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Title

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Journal

Military Medicine: international journal of AMSUS, 188(7-8)

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Publication Date

2022-05-18

DOI

10.1093/milmed/usac127

Peer reviewed

Motives for and Barriers to Research Participation Among Racially and Ethnically Diverse Veterans

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ABSTRACT

Introduction:

Veterans in general—and especially those who identify as Veterans of color—are underrepresented in health-related treatment research. This contributes to health inequity by hindering the development of evidence-based treatment recommendations for people of color. This project utilized culturally centered research procedures to identify health-related research priorities and examine motives for and barriers to research participation in a diverse sample of Veterans.

Materials and Methods:

Veterans ($N = 330$, 32% female; 36% Black, 28% White, 15% Latinx, 12% Asian, 4% Multiracial) reported their experiences with and perspectives on health-related research online from remote locations. Linear regression was used to test associations between discrimination and motives/barriers for research. All procedures were approved by the Institutional Review Board (#2033562).

Results:

Participants identified psychological concerns, particularly PTSD, as research priorities for Veterans in their communities, but also prioritized physical problems (e.g., brain injury) and social concerns (e.g., homelessness, access to care). Perceptions of, motives for, and barriers to research were similar across racial/ethnic groups. The most common motive was contributing to research that seems important, and the most common barrier was not knowing about research opportunities. Every-day experiences with discrimination (e.g., people acting as if they are afraid of you because of your race/ethnicity) were associated with more barriers to research among Black participants.

Conclusions:

Experiences of racial/ethnic discrimination are associated with different research-related outcomes across racial/ethnic groups. Efforts to engage diverse populations should prioritize access to (not willingness to participate in) health-related research.

INTRODUCTION

Racial/ethnic disparities in access to healthcare have been documented across populations, including those with

substance use disorders,^{1,2} those who are chronically ill,³ and those experiencing Alzheimer's disease and related dementias.⁴ Some scholars propose that these racial/ethnic disparities arise not only as a result of individual bias or prejudice but also as a result of structural racism.⁵⁻⁷ Structural racism refers to the systemic ranking of certain human groups as inferior and the differential allocation of societal resources to those groups.^{5,8} In the context of healthcare, racial/ethnic disparities may persist as a result of individual characteristics and communication styles,⁹ but the characteristics of the healthcare system (e.g., healthcare/insurance costs and availability of providers) likely also play a role.^{6,10} We propose that underrepresentation in research is another systemic barrier to healthcare equity, as it precludes evidence for best practice guidelines for people of color.⁷

Veterans experience unique barriers to research participation (e.g., concern about loss of benefits) that make research engagement more difficult for Veterans than civilian populations.¹¹ These barriers to research are compounded among Veterans of color, who are underrepresented in research studies.¹²⁻¹⁵ This is problematic because the U.S. military is

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The National Institutes of Health and the Department of Defense had no role in study design; data collection, analysis, or interpretation; manuscript preparation; or the decision to submit the article for publication.

doi:<https://doi.org/10.1093/milmed/usac127>

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more racially diverse than the general population.^{16,17} In this case, failure to include the perspectives of people of color in military and Veteran research may also contribute to health disparities in these communities.

Consistent with publishing standards on racial health inequities^{7,18} and community-based participatory research recommendations,¹⁹ this research represents a first step in reducing health disparities among Veterans of color by examining motives for and barriers to research participation in a diverse sample of Veterans. First, we identified the health issues viewed as research priorities across racial/ethnic groups. Second, we evaluated motives for and barriers to research participation across racial/ethnic groups. Finally, we examined the role of racial discrimination in research engagement, hypothesizing that Veterans of color with more daily experiences with discrimination would report more skepticism toward research, less willingness, weaker motives, and stronger barriers to participation.

METHODS

Participants and Procedure

The Institutional Review Board approved all procedures, which were preregistered on Open Science Framework (<https://osf.io/dxhj6>) before data collection. Individuals were recruited using Qualtrics research panels, an online participant pool for scientific research. Members of the panels who reported serving in the U.S. military on their profile were sent an email from Qualtrics, indicating that a new survey was available. Participants provided informed consent before completing the survey. Incentives ranged in value from \$5.69 to \$7.31.

