



Sociodemographic diversity in cancer clinical trials: New findings on the effect of race and ethnicity

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ABSTRACT

Background: Cancer clinical trials (CCT) offer significant potential benefit, not only for future patients but also for enrolled participants, yet a very small minority of cancer patients participate, resulting in low levels of enrollment that have stalled clinical trials dramatically. Though many have endeavored to study this phenomenon, relatively little research has explored the demographic factors which may affect CCT enrollment. Understanding patient demographics is critical to optimizing enrollment, evaluating generalizability, and ensuring equity of CCT.

Methods: To better understand the effect of social determinants of health on CCT enrollment, the authors constructed a multivariable logistic regression model to analyze data collected in the last ten years in the CDC Behavioral Risk Factor Surveillance System (BRFSS) Survey, an annual national survey conducted among the non-institutionalized adult population of the U.S.

Results: In multivariable regression analysis, enrollment varied significantly with sociodemographic factors. Individuals of higher income, Hispanic ethnicity, and younger age were most likely to participate in CCTs. Enrollment did not vary significantly by educational attainment.

Conclusion: Our multivariable analysis indicated people of color are more likely to participate in CCT, perhaps demonstrating that structural barriers shape participation more than race alone. Efforts to improve CCT enrollment may benefit from a shift in focus towards access to care by alleviating structural and financial barriers to enrollment.

1. Introduction

Cancer is the second-leading cause of death in the United States, and though legions of scientists and clinicians are dedicated to developing new treatments, there are many barriers to successful clinical trials which have limited our advances in cancer treatment, with enrollment of participants posing a key barrier [1–5]. Though clinical trials offer significant potential benefits, not only for future patients but also for enrolled participants, reaching enrollment goals continues to be a challenge for researchers [3,4,6]. This difficulty recruiting participants poses a threat to cancer care, since clinical trials are critical to the development of new and improved treatment regimens. As one might expect, there is a strong positive correlation between clinical trial enrollment rates and the rate at which new treatments emerge, wherein diseases with greater participation in clinical trials see the emergence of more evidence-based treatments [4]. Currently, there are 122,000 ongoing clinical trials in the United States, approximately 34,000 of which

focus on cancer [36]. Yet cancer clinical trial participation consistently hovers around just 5% of cancer patients, and 75% of clinical trials will fail to reach enrollment goals [3,5]. Because enrollment continues to be such an obstacle to successful clinical trials, there has been much research and speculation on barriers limiting participation.

Many investigators focus on concerns cited by patients that limit their participation: fear of reduced quality of life, potential side effects, concern about receiving a placebo, and dislike of randomization, to name a few [3]. Some examine concerns of potential referring physicians, including financial disincentives, physician preference for existing treatments, time-consuming enrollment paperwork, and fear of harming the physician-patient relationship [3,4]. However, increasing attention is being paid to the structural and logistical barriers that shape who participates in cancer clinical trials. To participate in a trial during their treatment, patients must have access to a cancer clinic including transportation, childcare, and a method of payment, typically health insurance. Additionally, patients must meet inclusion criteria, a

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challenge especially for those with comorbidities or a later stage of diagnosis [4,7,8]. Taken in total, there are many barriers to enrollment and each patient's decision to participate is likely multi-factorial, based on their circumstances, their beliefs, and the beliefs of their healthcare team.

Although current research indicates there are numerous barriers to cancer clinical trial participation for all patients, it appears that certain demographic factors may make it even less likely for patients to enroll. Though our understanding of rates of inclusion on the basis of demographic factors is somewhat limited by the information collected upon enrollment, there have been several studies exploring the relationship between demographic factors and cancer clinical trial participation, and the area is growing rapidly as many work to improve the recruitment and enrollment process to increase clinical trial participation for cancer and other diseases [9,10].

