



# Willingness to Participate in Health Research Among Community-Dwelling Middle-Aged and Older Adults: Does Race/Ethnicity Matter?

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## Abstract

**Introduction** Older adults, including racial and ethnic minorities, are underrepresented in research. As the US population ages, the number of older racial and ethnic minority individuals will increase. Including these individuals in research is an important step towards reducing health disparities.

**Methods** We used data from HealthStreet, a University of Florida community engagement program which uses community health workers to assess the health of the community, to assess willingness to participate in different types of health research by race/ethnicity. Descriptive statistics and logistic regression models were used to assess willingness to participate among adults aged 50 and older, by race/ethnicity ( $n = 4694$ ).

**Results** Our sample was 42.0% non-Hispanic White, 52.8% non-Hispanic Black, and 5.2% Hispanic. Non-Hispanic White participants reported more past research participation than non-Hispanic Black and Hispanic participants (28.7% vs. 19.0% and 19.2%, respectively). Compared with non-Hispanic White participants, non-Hispanic Black participants were less willing to participate in most types of studies, while Hispanic participants were less willing to participate in studies that might be seen as invasive (required blood sample, genetic sample, or participants to take medicine, or use of medical equipment).

**Conclusions** Our study provides investigators with a general profile of research preferences by race/ethnicity; compared with non-Hispanic White individuals, non-Hispanic Black individuals are less willing to participate in most studies, while Hispanic individuals are less willing to participate in studies that may be seen as invasive or demanding. It is imperative to include diverse older adults in health research. By tailoring research based on preferences we can improve recruitment in underrepresented populations.

**Keywords** Minorities · Older adults · Research participation · Recruitment

## Introduction

Older adults, including racial and ethnic minorities, are underrepresented in research, yet represent a growing population in the United States (US). As the US population ages, the number of older racial and ethnic minority adults will increase. Between 2010 and 2018 the median age in the US increased

most among racial and ethnic minority populations compared with non-Hispanic White populations [1]. The racial and ethnic composition of those aged 65 and older is projected to change between 2018 and 2060 [2]. The proportion of non-Hispanic White adults in the population aged 65 and older is projected to decrease from 76.7% in 2018 to 55.1% in 2060 [2], a 22% change. The proportion of Hispanic adults among those aged 65 and older is projected to almost triple from 8.4% in 2018 to 21.0% in 2060 [2]. Additionally, the proportion of non-Hispanic Black adults among those aged 65 and older is projected to increase from 9.1 to 12.8% [2].

Recruiting and retaining diverse populations for research is an imperative step in reducing health disparities given that screening, disease risk factors, and treatment effects differ by race and ethnicity [3–5]. Yet, racial and ethnic minority populations are largely underrepresented in health research [6], hence the reason for the National Institutes of Health

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(NIH) Revitalization Act of 1993 (and subsequent amended guidelines) that mandated the inclusion of women and ethnic minorities NIH funded research [7]. Since the passage of this act, less than 2 % of the National Cancer Institute's clinical trials primarily focus on any racial/ethnic minority group and many cancer clinical trials fail to report results by race and ethnicity [8]. Despite this low inclusion, minority adults report being willing to participate in health research [9].

Research has enumerated reasons for such exclusions. Reasons include socioeconomic constraints, language barriers [10, 11], provider referrals, access to health care, and recruitment. An underlying explanation of these reasons put forth has been that of mistrust. Historically, this can be understood through the unethical treatment of minority research participants such as the case of the Tuskegee syphilis study. Since then, many more cases of unethical treatment of minority research participants have occurred [12–14]. Past studies have found increased mistrust among racial and ethnic minority populations compared with Non-Hispanic White populations. In a study among older Black and Hispanic adults, a majority of respondents (60%) agreed that mistrust of researchers is a reason for not participating in research, yet also 95% agreed that Black and Hispanic populations should be included more often in research [15]. Similar to these findings of high willingness to participate in research, a qualitative study among Hispanic individuals living along the US–Mexico border also found strong willingness to participate in research with reasons including a desire to help others and access to health care [16]. Respondents also reported reasons outside of mistrust for lack of Hispanic participation in research, including low education and literacy, and lack of motivation [16].

