harming patient relationships. A focus-group study with community physicians revealed that some physicians unveiled their reluctance to engage Black patients in discussions about clinical trials, driven by a belief that Black individuals lack trust in physicians and medical institutions (Pinto et al., 2000).

One interesting finding from our study that challenges these previously described biases and the reported lack of awareness among minority groups, is the high rate of clinical trial invitation reported by NH Black participants. NH Black participants received the highest levels of invitation to participate in a clinical trial, whereas Hispanic/Latinx and NH Asian participants reported lowest rates of invitation. Prior invitation did not significantly correlate with any sociodemographic factors, emphasizing the differences primarily revolve around race and ethnicity, surpassing the effects of socioeconomic status, education, insurance status, or comorbidities. While 48 % of Black patients reported being invited to participate in clinical trials, actual enrollment stood at only 7 %. This gap between invitation and actual enrollment is notable, and future studies should examine why participants chose not to participate, or what may have deemed them ineligible. Indeed, the design of clinical trials has largely been questioned, as strict inclusion or exclusion criteria may render many minority populations, particularly Black individuals, ineligible for participation (Kim et al., 2017). A single-institution study of 235 Black cancer patients found that only 20 patients (8.5 %) were eligible based on inclusion criteria, with most patients excluded for co-existing comorbidities (Adams-Campbell et al., 2004).Trials not accounting for racial differences in laboratory values may also exclude otherwise eligible participants based on normal lab variations associated with their race (Vastola et al., 2018). Aside from eligibility criteria, multiple studies have also pointed to the mistrust minorities, specifically African Americans, hold with regards to healthcare professionals and medical institutions, and how this serves as an additional barrier to enrolment (Banda et al., 2012; Ford et al., 2008; Katz et al., 2006).

The paradox of cancer survivors trusting physician recommendations to enroll in clinical trials and yet failing to ultimately participate, may point to the significance of individual physician-patient trust and interactions. Our findings underscore the importance of equipping healthcare providers with the knowledge and communication skills needed to effectively discuss clinical trial options with their patients, particularly those from minority backgrounds. Reducing the gap between invitation and enrollment, alongside improving overall awareness rates of clinical trials is crucial, and our findings may help direct future interventions.

To conduct this analysis, we were able to leverage data from a nationally representative survey of U.S. adults. However, several

Table 3
Predictors of Knowledge and Self-Reported Invitation to a Clinical Trial among Cancer Survivors Included in HINTS 2020.