Much research in the area has focused on clinical trial participation among minority racial and ethnic groups. Many of these studies have found that ethnic and racial minorities are less likely to participate in cancer clinical trials and this seems to be the prevailing assumption within the field [4,11,12], though some have disagreed [13–15]. Hypotheses to explain this phenomenon have had varying success and most agree the true explanation is likely multi-faceted, including potential factors such as limited access to cancer centers, lack of information, fear, and historical mistrust of health research in the wake of grossly unethical studies like the Tuskegee Syphilis Study [16,17]. Some research has also focused on differences in participation among patients of different socioeconomic status (SES). Since many clinical trials are not free to patients and, indeed, incur additional patient expenses for additional visits and testing, income is critical to consider in patient enrollment [8]. Existing research largely agrees that patients with low SES are less likely to participate, often due to structural and financial barriers associated with the increased visits and testing during trials, such as childcare, transportation, and inconvenient appointment times for working patients [4,8,17]. Others have evaluated the effect of age on rates of health research participation, largely finding that older patients are less likely to participate, perhaps due to stringent enrollment criteria which limit the participation of more elderly, less healthy potential participants [5]. Very little research has been done to understand the relationship between educational attainment and enrollment, yet some researchers have undertaken programs to improve educational materials available to patients considering enrollment in health research during the course of their treatment [18]. As more researchers endeavor to improve health research enrollment, more study will be needed to better understand how these and other sociodemographic factors shape patient participation in cancer clinical trials.

In designing trials and recruiting participants, it is critical that all populations participate in health research to ensure generalizable results. Without adequate diversity in participation during trials, applicability of trial outcomes to diverse patient groups is minimized. Apart from poor generalizability for future patients, lack of inclusion during trials is a threat to health equity for potential participants. 83% of oncologists surveyed report a belief that cancer clinical trials offer benefit to enrolled patients and there is evidence that people who take part in clinical trials have better health outcomes [4,6]. Exclusion of specific patient populations from clinical trials denies these groups access to 'state of the art' treatments and closer disease monitoring and management [19,20]. Since there is not scientific basis for exclusion based on demographic factors, such inequities in inclusion represent institutional bias that erodes justice in healthcare [9]. Therefore, it is critical to understand who is participating in cancer clinical trials, and, if there are disparities, why these exist and how they can be rectified. To build this foundational knowledge of which groups are more likely to participate in cancer clinical trials, we analyzed national Centers for Disease Control and Prevention (CDC) health behavior survey responses from 2007 to 2017 to identify any disparate cancer clinical trial participation on

the basis of sociodemographic factors such as race, ethnicity, educational attainment, income, or age. The authors hypothesized that racial and ethnic minorities, the less educated, the poor, and the elderly would be less likely to participate in cancer clinical trials as part of their cancer treatment.

2. Material and methods

2.1. Data source

Data for the current study was obtained from the CDC Behavioral Risk Factor Surveillance System [2]. The BRFSS is a national annual health-related telephone survey administered by the CDC Population Health Surveillance Branch every year since 1984. Its goal is to collect uniform state-specific health-related data from the noninstitutionalized adult population residing in the United States including the District of Columbia, Guam, and Puerto Rico. Survey questions are agreed upon each year by state BRFSS representatives and the CDC, and include a core component that every state must ask without alteration, as well as optional modules and state specific questions that states may elect to include. Many questions are pulled from other nationally established surveys like the National Health Interview Survey (NHIS) and any new questions must pass cognitive testing and field testing before addition to the survey. Households are chosen for inclusion by random digit dialing. The sample each year is independent of years prior. 51 projects used disproportionate stratified sampling, the details of which are explained in the survey's guidebook [34].

2.2. Study variables

Our primary objective was to determine the effect of demographic factors on clinical trial enrollment. Demographic traits of interest were selected based on availability in the dataset, consistent inclusion in the survey, and hypothesized or previously demonstrated relationship to clinical trial enrollment. When the same demographic variable was obtained in several ways in the survey (i.e. race was surveyed in several formats), the format most consistent across the survey years of interest was chosen. The primary variables of interest in this study were clinical trial participation, income, educational attainment, race, ethnicity, and age at diagnosis.

2.3. Criteria for inclusion

Survey years were chosen for inclusion in this study based on their use of the question "Did you participate in a clinical trial as part of your cancer treatment?". Subjects who responded "don't know/not sure" or who refused to answer were excluded from the final analyses. This question was a part of the optional module adopted on a state-by-state basis each year. It was included in six of the last ten survey years: 2017, 2016, 2014, 2012, 2010, and 2009. 2016 was excluded from the final analysis due to missing demographic information. Data for each year was downloaded from the CDC BRFSS website and compiled into one dataset (n = 20,053).