Furthermore, researcher/protocol-related reasons, such as long informed consent forms [17] and complex study designs [18], for non-participation in research may disproportionately impact minority individuals with low education levels, given the positive relationship between education level and receipt of informed consent [19]. Also, the absence of culturally appropriate study questionnaires or sampling tools [20] and understanding the consent and trust in the informed consent process are barriers to minority participation in research [21, 22]. Further, principal investigators usually do not have informed consents translated into multiple languages; hence, non-English speaking potential participants may not be offered opportunity to participate [23].

Age is also factor in research recruitment among minority older adults [24]. Among all adults, there are additional challenges of aging that may reduce likelihood to participate in research such as comorbid health conditions, age-related visual decline, or degenerative joint conditions that may impose mobility limitations and thus their ability to visit research sites [25, 26]. Polypharmacy, typically defined as

the use of five or more medications, is common among older adults [27] and the pharmacologic drug interaction effects from polypharmacy may make them ineligible for some studies [28]. Particularly among older Black adults, polypharmacy is associated with worse self-rated health and depression [29]. In addition to the high economic inequalities [30], comorbidities [31], and depression [32, 33], that disproportionately affect minorities, depression is also associated with economic hardship [34], lower social trust in others [35], and a decrease in willingness to participate in research [36]. In addition, low socioeconomic status is negatively associated with research participation [37]. Differences in participation among minorities also vary by age. Previous work has examined willingness to participate in health research among White and Black adults, aged 18 and older in the US and found no differences in willingness to participate in research by age among White adults [38]. However, among Black individuals, those who were aged 65 and older had a lower odds of reporting interest in participating research compared with their younger counterparts aged 18 to 24 [38]. It may be that this generation of Black older adults still is highly aware of the history of unethical research conducted in minority populations [38].

Thus, older adults have been found to be underrepresented in health research and the implications of this may affect treatment efficacy, health care utilization, and quality of life [39]. These factors reduce recruitment of older adults; they worsen the underrepresentation among minority older adults. Yet the advancement of precision medicine—specifically the US's All of Us Research Program—relies on data collection from demographically diverse populations, including racial and ethnic minorities as well as older adults, in order to allow for research benefits to be distributed to a larger population [40].

A number of strategies have been recommended to overcome barriers to participation in research by underrepresented older adults. Among Hispanic adults, strategies include recruitment through direct contact and recruitment using trained members of the target population [41]. Among older adults, strategies include attention to logistical concerns such as transportation and mobility, involvement of those caring for older adults, and eliminating study exclusion criteria [42, 43]. One method of integrating the recommendations above has been the use of community health worker (CHW) model. CHWs are trained individuals from the community they serve and have demonstrated an ability to recruit underrepresented populations into studies [9, 44].

Given the need to understand the research perceptions and beliefs of older racial and ethnic minorities [45], this analysis compares the willingness of community members to participate in different types of health research by race and ethnicity using a sample of community members across Florida recruited by CHWs.

## Methods

### Data Collection

We analyzed data collected through HealthStreet, a University of Florida community engagement program which utilizes CHWs to assess the health conditions and concerns of the community [46]. HealthStreet CHWs go into the community daily and recruit individuals where they live, work, and recreate. These individuals are generally first time interviewees who are approached in community areas such as recreational parks, local libraries, churches, laundromats, barbershops, public events, and community centers. Some of these locations are local partners that HealthStreet CHWs regularly visit. Once consented in the community, participants are interviewed by a CHW using the HealthStreet Intake Form. The Intake Form is a written form used by CHWs to conduct the interview. The interview takes about 20 min and elicits information on a wide variety of information including participant's sociodemographic characteristics, health conditions, health concerns, healthcare utilization, willingness to participate in research, and substance use. After the interview is completed, the individual is considered a HealthStreet member. HealthStreet members can utilize services offered at the physical HealthStreet location including health education classes, computers for public use, and blood pressure checks. Additionally, the HealthStreet program acts as a liaison between the research community at the University of Florida (UF) and community members. The HealthStreet Study Navigator maintains a database of ongoing research studies at UF. If participants indicate that they are interested in participating in future research studies and if they are eligible for studies based on information provided in their intake form, the Study Navigator will contact them to recruit them for a study.