	Self-Reported Any Knowledge of Clinical Trials (n = 509)		Invited to Participate in a Clinical Trial (n = 504)	
	Unadjusted PR (95 % CI)	Adjusted* aPR (95 % CI)	Unadjusted PR (95 % CI)	Adjusted* aPR (95 % CI)
Sex				
Male	Ref.	–	Ref.	–
Female	0.97 (0.77–1.22)		1.12 (0.61 – 2.06)	
Age Groups (years)				
49 years and below	0.86 (0.57–1.29)	–	0.98 (0.37–2.58)	–
50–64	1.07 (0.87–1.32)		0.77 (0.45 – 1.33)	
65+	Ref.		Ref.	
Census Region				
Northeast	Ref.	Ref.	Ref.	–
Midwest	0.84 (0.60–1.17)	0.91 (0.66–1.27)	1.74 (0.55–5.50)	
South	0.83 (0.65 – 1.07)	0.89 (0.71–1.12)	1.09 (0.45–2.63)	
West	1.03 (0.79–1.33)	1.12 (0.87–1.43)	1.33 (0.49–3.58)	
Race and Ethnicity				
NH-White	Ref.	Ref.	Ref.	Ref.
NH-Black	0.68 (0.39 – 1.19)	0.74 (0.39–1.39)	1.48 (0.70–3.15)	1.63 (0.78–3.43)
Hispanic/Latinx	0.78 (0.48–1.26)	0.81 (0.49–1.31)	0.71 (0.18–2.83)	0.84 (0.19–3.80)
NH-Other	1.03 (0.69 – 1.56)	0.87 (0.56–1.36)	0.81 (0.10–6.42)	0.80 (0.11–6.07)
Political Views				
Liberal	Ref.	Ref.	Ref.	–
Moderate	0.88 (0.72–1.08)	0.98 (0.80–1.19)	0.85 (0.45–1.60)	
Conservative	0.85 (0.67–1.08)	0.97 (0.77–1.20)	1.29 (0.48–3.49)	
Income level				
0-<$20,000	0.64 (0.42–0.99)	1.02 (0.67–1.55)	1.18 (0.49 – 2.78)	–
$20,000-<$50,000	0.79 (0.62 – 1.01)	1.02 (0.81–1.28)	0.78 (0.36–1.67)	
$50,000-<$100,000	0.90 (0.72 – 1.12)	1.15 (0.92–1.42)	0.86 (0.42–1.72)	
$100,000 or more	Ref.	Ref.	Ref.	
Educational Categories				
Less than High School	0.47 (0.24–0.92)	0.59 (0.32–1.09)	0.59 (0.03–9.84)	0.43 (0.04–4.25)
High School Graduate	0.57 (0.40–0.80)	**0.61 (0.45–0.83)**	0.38 (0.14–0.98)	0.35 (0.10–1.19)
Some College	0.78 (0.65–0.94)	0.84 (0.68–1.04)	0.89 (0.52–1.52)	0.82 (0.46–1.45)
College Graduate or More	Ref.	Ref.	Ref.	Ref.
Body Mass Index				
Underweight	0.94 (0.49 – 1.77)	1.23 (0.55–2.77)	2.40 (0.94–6.11)	2.84 (0.64–12.48)
Normal or Healthy weight	1.39 (1.06 – 1.85)	1.18 (0.94–1.49)	0.74 (0.35–1.57)	0.63 (0.31–1.27)
Overweight	1.25 (0.96 – 1.64)	1.06 (0.86–1.32)	0.93 (0.51–1.69)	0.77 (0.42–1.42)
Obese	Ref.	Ref.	Ref.	Ref.
Any Comorbid Condition	1.09 (0.82–1.47)	–	1.70 (0.84–3.46)	1.25 (0.61–2.52)
Insurance Status	1.97 (0.44–8.90)	–	–	–
Smoking Status				
Never smoker	Ref.	Ref.	Ref.	–
Ever smoker	0.86 (0.69–1.05)	0.88 (0.72–1.07)	0.85 (0.45–1.60)	
Current smoker	0.64 (0.37–1.12)	0.70 (0.41–1.18)	1.30 (0.48–3.49)	
Has Regular Provider	1.60 (0.99–2.58)	1.53 (0.95–2.46)	1.93 (0.64–5.87)	2.66 (0.65–10.91)
Self-Rated Quality of health care you received in the past 12 months				
Excellent	Ref.	–	–	–
Very Good	1.09 (0.92–1.29)			
Good	0.78 (0.52–1.16)			
Fair	0.71 (0.32–1.57)			
Poor	0.93 (0.37–2.34)			
Time Since Cancer Diagnosis				
Less than 1 year	0.95 (0.67–1.36)	–	0.41 (0.12–1.39)	0.41 (0.12–1.35)
2–5 Years	0.99 (0.74–1.33)		0.72 (0.34–1.52)	0.75 (0.34–1.64)
6–10 Years	1.09 (0.88–1.36)		0.97 (0.45–2.11)	0.99 (0.48–2.02)
11 + years	Ref.		Ref.	Ref.

*Only variables with a p value < 0.25 on the unadjusted analysis was included in the multivariable model, using a predictive framework

limitations should be considered when contextualizing our results. First, we have limited information regarding clinical characteristics of cancer diagnoses. For example, important factors such as stage at diagnosis, first-line treatment receipt, and hospital-level characteristics (e.g., NCI designated vs. not) were unavailable. These factors may impact a patient's opportunity to learn about or be invited to participate in a clinical trial based on the resources available at the hospital each patient receives care. Second, as this survey is not designed to oversample cancer survivors, there was a limited number of adults who self-reported to have a history of cancer. As such we were unable to compute race-stratified models to identify within population predictors of knowledge of and history of invitation to clinical trials. Given that racial groups are heterogenous, it is important to investigate important sociodemographic factors that impact a cancer survivor's history with clinical trials. Third, it is unclear whether questions regarding clinical trials were specific to a cancer context, or if patients' knowledge or history with clinical trials may have developed due to another chronic condition. Additionally, while factors influencing clinical trial participation were included, barriers to participation in clinical trials, especially structural or social factors, were not full ascertained within the dataset (Unger et al., 2019). Nonetheless, insights gained through the present analysis provide important insights into potential racial and ethnic differences in knowledge, attitudes, and perceptions of clinical trials within the healthcare setting. These insights are hypothesis generating and may inform future research questions to gain more detailed and cancer specific opportunities for intervention to improve use of clinical trials among cancer survivors in the U.S.