2.4. Statistical analysis

To ensure each level of the categorical variables was represented adequately, some of the categorical variables were regrouped. Race and ethnicity were combined from two variables into one to form four categories for analysis: Non-Hispanic White, Black Non-Hispanic, Hispanic, and Other (which includes multiracial respondents). Similarly, annual income was combined from eight categories into two: less than \$50,000 and greater than \$50,000. \$50,000 was chosen as the cut-off because census data indicate the median household income from 2013 to 2017, roughly the sample time period, was \$57,652, nearest to the \$50,000

category cut-off in the original data collection. While the researchers would have preferred to divide the data at \$57,652 exactly this was not possible as survey data was reported in brackets (25,000–35000, 35,000–50000, 50,000–75000, and so on). Therefore, the final groups roughly approximate respondents above and below the national median [35]. Finally, educational attainment was regrouped into four categories: less than high school education, high school graduate, some college, and college graduate.

As an initial step, descriptive statistics were used to explore each variable of interest. Confirmatory analyses were then used to assess the statistical association between clinical trial participation and each of the exposure variables. A two-sample T-test for the continuous independent variables and a Chi-square goodness-of-fit test for the categorical variables were used to assess the presence of association between the outcome and exposure variables. Finally, a bivariate and multivariable logistic regression model were fitted to calculate the unadjusted and adjusted Odds Ratios (OR) of clinical trial participation given the exposure variables of interest. From each fitted model, the unadjusted and adjusted ORs and 95% Confidence Intervals (CIs) of the ORs were calculated. In all our analyses, a two-sided 0.05 alpha level of significance was used to determine statistical significance between the outcome and exposure variables. All statistical analyses were performed using SAS™ 9.4 [38].

3. Results

Characteristics of the compiled survey population of interest ($n = 20,053$) are described in Table 1. The data indicate relatively steady rates of data collection and sample inclusion with a spike in 2010, presumably because more states chose to include the optional cancer module that year. Across all five years of included data, average cancer clinical trial participation was 6.51%, slightly higher than the commonly cited 5% rate of participation in health research in the general population [5]. Survey respondents were more commonly female than male. Additionally, the division of income into less than \$50,000 and greater than \$50,000 does appear to roughly split the group at its median, however the less than \$50,000 group is consistently somewhat larger.

Table 1
Demographic characteristics of sample by survey year.

Variable	Frequency (%)						
	2017 (n = 3085)	2014 (n = 3425)	2012 (n = 2124)	2010 (n = 7588)	2009 (n = 3831)	Cumulative (n = 20,053)	
Participate in Clinical Trials	<i>Yes</i>	242 (7.8)	270 (7.9)	162 (7.6)	399 (5.3)	233 (6.1)	1306 (6.5)
	<i>No</i>	2843 (92.2)	3155 (92.1)	1962 (92.4)	7189 (94.7)	3598 (93.9)	18,747 (93.5)
Race	<i>Non-Hispanic White</i>	2732 (89.7)	3131 (92.3)	1680 (79.8)	6632 (88.6)	3425 (90.1)	17,600 (88.8)
	<i>Hispanic</i>	150 (4.9)	137 (4.0)	55 (2.6)	259 (3.5)	62 (1.6)	663 (2.2)
	<i>Non-Hispanic Black</i>	37 (1.2)	32 (0.9)	178 (8.5)	281 (3.8)	197 (5.2)	725 (4.8)
	<i>Other</i>	126 (4.1)	93 (2.7)	193 (9.2)	314 (4.2)	116 (3.1)	842 (4.3)
Annual Household Income	<i>< \$50,000</i>	1990 (64.5)	1926 (56.2)	1188 (55.9)	5222 (68.8)	2480 (64.7)	12,806 (63.9)
	<i>> \$50,000</i>	1095 (35.5)	1499 (43.8)	936 (44.1)	2366 (31.2)	1351 (35.3)	7247 (36.1)
Education	<i>Less than high school</i>	175 (5.7)	240 (7.0)	201 (9.5)	682 (9.0)	356 (9.3)	1654 (8.3)
	<i>High school graduate</i>	949 (30.8)	1245 (36.4)	644 (30.3)	2357 (31.1)	1072 (28.0)	6267 (31.3)
	<i>Some college</i>	912 (29.6)	953 (27.8)	576 (27.1)	1921 (25.3)	914 (23.9)	5276 (26.3)
	<i>College graduate</i>	1049 (34.0)	987 (28.8)	703 (33.1)	2628 (34.6)	1489 (38.9)	6856 (34.2)
Sex	<i>Male</i>	1141 (37.0)	1145 (33.4)	709 (33.4)	2612 (34.4)	1321 (34.4)	6928 (34.6)
	<i>Female</i>	1944 (63.0)	2280 (66.6)	1415 (66.2)	4976 (65.6)	2510 (65.5)	13,125 (65.5)
Mean Age (Standard Deviation)	53.9 (15.5)	53.5 (16.2)	52.9 (15.5)	53.8 (16.0)	52.5 (16.1)	53.4 (15.9)	