Participants are invited to take part in research dissemination activities, such as our Town Hall series, “Our Community, Our Health,” and are given information on study findings, community services, and other opportunities for engagement through our newsletter and calendar and through social media. Community members' information on their health concerns and conditions help guide study development and research priorities through the Clinical and Translational Science Institute (CTSI) at UF. Focus groups held at HealthStreet invite further participation in shaping UF research design, protocols, and consent forms as well as helping to interpret study findings. A Community Advisory Board through the CTSI helps to guide HealthStreet community engagement and provides additional participation opportunities. Hundreds of community-based organizations participate with HealthStreet and its members through community meetings, support groups, services, and collaborative activities.

### Analytical Sample

Participants who completed the interview between October 2011 and November 2019, who were 50 years of age or older, and had complete information on variables used in these analyses were included. We only included individuals who reported their ethnicity as Hispanic or those who reported their ethnicity as non-Hispanic and their “race” as White or Black ( $n = 4694$ ). Written informed consent was obtained from all participants, and ethics approval was obtained from the University of Florida Institutional Review Board. A majority of our study sample reported identifying as non-Hispanic Black, while in the US only about 13% of the population is non-Hispanic Black [47]. The education of our sample is similar to that of the US; in the US 87.7% of individuals aged 25 and over have a high school diploma or higher [47], while 79.1 to 87.3% of our sample of adults aged 50 and older report a high school diploma or higher, depending on race. Additionally, as our analytical sample consists of a higher proportion of older adults compared with the US, the unemployment rate is higher than the national average [48].

### Measures

**Independent Variable** Race/ethnicity was categorized as non-Hispanic White, non-Hispanic Black, and Hispanic, based on participant self-report. Participants are asked “are you Hispanic or Latino?” They are then asked for their “race” with American Indian/Alaskan Native, Asian, Black/African-American, Native Hawaiian/Pacific Islander, White, or other as response options. We excluded those who reported their race as American Indian/Alaskan native ( $n = 60$ ), Asian ( $n = 37$ ), or Native Hawaiian/Pacific Islander ( $n = 67$ ), due to small numbers in these groups. Additionally, we excluded those who report their ethnicity as non-Hispanic and their race as other ( $n = 75$ ). If participants reported being Hispanic, they were categorized as Hispanic regardless of their reported race. Individuals who reported they were not Hispanic were further classified as non-Hispanic White or non-Hispanic Black.

**Dependent Variables** As a part of the HealthStreet questionnaire participants are asked about their past research participation, their willingness to participate in different types of health studies, their interest in participating in a research study, and their willingness to donate their brain for research. Participants are first asked “Have you ever been in a health research study?” Then they are asked the stem question “would you volunteer for a health research study...” with different research study conditions: (1) “that only asked questions about your health,” (2) “if researchers wanted to see your medical records,” (3) “if you had to give a blood sample,” (4) “if you were asked to give a sample for genetic studies,” (5) “if you might have to take medicine,” (6) “if you were asked to

stay overnight in a hospital or clinic,” and (7) “if you might have to use medical equipment” with “yes” or “no” as response options. Participants are also asked if they would participate in a study without compensation (yes/no) and how interested they are in being in a research study (definitely/maybe/not at all). Since 2015, participants are asked how likely they would be to donate their brain for research (likely/somewhat likely/not at all likely).

*Covariates* include age (50–59, 60–69, 70–79, 80+), gender (male, female), marital status (currently married, not married (never married, separated, or divorced), widowed), education level (less than high school, at least high school or GED), health insurance status (insured, uninsured), food insecurity (yes, no), and recruitment site (Gainesville, Jacksonville, Miami, or other location), all elicited through the HealthStreet intake form. Participants were asked “have there been times in the last 12 months when you did not have enough money to buy food that you or your family needed?” This provided the basis for our food insecurity variable.