5. Conclusion

In conclusion, our study contributes to the growing body of literature on clinical trial disparities by examining knowledge, attitudes, and

participation among U.S. cancer survivors from diverse racial and ethnic backgrounds. The findings emphasize the importance of targeted educational efforts, the central role of healthcare providers in disseminating information, and the need for comprehensive patient-value based strategies to improve inclusivity in clinical trial recruitment. Addressing these disparities is vital for ensuring equitable access to cutting-edge cancer treatments and advancing the overall quality of cancer care for all populations.

Funding

No funding was obtained for the present study.

CRediT authorship contribution statement

Sarah Commaroto: Formal analysis, Writing – original draft. **Marlene Camacho-Rivera:** Conceptualization, Formal analysis, Methodology, Writing – review & editing. **Yi Guo:** Formal analysis, Visualization, Writing – review & editing. **Young-Rock Hong:** Conceptualization, Formal analysis, Methodology, Writing – review & editing. **Kea Turner:** Formal analysis, Methodology, Writing – review & editing. **Imran K. Islam:** Project administration, Visualization, Writing – review & editing. **Argelis Rivera:** Conceptualization, Writing – review & editing. **Jessica Y. Islam:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Software, Supervision, Visualization, 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.

Data availability

Data will be made available on request.

References

Adams-Campbell, L.L., Ahaghotu, C., Gaskins, M., Dawkins, F.W., Smoot, D., Polk, O.D., Gooding, R., DeWitty, R.L., 2004. Enrollment of African Americans onto clinical treatment trials: study design barriers. J. Clin. Oncol. 22, 730–734.

Banda, D.R., Germain, D.S., McCaskill-Stevens, W., Ford, J.G., Swain, S.M., 2012. A critical review of the enrollment of black patients in cancer clinical trials. Am. Soc. Clin. Oncol. Educ. Book 153–157.

Barros, A.J., Hirakata, V.N., 2003. Alternatives for logistic regression in cross-sectional studies: an empirical comparison of models that directly estimate the prevalence ratio. BMC Med. Res. Method. 3, 21.

Behrens, T., Taeger, D., Wellmann, J., Keil, U., 2004. Different methods to calculate effect estimates in cross-sectional studies. a comparison between prevalence odds ratio and prevalence ratio. Methods Inf. Med. 43, 505–509.

Camacho-Rivera, M., Gonzalez, C.J., Morency, J.A., Blake, K.D., Calixte, R., 2020. Heterogeneity in trust of cancer information among hispanic adults in the united states: an analysis of the health information national trends survey. Cancer Epidemiol. Biomark. Prev. 29, 1348–1356.

Duma, N., Vera Aguilera, J., Paludo, J., Haddox, C.L., Gonzalez Velez, M., Wang, Y., Leventakos, K., Hubbard, J.M., Mansfield, A.S., et al., 2018. Representation of minorities and women in oncology clinical trials: review of the past 14 years. J. Oncol. Pract. 14, e1–e10.

Eggly, S., Barton, E., Winckles, A., Penner, L.A., Albrecht, T.L., 2015. A disparity of words: racial differences in oncologist-patient communication about clinical trials. Health Expect. 18, 1316–1326.

Fareed, N., Jonnalagadda, P., Swoboda, C.M., Samineni, P., Griesenbrock, T., Huerta, T., 2021. Socioeconomic factors influence health information seeking and trust over time: evidence from a cross-sectional, pooled analyses of HINTS data. Am. J. Health Promot. 35, 1084–1094.

Ford, J.G., Howerton, M.W., Bolen, S., Gary, T.L., Lai, G.Y., Tilburt, J., Gibbons, M.C., Baffi, C., Wilson, R.F., et al., 2005. Knowledge and access to information on recruitment of underrepresented populations to cancer clinical trials. Evid Rep Technol Assess (Summ):1-11.

Ford, J.G., Howerton, M.W., Lai, G.Y., Gary, T.L., Bolen, S., Gibbons, M.C., Tilburt, J., Baffi, C., Tanpitukpongse, T.P., et al., 2008. Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review. Cancer 112, 228–242.

Hamel, L.M., Penner, L.A., Albrecht, T.L., Heath, E., Gwede, C.K., Eggly, S., 2016. Barriers to clinical trial enrollment in racial and ethnic minority patients with cancer. Cancer Control 23, 327–337.

Hillyer, G.C., Beauchemin, M., Hershman, D.L., Kelsen, M., Brogan, F.L., Sandoval, R., Schmitt, K.M., Reyes, A., Terry, M.B., et al., 2020. Discordant attitudes and beliefs about cancer clinical trial participation between physicians, research staff, and cancer patients. Clin. Trials 17, 184–194.