A total of 602 Veterans completed the online survey. Responses were excluded if they were non-sensical ($n = 118$), only included demographic information ($n = 101$), were implausible ($n = 13$), or violated 2+ invalid response indicators ($n = 36$). Given the focus of this manuscript on race/ethnicity, four participants who declined to disclose their race/ethnicity were also excluded from the sample. A total of 330 participants, 239 (72%) of whom identified as a Veteran of color, were included (see demographics in Table I).

Measures

Participants reported on research priorities; perceptions, motives for, and barriers to participating in research; and experiences with discrimination online from remote locations.

Research priorities

Participants responded via open text to the following question: “What 1-2 health problems or issues do you see as most important for Veterans in your community right now?”

Perceptions

Participants indicated how often they have the opportunity to contribute to research as a participant (the one providing data)

TABLE I. Characteristics of the Sample ($N = 330$)

Age, M (SD)	41.4 (14.7)
Gender, n (%)	–
Female	106 (32%)
Male	218 (66%)
Transgender	1 (<1%)
Gender non-binary	5 (2%)
Other	0 (0%)
Sexual orientation, n (%)	–
Straight or heterosexual	288 (87%)
Lesbian or gay	14 (4%)
Bisexual	19 (6%)
Queer, pansexual, or questioning	7 (2%)
Other	2 (<1%)
Race/Ethnicity, n (%)	–
American Indian or Alaska Native	18 (6%)
Asian or Asian American	38 (12%)
Black or African American	118 (36%)
Hispanic, Latino/a, or Latinx	48 (15%)
Multiracial or Multi-ethnic	13 (4%)
Native Hawaiian or Pacific Islander	4 (1%)
White, Caucasian, or European	91 (28%)
Military affiliation, n (%)	–
Active duty	72 (22%)
Reserves/guard	60 (18%)
Separated/discharged/retired	198 (60%)
Branch of service, n (%)	–
Air Force	56 (17%)
Army	171 (52%)
Coast Guard	19 (6%)
Marines	42 (13%)
Navy	42 (13%)
Years in service, M (SD)	8.1 (6.4)
Number of deployments, M (SD)	2.1 (1.9)

M = mean; n = number of participants; SD = standard deviation.

on a scale from 0 (*never*) to 4 (*always*). They then rated their agreement with the statements (1) that Veterans benefit from research and (2) that they are willing to contribute to research as a participant on a scale from 0 (*strongly disagree*) to 4 (*strongly agree*).

Motives

Motives for research participation were drawn from previous studies.^{11,20} Participants were provided the following prompt: “Consider all of the times you have thought about participating in a research study. How often do you consider participating for the following reasons?” (see Table III for reasons). Response options were 0 (*almost never/never*), 1 (*some of the time*), 2 (*about half of the time*), 3 (*most of the time*), and 4 (*almost always/always*).

Barriers

Barriers to participation were also drawn from previous studies.^{11,21} Participants were provided the following prompt: “To what extent do you agree or disagree that the following issues would prevent you from participating in a research study?” (see Table III for barriers). Response options ranged from

0 (*strongly disagree*) to 4 (*strongly agree*). Given limited variability across barriers, data were recoded in [Table III](#) to indicate the percentage of participants who agreed or strongly agreed that they did not participate in research for each reason.

Discrimination

The 9-item Everyday Discrimination Scale²² was used to assess how often participants experience discrimination in their day-to-day lives. Items in this study were revised to specify racial/ethnic discrimination; for example, “You are treated with less respect than other people because of your race/ethnicity.” Response options ranged from 0 (*never*) to 5 (*almost every day*). This measure has been validated as a measure of discriminatory experiences in diverse samples^{23,24} and demonstrated excellent internal consistency in this sample ($\alpha = 0.96$).

Data Analysis Plan

Research questions regarding research priorities, perceptions, motives, and barriers were answered using descriptive statistics. Linear regression was used to examine associations between experiences with discrimination and motives/barriers for research. Regression models controlled for gender (male coded 1, all other genders coded 0) and age in years. Consistent with recommendations to have 10 participants per predictor,²⁵ regression models were conducted separately for

each racial/ethnic minority group that included at least 30 participants (Asian, Black, and Latinx). Change in R^2 , which quantifies the amount of variance in an outcome explained by the predictors,²⁶ was used to estimate effect size.