3.1. Race and clinical trial participation

Data from the BRFSS survey indicate Hispanic and Non-Hispanic Black respondents were more likely to participate in cancer clinical trials than White respondents both in bivariate (unadjusted OR 1.858, 95% CI 1.372–2.516; unadjusted OR 1.354, 95% CI 1.065–1.721; see Table 2) and multivariable modeling (adjusted OR 1.835, 95% CI 1.346–2.500; adjusted OR 1.398, 95% CI 1.092–1.788; see Table 3). As seen in Table 2, across 17,600 Non-Hispanic White respondents, clinical trial participation was 6.24% compared to 11.0% in 445 Hispanic respondents, 8.27% in 943 Non-Hispanic Black respondents, and 6.53% in 842 respondents of other race/ethnicity.

3.2. Income and clinical trial participation

Among 20,053 respondents, income showed a significant positive correlation with clinical trial participation. 12,806 respondents reported annual household income less than \$50,000 while 7247 reported annual household income greater than \$50,000. Compared with households earning less than \$50,000 annually, respondents in households earning more than \$50,000 annually were 1.175 times as likely to participate in a cancer clinical trial in the multivariable analysis (95% CI 1.034–1.335). Among respondents in the lower income group, 6.10% report participation in a clinical trial as part of their cancer treatment compared to 7.24% in the higher income group.

3.3. Education and clinical trial participation

In bivariate analysis, education was not significantly associated with participation in cancer clinical trials. To ensure completeness of the multivariable model, however, education was still included in the final analysis. It was not significantly associated with CCT participation in the multivariable model either.

3.4. Age and clinical trial participation

The mean age of participants in the dataset did not vary much, ranging from 52.56 in 2009 (standard deviation = 16.05) to 53.89 in 2017 (standard deviation = 15.54). There was, however, great range in age at diagnosis in the dataset every year, ranging from 1 year old to 97 years old. Respondents diagnosed with cancer at a younger age were more likely to participate in cancer clinical trials (adjusted OR 0.996,

Table 2
Rates of participation by demographic factor, unadjusted.

Variable		Respondents Reporting Clinical Trial Participation	
		Yes	No
Race	<i>Non-Hispanic White</i>	1099 (6.2%)	16,501 (93.8%)
	<i>Hispanic</i>	49 (11.0%)	396 (89.0%)
	<i>Non-Hispanic Black</i>	78 (8.3%)	865 (91.7%)
	<i>Other</i>	55 (6.5%)	787 (93.5%)
Annual Household Income	<i>< \$50,000</i>	781 (6.1%)	12,025 (93.9%)
	<i>> \$50,000</i>	525 (7.2%)	6722 (92.8%)
Education	<i>Less than high school</i>	110 (6.7%)	1544 (93.3%)
	<i>High school graduate</i>	351 (5.6%)	5916 (94.3%)
	<i>Some college</i>	357 (6.8%)	4919 (93.2%)
	<i>College graduate</i>	488 (7.1%)	6368 (92.9%)
Sex	<i>Male</i>	418 (6.0%)	6510 (94.0%)
	<i>Female</i>	888 (6.8%)	12,237 (93.2%)
Mean Age at Diagnosis (Standard Deviation) [Range]		53.5 (16.0)	51.9 (15.1)
*N		*18,149	*1268

Table 3
Rates of participation by demographic factor.