## Analysis

Descriptive statistics were calculated for sociodemographic characteristics, and chi-square tests of independence were used to test differences by race/ethnicity. Lastly, descriptive statistics were calculated for research participation variables and chi-square tests of independence were used to test differences by race/ethnicity. Multivariate logistic regression models were used to assess the odds of willingness to participate in research, with race/ethnicity as the independent variable and each type of research study as the dependent variable. Individual models were used for each type of research study, controlling for age, gender, marital status, education level, health insurance status, food insecurity, and recruitment site. SAS® software version 9.4 was used for the analyses.

## Results

Among the 4694 individuals included in these analyses, 42.0% were non-Hispanic White, 52.8% were non-Hispanic Black, and 5.2% were Hispanic. Non-Hispanic Black individuals were significantly younger than their non-Hispanic White and Hispanic counterparts. All three groups were mostly female; however, the non-Hispanic White group had a significantly larger proportion of females compared with the non-Hispanic Black group (61.4% vs. 55.5%). Non-Hispanic Black adults were largely not currently married compared with non-Hispanic White and Hispanic adults ( $p < 0.001$ ). Most participants reported at least having a GED or high school education. The non-Hispanic White group had a larger proportion of individuals with at least a GED or high school education compared with the non-Hispanic Black and

Hispanic groups (87.3% vs. 79.1% and 82.0%, respectively). Over half of all three groups reported having health insurance; however, non-Hispanic White individuals reported higher health insurance coverage compared with their non-Hispanic Black counterparts (73.4% vs. 68.8%). Food insecurity differed significantly between all three groups. Hispanic participants reported the lowest prevalence of food insecurity (40.4%), followed by non-Hispanic White participants (43.2%) and then non-Hispanic Black participants (53.1%). Recruitment site differed significantly between all three groups. Over half of non-Hispanic White and non-Hispanic Black participants were recruited from Gainesville (75.5% and 58.1%). The majority of the remaining non-Hispanic White participants were recruited from other location (14.8%) and Jacksonville (9.1%), while the majority of the remaining non-Hispanic Black participants were recruited from Jacksonville (36.5%). Hispanic participants were recruited from Gainesville (54.3%), Miami (24.9%), Jacksonville (12.2%), and other rural counties (8.6%) (Table 1).

Overall, our sample reported low past research participation but high willingness to participate in research (Table 2). Some differences emerged by race and ethnicity. Non-Hispanic White individuals reported significantly higher past participation in a health research study compared with their non-Hispanic Black and Hispanic counterparts (28.7% vs. 19.0% and 19.2%, respectively). Adults in our sample generally were willing to participate in research with willingness ranging from 56.3 to 95.6% based on the type of study. Among all three racial/ethnic groups, studies that only asked questions about health had the highest willingness, while those that would require taking medicine had the lowest willingness to participate.

After adjusting for covariates, including age, gender, marital status, education level, health insurance status, food insecurity, and recruitment site, many racial/ethnic differences in willingness to participate in research persisted (Table 3). Compared with non-Hispanic White participants, non-Hispanic Black participants had a lower odds of reporting report previous participation in a health research study (OR = 0.71, 95% CI = 0.61–0.83,  $p < 0.0001$ ). For studies that were minimally invasive (only asked questions about health or required medical record review), non-Hispanic Black individuals were less willing to participate compared with non-Hispanic White individuals (OR = 0.70, 95% CI = 0.52–0.94,  $p = 0.0191$ ; OR = 0.65, 95% CI = 0.53–0.80,  $p < 0.0001$  respectively). For studies that were more invasive (required blood sample, genetic sample, participants to take medicine, or use of medical equipment), both non-Hispanic Black and Hispanic participants reported less willingness to participate compared with White participants. There were no racial/ethnic differences in willingness to participate in studies that would require staying in a hospital or clinic overnight. Non-Hispanic Black individuals reported less interest in