RESULTS

Research Priorities

A total of 274 participants provided open-text responses identifying health-related research priorities among Veterans in their communities. Responses were grouped broadly into psychological ($n = 175$), medical ($n = 86$), and social ($n = 84$) issues. Of the 178 who prioritized psychological issues, 82 specifically cited PTSD, 16 cited sleep disturbance, 9 cited alcohol/drug use, 9 cited depression, and 7 cited suicidal ideation. Specific medical research priorities included physical injuries, such as disabilities and back problems ($n = 26$), coronavirus disease ($n = 13$), cancer ($n = 10$), chronic pain ($n = 8$), high blood pressure ($n = 6$), heart disease ($n = 6$), and diabetes ($n = 6$). Finally, social research priorities included lack of access to quality healthcare ($n = 41$), housing or homelessness ($n = 37$), difficulty with employment and/or benefits ($n = 12$), and social support ($n = 7$; e.g., “helping them comprehend that they are not alone” and “not being treated equally, not being heard or taken seriously”). Psychological issues were the most commonly cited health concern across each racial/ethnic group (see [Table II](#)).

TABLE II. Self-identified Research Priorities and Perceived Importance of Treatment for Health Conditions Across Racial/ethnic Groups ($N = 330$)

	Am. Indian/ Al. Native ($n = 18$)	Asian/Asian American ($n = 38$)	Black or African Am. ($n = 118$)	Hispanic or Latino/a/x ($n = 48$)	Native Haw./ Pac. Islander ($n = 4$)	Multi-racial/ multi-ethnic ($n = 13$)	White ($n = 91$)
Self-identified priorities^a							
Psychological issues	9 (50%)	24 (63%)	61 (52%)	30 (63%)	2 (50%)	9 (69%)	43 (47%)
Medical issues	2 (11%)	6 (16%)	40 (34%)	12 (25%)	1 (25%)	5 (39%)	20 (22%)
Social issues	6 (33%)	7 (18%)	34 (29%)	8 (17%)	1 (25%)	3 (23%)	25 (28%)
Perceived importance^b							
PTSD	2.94 (1.16)	3.00 (1.12)	3.08 (0.86)	3.33 (0.78)	3.25 (0.50)	3.46 (0.52)	2.98 (0.88)
Brain injuries	3.56 (0.62)	2.87 (0.84)	3.10 (0.83)	3.17 (0.60)	2.50 (1.00)	3.31 (0.75)	3.04 (0.76)
Suicidal thoughts	3.17 (1.04)	2.87 (1.02)	2.98 (0.92)	3.27 (0.87)	2.75 (0.50)	3.31 (0.86)	2.96 (0.88)
Depression	3.11 (0.90)	2.92 (1.12)	2.94 (0.86)	3.31 (0.66)	2.50 (0.58)	3.00 (1.08)	2.92 (0.76)
Physical injuries	3.28 (0.90)	2.79 (0.84)	2.98 (0.76)	3.00 (0.72)	2.75 (0.50)	2.85 (0.69)	3.03 (0.67)
Chronic medical conditions	2.83 (0.71)	2.79 (0.94)	2.97 (0.84)	2.94 (0.73)	2.00 (1.16)	2.85 (0.80)	3.04 (0.71)
Chronic pain	3.17 (0.62)	3.03 (0.82)	2.78 (0.80)	2.92 (0.61)	2.00 (1.16)	3.00 (0.58)	2.88 (0.61)
Anxiety	2.83 (0.79)	2.84 (0.92)	2.83 (0.85)	3.02 (0.85)	2.75 (0.96)	2.85 (0.56)	2.74 (0.80)
Alcohol or drug problems	3.28 (0.90)	2.55 (0.89)	2.70 (0.98)	2.90 (0.81)	2.50 (1.00)	2.85 (1.07)	2.78 (0.88)
Sleep problems	2.83 (0.86)	2.53 (1.13)	2.64 (0.95)	2.77 (0.75)	1.75 (1.50)	2.38 (1.04)	2.58 (0.83)

Am. = American; Al. = Alaska; Haw. = Hawaiian; Pac. = Pacific.

^aNumber and percentage of participants who identified psychological, medical, and social issues as health priorities in their communities in open-text responses.

^bMean and SD of perceived importance of each health condition on a scale from 0 (*not important*) to 4 (*probably most important*).