	Bivariate Analysis		Multivariable Analysis	
	OR (95% CI)	P-value	OR (95% CI)	P-value
Race: Hispanic vs. Non-Hispanic White	1.858 (1.372–2.516)	0.001	1.835 (1.346–2.500)	0.0001
Race: Non-Hispanic Black vs. Non-Hispanic White	1.286 (1.079–1.531)	0.0132	1.398 (1.092–1.788)	0.0078
Race: Other vs. Non-Hispanic White	1.049 (0.793–1.388)	0.7363	1.081 (0.816–1.434)	0.5866
Annual Household Income: > \$50,000 vs. < \$50,000	1.203 (1.072–1.349)	0.0016	1.175 (1.034–1.335)	0.0132
Education: High school graduate vs. less than high school	0.833 (0.667–1.039)	0.1053	0.808 (0.641–1.019)	0.0721
Education: Some college vs. less than high school	1.019 (0.817–1.271)	0.8696	0.978 (0.775–1.234)	0.8484
Education: College graduate vs. less than high school	1.076 (0.868–1.333)	0.5046	1.000 (0.792–1.262)	0.9976
Sex	1.130 (1.002–1.274)	0.0458	1.104 (0.973–1.253)	0.1254
Age	0.994 (0.990–0.997)	0.0006	0.996 (0.992–0.999)	0.0194

95% CI 0.992–0.999). However, though the results were statistically significant, the confidence interval was very near 1 and the absolute difference in age between participants and non-participants was rather small, with participants having a mean age of 51.94 at diagnosis compared to 53.52 in non-participants (1.58 years different).

3.5. Sex and clinical trial participation

Sex was significant in bivariate analysis (unadjusted OR 1.130, 95% CI 1.002–1.274). However, this did not account for the differential clinical trial availability for sex-based cancers. Sex was included in multi-

variable analysis since previous trials have indicated it is associated with participation in clinical trials even when availability of trials and incidence of cancer is accounted for [5,11,21]. However, sex was not significantly associated with CCT participation in the multivariable model (adjusted OR 1.104, 95% CI 0.973–1.253).

4. Discussion

To maximize enrollment and ensure that clinical trial participants mirror the population to which their results will be applied, it is critical to first understand who is currently participating in health research, then understand why, so that interventions can be designed and tested to improve any disparities. This study helped to inform our understanding of who is participating in cancer clinical trials, indicating there are indeed inequities across sociodemographic lines. In this analysis, people of color, people who earn more than the national median household income, and the young were more likely to participate in clinical trials during their cancer treatment. While this study alone cannot explain why these trends exist or how to rectify them, it does point towards the possible influence of financial and structural barriers limiting participation, indicating that initiatives to reduce costs and assist in the logistics of participation may be the most efficacious method to increase enrollment among diverse groups.

Racial/ethnic disparities in clinical trial participation have been evaluated in several previous studies. Many have found that people of color are underrepresented [5,11,12], while some have found equal representation between ethnic/racial groups [13–15]. In contrast to these studies, we found people of color were more likely to participate in cancer clinical trials than white cancer patients when controlling for other demographic factors. It is possible that this difference in findings is due to the nature of our multivariable analysis in controlling for income, sex, and age at diagnosis. By controlling for these other factors, we were able to better isolate the effects of race/ethnicity alone. However, the very small proportion of non-white respondents (less than 10% in any given year) also makes our conclusions less generalizable. Yet, based on this study, it appears that the widely held belief that people of color are less likely to participate in health research may not tell the whole story. Since several previous studies focused on bivariate analysis of race vs. participation, it could be that the effects of income, sex, or age were muddling the true picture [5,11,12]. Future studies are necessary to help understand the relationship between race and clinical trial participation, particularly studies as to what is driving the disparate enrollment of different racial and ethnic groups.

Analysis of rates of participation by income showed that higher income patients were more likely to participate in clinical trials even when controlling for other factors like race/ethnicity, sex, and age at diagnosis. This is in keeping with previous studies which have also shown increased enrollment among higher income individuals [8,13]. More recent studies have begun testing interventions to lessen the financial burden associated with clinical trial participation. For instance, the pilot study of the Massachusetts General Cancer Care Equity Program which provided evidence that financial assistance increased cancer clinical trial enrollment, particularly among racial and ethnic minorities, as well as studies like AAMEN which improved minority enrollment simply by offering transportation services to trial appointments [8,22]. These interventions have shown great promise, significantly increasing enrollment especially among minority racial/ethnic groups. While further research is certainly necessary, our study helps to support the idea that cost and logistical barriers such as time off work, child-care, and transportation pose major barriers to participation in cancer clinical trials. While the cost burden of cancer clinical trials is already quite high for research groups, emerging research on social determinants of health in trial enrollment, including this study, support shifting resources from advertising or other areas of the trial into support programs to lessen financial burdens of trial participation as a means of in-

creasing clinical trial enrollment. Since recruitment and enrollment are such expensive processes for clinical research groups, such increases in efficiency would be a welcome innovation in the field [23].