**Table 1** Sociodemographic characteristics of HealthStreet participants aged 50+, by race/ethnicity (n = 4694)

	Non-Hispanic White (n = 1970; 42.0%)	Non-Hispanic Black (n = 2479; 52.8%)	Hispanic (n = 245; 5.2%)	p value
Age <sup>B,C</sup>				< 0.0001
50–59	880 (44.7%)	1435 (57.9%)	112 (40.2%)	
60–69	687 (34.9%)	804 (32.4%)	84 (35.4%)	
70–79	310 (15.7%)	203 (8.2%)	38 (18.3%)	
80+	93 (4.7%)	37 (1.5%)	11 (6.1%)	
Gender <sup>C</sup>				0.0004
Male	761 (38.6%)	1102 (44.5%)	97 (39.6%)	
Female	1209 (61.4%)	1377 (55.5%)	148 (60.4%)	
Marital status <sup>B,C</sup>				< 0.0001
Currently married	577 (29.3%)	566 (22.8%)	86 (35.1%)	
Not married	1123 (57.0%)	1626 (65.6%)	124 (50.6%)	
Widowed	270 (13.7%)	287 (11.6%)	35 (14.3%)	
Education level <sup>A,C</sup>				< 0.0001
Less than high school	251 (12.7%)	519 (20.9%)	44 (18.0%)	
At least GED/high school	1719 (87.3%)	1960 (79.1%)	201 (82.0%)	
Health insurance status <sup>C</sup>				0.0022
Insured	1446 (73.4%)	1706 (68.8%)	181 (73.9%)	
Uninsured	524 (26.6%)	773 (31.2%)	64 (26.1%)	
Food insecurity <sup>B,C</sup>				< 0.0001
Yes	850 (43.2%)	1316 (53.1%)	99 (40.4%)	
No	1120 (56.9%)	1163 (46.9%)	146 (59.6%)	
Recruitment site <sup>A,B,C</sup>				< 0.0001
Gainesville	1488 (75.5%)	1439 (58.1%)	133 (54.3%)	
Jacksonville	180 (9.1%)	904 (36.5%)	30 (12.2%)	
Miami	10 (0.5%)	22 (0.9%)	61 (24.9%)	
Other	292 (14.8%)	144 (4.6%)	21 (8.6%)	

A:  $p < 0.05$  between Hispanics and non-Hispanic Whites; B:  $p < 0.05$  between Hispanics and non-Hispanic Blacks; C:  $p < 0.05$  between non-Hispanic Whites and non-Hispanic Blacks

participating in a research study and less interest in brain donation, compared with their non-Hispanic White counterparts.

## Discussion

In our community dwelling sample of Floridians, we found that adults aged 50 and older report high levels of willingness to participate in health research, despite low levels of reported past research participation. Non-Hispanic Whites reported significantly more past participation in health research compared with their non-Hispanic Black or Hispanic counterparts. This high willingness but low past participation reported by our sample may indicate that there is a lack of opportunity or knowledge of opportunity for research participation among diverse populations and many barriers to research participation remain in place and need to be addressed; this is consistent with what has been reported in the literature [10, 11].

Social determinants of health can provide a framework of understanding participation in research [49]. Social determinants of health are social and economic conditions (e.g., education and access to care) that may affect an individual’s health and may also impact not only an individual’s willingness to participate in research, but their ability to do so [49]. In our sample, over three-fourths of all participants report at least a high school education. Additionally, Hispanics reported the least amount of food insecurity, a proxy for socioeconomic status, followed by non-Hispanic Whites and non-Hispanic Blacks.

Prior research has examined willingness to participate in research among underrepresented groups; however, these studies are typically qualitative and do not focus on older adults. Unlike Ceballos and colleagues [16] who qualitatively examined willingness to participate in research among Latinos living in a border town, we quantitatively examined willingness to participate in research in an older community-dwelling multiracial population. Garza and colleagues examined

**Table 2** Willingness to participate in research among HealthStreet participants aged 50+, by race/ethnicity ( $n = 4694$ )