Perceptions

Perceptions of research across racial/ethnic groups are presented in Table III. In the full sample, participants indicated that they “rarely” to “sometimes” have the opportunity to participate in research studies ($M = 1.76$, $SD = 1.16$). Most agreed that Veterans benefit from research ($M = 2.9$, $SD = 0.96$) and that they would be willing to participate ($M = 3.10$, $SD = 0.91$).

Motives

Motives for and barriers to research across racial/ethnic groups are presented in Table III. There was limited variability across motives, with the majority of participants indicating that they participate in research for each reason “about half of the time” or “most of the time.” The most common motives were to contribute to research that seems important ($M = 2.73$, $SD = 1.16$) and to improve care for future patients ($M = 2.66$, $SD = 1.20$).

Barriers

In terms of barriers to research, the most common issue was not knowing about research opportunities ($M = 2.19$, $SD = 1.28$), followed by not wanting to travel ($M = 1.89$, $SD = 1.30$) and not having time to participate ($M = 1.81$, $SD = 1.23$). This pattern was relatively consistent across racial/ethnic groups (see Table III). Notably, 20% of participants agreed or strongly agreed that they did not participate in research because they do not trust the researchers. After excluding responses that seemed implausible (e.g., \$1,000/h), participants recommended payment of \$35/h ($SD = \63; range \$0-\$500/h).

Impact of Racial Discrimination

Linear regression was used to examine associations between everyday experiences with racial discrimination and research participation among Veterans of color, controlling for gender and age. Among Asian Veterans ($n = 38$), everyday experiences with discrimination were not significantly associated with perceptions that Veterans benefit from research ($B = 0.01$, $P = 0.35$), willingness to participate in research ($B = -0.01$, $P = 0.43$), motives for research participation ($B = 0.09$, $P = 0.24$), or barriers to participation ($B = 0.04$, $P = 0.71$). Similarly, among Latinx Veterans ($n = 48$), discrimination was not significantly associated with perceptions of benefit ($B = -0.02$, $P = 0.16$), willingness to participate ($B = -0.01$, $P = 0.65$), motives ($B = 0.05$, $P = 0.96$), or barriers to research participation ($B = 0.15$, $P = 0.12$). Among Black Veterans ($n = 118$), discrimination was also not significantly associated with perceptions of benefit ($B = 0.01$, $P = 0.89$), willingness to participate ($B < 0.001$, $P = 0.96$), or motives for participation ($B = 0.01$, $P = 0.94$). However, Black Veterans’ experiences with discrimination were associated with more barriers to research participation ($B = 0.29$, $P < 0.001$; 95% CI = 0.15-0.43; adj. $R^2 = 0.17$).

DISCUSSION

This is the first study to examine research priorities as well as motives for and barriers to research participation in a sample comprised primarily of Veterans of color. Somewhat in contrast to hypotheses, experiences with discrimination were not consistently associated with perceptions of, motives for, or barriers to participating in research among Black, Latinx, or Asian Veterans. Indeed, perceptions that Veterans benefit from research, opportunities, willingness to participate, and even motives and barriers to participate were highly similar across groups. Overall, participants expressed strong interest in participating in health-related research. This echoes findings that people of color are willing to participate in health-related research, in which case efforts to increase engagement of this population should focus on access (not willingness) to participate.²⁷

The most consistently identified health-related research priority among Veterans was PTSD. This was the most frequently cited health concern in spontaneous (open text) responses, and it was identified consistently across racial/ethnic groups. Several participants reported that PTSD creates a cascade of social/health issues that compound its negative effects. For example, PTSD-related nightmares were described as contributing to sleeplessness, which contributes to depression, which makes it difficult to maintain employment. Employment and other social issues, particularly housing and homelessness, were also identified frequently as research priorities. The social issues identified in open-text responses seemed to map onto social determinants of health²⁸, specifically, economic stability, educational access and quality, health care access and quality, neighborhood/built environment, and social/community context. One recent study found that both individual-level (e.g., education and poverty) and community-level (e.g., rates of health insurance and income inequality) social determinants of health were associated with health-related outcomes (in this case, recovery from alcohol use disorder) 3 years after treatment.²⁹ Thus, social determinants of health may be important endpoints to consider in future research studies.