Katz, R.V., Kegeles, S.S., Kressin, N.R., Green, B.L., Wang, M.Q., James, S.A., Russell, S.L., Claudio, C., 2006. The tuskegee legacy project: willingness of minorities to participate in biomedical research. J. Health Care Poor Underserved 17, 698–715.

Kim, E.S., Bruinooge, S.S., Roberts, S., Ison, G., Lin, N.U., Gore, L., Uldrick, T.S., Lichtman, S.M., Roach, N., et al., 2017. Broadening eligibility criteria to make clinical trials more representative: american society of clinical oncology and friends of cancer research joint research statement. J. Clin. Oncol. 35, 3737–3744.

Klabunde, C.N., Springer, B.C., Butler, B., White, M.S., Atkins, J., 1999. Factors influencing enrollment in clinical trials for cancer treatment. South. Med. J. 92, 1189–1193.

Kwiatkowski, K., Coe, K., Bailar, J.C., Swanson, G.M., 2013. Inclusion of minorities and women in cancer clinical trials, a decade later: Have we improved? Cancer 119, 2956–2963.

Murthy, V.H., Krumholz, H.M., Gross, C.P., 2004. Participation in cancer clinical trials: race-, sex-, and age-based disparities. J. Am. Med. Assoc. 291, 2720–2726.

Niranjan, S.J., Martin, M.Y., Fouad, M.N., Vickers, S.M., Wenzel, J.A., Cook, E.D., Konety, B.R., Durant, R.W., 2020. Bias and stereotyping among research and clinical professionals: perspectives on minority recruitment for oncology clinical trials. Cancer 126, 1958–1968.

Niranjan, S.J., Wenzel, J.A., Martin, M.Y., Fouad, M.N., Vickers, S.M., Konety, B.R., Durant, R.W., 2021. Perceived institutional barriers among clinical and research professionals: minority participation in oncology clinical trials. JCO Oncol. Pract. 17, e666–e675.

Noteboom, E.A., May, A.M., van der Wall, E., de Wit, N.J., Helsper, C.W., 2021. Patients' preferred and perceived level of involvement in decision making for cancer treatment: a systematic review. Psychooncology 30, 1663–1679.

Oyer, R.A., Hurley, P., Boehmer, L., Bruinooge, S.S., Levit, K., Barrett, N., Benson, A., Bernick, L.A., Byatt, L., et al., 2022. Increasing racial and ethnic diversity in cancer clinical trials: an american society of clinical oncology and association of community cancer centers joint research statement. J. Clin. Oncol. 40, 2163–2171.

Pinto, H.A., McCaskill-Stevens, W., Wolfe, P., Marcus, A.C., 2000. Physician perspectives on increasing minorities in cancer clinical trials: an Eastern Cooperative Oncology Group (ECOG) Initiative. Ann. Epidemiol. 10, S78–S84.

Rivers, D., August, E.M., Sehovic, I., Lee Green, B., Quinn, G.P., 2013. A systematic review of the factors influencing African Americans' participation in cancer clinical trials. Contemp. Clin. Trials 35, 13–32.

Rothman, K.J., 1990. No adjustments are needed for multiple comparisons. Epidimiology 1, 43–46.

Salman, A., Nguyen, C., Lee, Y.H., Cooksey-James, T., 2016. A Review of barriers to minorities' participation in cancer clinical trials: implications for future cancer research. J. Immigr. Minor. Health 18, 447–453.

Seidman, J., Masi, D., Gomez-Rexrode, A.E., 2019. Personalizing value in cancer care: the case for incorporating patient preferences into routine clinical decision making. J. Particip. Med. 11, e13800.

Unger, J.M., Gralow, J.R., Albain, K.S., Ramsey, S.D., Hershman, D.L., 2016. Patient income level and cancer clinical trial participation: a prospective survey study. JAMA Oncol. 2, 137–139.

Unger, J.M., Vaidya, R., Hershman, D.L., Minasian, L.M., Fleury, M.E., 2019. Systematic review and meta-analysis of the magnitude of structural, clinical, and physician and patient barriers to cancer clinical trial participation. J. Natl Cancer Inst. 111, 245–255.

Vastola, M.E., Yang, D.D., Muralidhar, V., Mahal, B.A., Lathan, C.S., McGregor, B.A., Nguyen, P.L., 2018. Laboratory eligibility criteria as potential barriers to participation by black men in prostate cancer clinical trials. JAMA Oncol. 4, 413–444.

Walker, D.M., Swoboda, C.M., Shiu-Yee, K., Tarver, W.L., Nolan, T.S., Joseph, J.J., 2023. Diversity of participation in clinical trials and influencing factors: findings from the health information national trends survey 2020. J. Gen. Intern. Med. 38, 961–999.