	Non-Hispanic White ( $n = 1970$ ; 42.0%)	Non-Hispanic Black ( $n = 2479$ ; 52.8%)	Hispanic ( $n = 245$ ; 5.2%)	<i>p</i> value
Have you ever been in a health research study? <sup>A,C</sup>	565 (28.7%)	471 (19.0%)	47 (19.2%)	< 0.0001
Would you volunteer for a health research study:				
That only asked questions about your health? <sup>C</sup>	1884 (95.6%)	2336 (94.2%)	233 (95.1%)	0.1072
If researchers wanted to see your medical records? <sup>C</sup>	1777 (90.2%)	2148 (86.7%)	222 (90.6%)	0.0006
If you had to give a blood sample? <sup>A,C</sup>	1834 (93.1%)	2148 (86.7%)	215 (87.8%)	< 0.0001
If you were asked to give a sample for genetic studies? <sup>A,C</sup>	1803 (91.5%)	2124 (85.7%)	211 (86.1%)	< 0.0001
If you might have to take medicine? <sup>A,B</sup>	1367 (69.4%)	1662 (67.0%)	138 (56.3%)	0.0002
If you were asked to stay overnight in a hospital or clinic? <sup>A,B</sup>	1580 (80.2%)	1978 (79.8%)	175 (71.4%)	0.0052
If you might have to use medical equipment? <sup>A,C</sup>	1789 (90.8%)	2149 (86.7%)	211 (86.1%)	< 0.0001
Would you participate in a study if you did not get paid? <sup>A,C</sup>	1666 (84.6%)	1921 (77.5%)	187 (76.3%)	< 0.0001
How interested are you being in a research study? <sup>B,C</sup>				< 0.0001
Definitely	1171 (59.4%)	1256 (50.7%)	148 (60.4%)	
Maybe	690 (35.0%)	1039 (41.9%)	84 (34.3%)	
Not at all	109 (5.5%)	184 (7.4%)	13 (5.3%)	
How likely would you be to donate your brain for research? <sup>*B,C</sup>				< 0.0001
Likely	591 (30.0%)	285 (11.5%)	82 (33.5%)	
Somewhat likely	250 (12.7%)	230 (9.3%)	39 (15.9%)	
Not at all likely	265 (13.5%)	526 (21.2%)	51 (20.8%)	
Did not respond	864 (43.8%)	1438 (58.0%)	73 (29.8%)	

A:  $p < 0.05$  between Hispanics and non-Hispanic Whites; B:  $p < 0.05$  between Hispanics and non-Hispanic Blacks; C:  $p < 0.05$  between non-Hispanic Whites and non-Hispanic Blacks; \*This question was added in 2015. Of those who did not respond, 99% were interviewed before the question was added

willingness to participate in biomedical research among Latinos and African Americans aged 18 and older [50]. Similar to our study, they examined willingness quantitatively; however, they did not focus on older adults. Regardless, our findings were similar. In their sample, 17.1% of non-Hispanic Black participants and 9.9% of Hispanic participants reported past participation in health research [50] compared with 19.0% of non-Hispanic Black participants and 19.2% of Hispanic participants in our sample. However, both of our studies found a high willingness to participate among these two groups.

When examining willingness to participate in different types of health research, some racial and ethnic differences emerged in preferences. Non-Hispanic Whites individuals reported the most willingness to participate in research. Hispanic and non-Hispanic White participants reported similar willingness to participate in studies that only asked questions about their health or if researchers wanted to see their medical records. These may be seen as not as inconveniencing or burdensome compared with their other types of studies we asked about. However, once we asked about more burdensome types of studies, Hispanic individuals reported a lower willingness to participate. Compared with non-Hispanic White adults, non-Hispanic Black and Hispanics

adults reported lower willingness to participate in a research study if they had to give a blood sample, give a sample for genetic studies, or take medicine. This may be due to multiple barriers. In addition to lack of trust, language can be a large barrier to participation. For many Hispanic individuals, especially immigrant populations, the primary spoken language may not be English. This may impede an individual's ability to access health information in their primary language and may limit their understanding of study requirements, trust in the researchers, and ability to consent if study materials are not provided in their primary language [10, 11]. It also is important to note that the drop in willingness to participate in more demanding study types may be due to the wording of the questions. Many older individuals do want to participate in research because of altruism; however, the general wording of the questions may be too vague. For instance, if participants were asked if they were interested in participating in a drug study for Alzheimer's disease treatments, they may be more likely to participate, given that Alzheimer's currently does not have a cure and it is a disease that severely impacts quality of life. Our findings are consistent with previous research. One recent study examined racial and ethnic differences in willingness to be contacted about Alzheimer's disease research participation,