Surprisingly, educational attainment was not significantly associated with clinical trial participation in bivariate analysis in this study. There are very few published studies on the relationship between education and health research participation; however, there are several studies which have attempted to increase enrollment by increasing or somehow improving patient educational materials about clinical trials [24–26]. Since educational attainment is highly correlated with health literacy [32], our conclusion that there is not a significant association between educational attainment and enrollment may indicate that health literacy and understanding of clinical trials is not as much of an obstacle as some may have previously assumed. This may indicate that efforts to increase enrollment should not focus on educational materials and improving patient understanding of clinical trials, and instead those resources should be devoted to lessening the financial burden of clinical trial participation for patients. Nevertheless, there is significant evidence that awareness of clinical trials, particularly awareness of clinical trials through discussions and recommendations from a trusted physician, are associated with increased rates of participation [23,27,33]. This study certainly does not change that finding, and physicians should all take their responsibility to present patients with all treatment options seriously.

We found that 6.77% of women report participation in cancer clinical trials compared to 6.03% of men, but suspect this overrepresentation is due at least in part to the different rates of cancer between the sexes and the differences in clinical trial availability in these sex-specific cancers. For instance, there are currently 4692 clinical trials available related to breast cancer in the United States, almost exclusively offering enrollment to women [36]. Further study using different datasets would be helpful to more completely understand the relationship between sex and health research participation.

This study also demonstrated that patients of more advanced age at diagnosis were less likely to participate in cancer clinical trials than their younger counterparts, a finding consistent with the majority of prior research on the subject [5,28,29]. Prior analyses of participation in clinical trials by age have indicated enrollment criteria are a significant barrier to participation among the elderly since they have a heavier burden of comorbidities which can bar their entry into clinical trials [28,29]. With strict criteria limiting participation of cancer patients with conditions like cerebrovascular and cardiovascular disease, it can be challenging for older patients to find trials for which they meet the enrollment criteria to participate [11,30]. Elderly patients are often underrepresented in health research but are also consistently turned away from participation due to higher incidence of comorbidities that bar them from clinical trial participation. While some stringency is important to standardizing clinical trials, a careful balance must be struck between controlling confounders and enrolling participants. Since enrollment is so low across the board and even more so among the elderly, the poor, and racial/ethnic minorities (groups with increased burden of comorbidities) lessening the restrictions on enrollment of patients with common comorbidities may increase absolute enrollment and reduce disparities in participation [29,31]. The balance between controlling for confounders by harshly regulating participation and allowing maximal enrollment is currently too skewed towards controlling for confounders in a way that is unintentionally causing disparate enrollment.

Taken in total, the results of this study help confirm that there are sociodemographic disparities in cancer clinical trials, indicating there are deficiencies in equity and generalizability as the system stands now. No single solution will be able to solve these disparities, but when taken in concert with previous studies in the area, several recommendations can be made to improve enrollment in cancer clinical trials: lessen financial barriers to participation, improve logistical accessibility of can-

cer clinical trials, and loosen restrictions on the enrollment of patients with comorbidities.

While changes to clinical trial enrollment can be difficult, they are critical to ensuring optimal treatment for the millions of patients diagnosed with cancer each year in the United States and around the world. These changes can only come from research to understand why we see disparities in enrollment and which interventions are best at improving these inequities. While research in the area is growing, more is needed to facilitate the process of improving and streamlining clinical trials.

4.1. Limitations

This study focused on data collected in the national CDC BRFSS survey, including surveys that met inclusion criteria from 2007 to 2017. This dataset was chosen because it is a large and well-established sampling of the noninstitutionalized adult population of the United States that collects extensive demographic information on respondents. However, there are several limitations to consider in the analysis of this study. First, since the data is gathered in a voluntary, self-reported survey, it is vulnerable to misreporting, misclassification, and response bias. In particular, only living patients were eligible to respond, meaning responses could not be collected from patients who died despite treatment, perhaps biasing responses towards respondents who were diagnosed with a less aggressive or earlier staged cancer. Second, since the questions on cancer clinical trials were part of an optional module, they were administered in only some states in some years. However, the sample size was still quite large, and the results were amply powered for analysis. Finally, the survey does not give any insight into motivations and opportunities to participate in cancer clinical trials. Further study is necessary to parse out why certain groups are more likely to participate, whether it be cultural differences, financial and structural barriers, different eligibility, different rates of invitation to participate, or other factors.

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.

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