**Table 3** Odds of willingness to participate in different types of research among HealthStreet participants aged 50+, by race/ethnicity (ref = non-Hispanic White), adjusted for sociodemographic factors (*n* = 4694)

	OR (95% CI)	<i>p</i> value
Have you ever been in a health research study?		
Non-Hispanic Black	0.71 (0.61, 0.83)	< 0.0001
Hispanic	0.76 (0.53, 1.09)	0.1292
Would you volunteer for a research study: that only asked questions about your health?		
Non-Hispanic Black	0.70 (0.52, 0.94)	0.0191
Hispanic	0.83 (0.43, 1.62)	0.5894
If researchers wanted to see your medical records?		
Non-Hispanic Black	0.65 (0.53, 0.80)	< 0.0001
Hispanic	0.95 (0.59, 1.54)	0.8297
If you had to give a blood sample?		
Non-Hispanic Black	0.49 (0.39, 0.61)	< 0.0001
Hispanic	0.48 (0.31, 0.75)	0.0013
If you had to give a sample for genetic studies?		
Non-Hispanic Black	0.57 (0.46, 0.70)	< 0.0001
Hispanic	0.52 (0.34, 0.80)	0.0026
If you might have to take medicine?		
Non-Hispanic Black	0.74 (0.64, 0.85)	< 0.0001
Hispanic	0.73 (0.54, 1.00)	0.0474
If you were asked to stay overnight in a hospital or clinic?		
Non-Hispanic Black	0.85 (0.72, 1.00)	0.0530
Hispanic	0.76 (0.54, 1.07)	0.1093
If you might have to use medical equipment?		
Non-Hispanic Black	0.65 (0.53, 0.81)	< 0.0001
Hispanic	0.59 (0.38, 0.90)	0.0141
Would you participate in a study if you did not get paid?		
Non-Hispanic Black	0.57 (0.48, 0.67)	< 0.0001
Hispanic	0.58 (0.41, 0.83)	0.0026
How interested are you being in a research study? (definitely/maybe vs no)		
Non-Hispanic Black	0.56 (0.43, 0.74)	< 0.0001
Hispanic	0.82 (0.44, 1.52)	0.5223
How likely would you be to donate your brain for research? (likely/somewhat likely vs no)		
Non-Hispanic Black	0.28 (0.23, 0.34)	< 0.0001
Hispanic	0.67 (0.45, 1.00)	0.0518

Depicts odds ratios from separate multivariate logistic models with race and ethnicity as the independent variable and each type of research study as the dependent variable. Individual models were used for each type of research study, controlling for age, gender, marital status, education level, health insurance status, food insecurity, and recruitment site. Unless noted, all variables were answered yes vs. no.

by type of study, among adults aged 50 and older [51]. They found, compared with non-Hispanic White participants, non-Hispanic Black and Hispanic participants were less likely to be willing to be contacted for studies that were more demanding (cognitive testing, brain imaging, blood draws, and investigational medicines) [51].

Additionally, it should be noted that the sample of our Hispanic population may not be reflective of the Hispanic population of the US [52]. In our sample, about 22.0% of

Hispanics reported the US as their country of birth. Among those who were not born in the US, Cuba (31.0%), Colombia (19.4%), and Puerto Rico (14.2%) were the most common countries of birth. Additionally, while nationally the Hispanic population has the youngest median age, compared with other racial and ethnic groups, in our sample, non-Hispanic White and Hispanic adults tended to be older compared with their non-Hispanic Black counterparts. This suggests that our sample is comprised of a different Hispanic

population compared with the US population, as a whole, where most Hispanic adults are of Mexican origin.

Consistent with our previous work, which focused on brain donation among all HealthStreet participants [53], we found that non-Hispanic White and Hispanic adults aged 50 and older reported being likely or somewhat likely to donate their brain for research, compared with their non-Hispanic Black counterparts who mostly reported being not at all likely to be willing to donate their brain. Lambe and colleagues [54] examined perceptions of brain donation among Black adults aged 55 and older; their participants expressed that the brain donation was too intrusive and demanding, that the resulting research would not benefit their communities, and some distrust of researchers.

Additionally, the overall high willingness ranging from 56.3 to 95.6% reported based on the type of study may be because interviews are conducted by trained CHWs who are from the communities they serve; this may increase trust among community members. Face-to-face interviewing has been found to be an effective strategy in older adults' recruitment [55, 56] and when conducted by well trained, culturally sensitive members of the same community, in this case CHWs, gives credence to the integrity of our data.

The ongoing COVID-19 pandemic emphasizes the importance of recruiting underrepresented populations. These individuals carry a disproportionate risk of severe COVID-19 and complications compared with their White counterparts, and the risk increases with age. In the US, Black individuals only comprise of 13.4% of the US population; however, they represent 28 to 70.5% of COVID-19 deaths, ranging by state [57]. Our findings show that the lack of inclusion of minority individuals is not due to a lack of interest in their part. It is our responsibility as researchers to include these individuals in studies; however, this is not enough. We recognize that we must also design more comprehensive assessments, which disentangle the complex issues associated with race and ethnicity, such as perceived discrimination [58].

**Limitations** Although HealthStreet provides real-time information collected through CHWs on a wide variety of factors, some limitations must be considered. The HealthStreet sample is a convenience sample, not a representative sample of the US population; however, this is beneficial for these analyses given the oversampling of low-income and Black populations. There is also potential selection bias; the perceptions of the individuals included in our analysis may be more positive because they already consented to participating in HealthStreet. Among all community members who have been approached to participate in HealthStreet since 2011, only 16% have refused to participate. This reduces the concern of bias in the study sample. Additionally, relative to the number of non-Hispanic White and Black adults included, there is a low number of Hispanics included in these analyses.

Compared with the demographics of Florida, HealthStreet has a low number of Hispanic participants because HealthStreet is primarily focused on recruitment in Gainesville and Jacksonville. The small sample size of Hispanic participants may explain why the results for some types of research studies were not statistically significant in this group. Future studies are needed with larger samples of Hispanic individuals. The low number of Hispanic adults included also limited us from further examining country of origin in these analyses, which is important to consider, given the heterogeneity of the Hispanic population in the US. It also did not allow us to distinguish between Hispanic White and Hispanic Black individuals.

Finally, we want to note that we are treating “race” herein as a factual construct, when we know race is a social construction and that we are really measuring societal divisions and factures, more appropriately identified as “racism” [59]. Here “race” is a marker for the kind of prejudicial treatment that may produce differences in attitudes towards and participation in research through multiple social processes.

**Conclusions** Overall, we found high willingness to participate in different types of research studies among non-Hispanic White, non-Hispanic Black, and Hispanic individuals aged 50 and older. We found some racial and ethnic differences in willingness to participate in various research types; this underscores the importance of the fit of the study protocol to the study participants, especially in studies that focus on a particular racial/ethnic group for optimal study recruitment. Our study provides investigators with a general profile of different racial and ethnic groups with specific research types they may not be inclined to participate in, such that investigators can refine recruitment efforts particularly when they have participants from certain racial or ethnic groups. We found that, compared with non-Hispanic White individuals, non-Hispanic Black individuals are less willing to participate in most studies, while Hispanic individuals are less willing to participate in studies that may be seen as invasive or demanding (required blood sample, genetic sample, participants to take medicine, or use of medical equipment). Future studies should examine whether intra-racial differences exist in willingness to participate in various research types among Hispanic adults based on the country of origin.

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## Compliance with Ethical Standards

**Disclaimer** The content is solely the responsibility of the authors and does not necessarily represent the official view of the National Institutes of Health.

**Conflict of Interest** The authors declare that they have no conflict of interest.

**Ethics Approval** HealthStreet, a community engagement program at the University of Florida, was approved by the University's Institutional Review Board (reference number: IRB201600459).

**Consent to Participate** Written informed consent was obtained from participants.

**Consent for Publication** Not applicable.

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