The most common barrier to research participation across almost all racial/ethnic groups was not knowing about research opportunities. One in three participants indicated that they were not willing to travel or did not have time; however, this indicates that the majority of Veterans of color are willing to make these sacrifices to participate. The majority of participants (80%) also indicated that distrust of researchers was not a significant barrier to participation. However, one in five participants across the full sample—and one in four Asian and Black participants—reported an element of distrust toward research participation. Descriptively, they also expressed more concern about being assigned to a new (experimental) treatment group.

The impact of racial discrimination on research participation varied across diverse racial/ethnic groups. Although discrimination was not associated with willingness, motives,

TABLE III. Perceptions, Motives, and Barriers to Research Across Racial/ethnic Groups (N = 330)

	Full sample (N = 330)	Am. Indian/Al. Native (n = 18)	Asian/Asian American (n = 38)	Black or African Am. (n = 118)	Hispanic or Latino/a/x (n = 48)	Native Haw./Pac. Islander (n = 4)	Multi-racial/ multi-ethnic (n = 13)	White (n = 91)
Everyday discrimination, M (SD)	13.3 (12.8)	8.9 (9.0)	15.0 (11.5)	17.0 (12.1)	11.6 (12.4)	9.8 (12.1)	15.7 (10.5)	–
Veterans benefit from research, M (SD) ^a	2.9 (1.0)	2.9 (0.8)	2.7 (1.0)	2.9 (0.9)	2.7 (0.9)	2.3 (1.7)	2.9 (1.2)	3.1 (0.9)
Opportunities to participate, M (SD) ^a	1.8 (1.2)	1.7 (1.3)	1.8 (1.1)	1.8 (1.2)	1.8 (1.0)	1.8 (1.0)	1.1 (0.9)	1.8 (1.3)
Willingness to participate, M (SD) ^a	3.1 (0.9)	2.7 (1.2)	2.9 (0.9)	3.1 (0.9)	3.2 (0.8)	3.8 (0.5)	3.3 (0.9)	3.1 (0.9)
Motives for Participation, M (SD) ^{a,b}	12.7 (4.6)	10.9 (5.6)	11.8 (4.7)	13.4 (4.5)	13.3 (3.9)	9.3 (3.2)	11.5 (4.9)	12.5 (4.9)
Contribute to important research	2.7 (1.2)	2.7 (1.2)	2.4 (1.6)	2.4 (1.2)	2.9 (1.2)	2.8 (0.9)	1.8 (0.5)	2.8 (1.2)
Improve care for future patients	2.7 (1.2)	2.6 (1.2)	2.3 (1.4)	2.3 (1.4)	2.7 (1.1)	2.9 (0.9)	3.0 (1.4)	2.7 (1.3)
Share my experiences	2.6 (1.2)	2.5 (1.2)	2.2 (1.3)	2.4 (1.2)	2.6 (1.3)	2.7 (1.1)	2.0 (1.2)	2.7 (1.2)
Better myself (e.g., learn, improve)	2.4 (1.3)	2.4 (1.3)	2.1 (1.5)	2.4 (1.3)	2.6 (1.2)	2.5 (1.1)	1.8 (1.0)	2.4 (1.3)
Earn compensation/payment	2.3 (1.4)	2.4 (1.4)	1.9 (1.5)	2.3 (1.2)	2.6 (1.3)	2.4 (1.4)	0.8 (1.5)	1.9 (1.4)
Barriers to participation, M (SD) ^{a,b}	16.4 (8.6)	17.3 (8.0)	19.4 (7.5)	16.5 (9.3)	16.4 (7.9)	17.0 (7.4)	15.0 (7.8)	15.0 (8.4)
Don't know about opportunities ^c	150 (46%)	8 (44%)	20 (53%)	54 (46%)	21 (44%)	2 (50%)	10 (77%)	35 (39%)
Can't/don't want to travel ^c	119 (36%)	8 (44%)	14 (37%)	41 (35%)	16 (33%)	1 (25%)	4 (31%)	35 (39%)
Don't have time to participate ^c	115 (35%)	11 (61%)	17 (45%)	38 (32%)	14 (29%)	0 (0%)	6 (46%)	29 (32%)
Don't want experimental treatment ^c	88 (27%)	5 (28%)	12 (32%)	36 (31%)	12 (25%)	1 (25%)	4 (31%)	22 (24%)
Don't want placebo treatment ^c	88 (27%)	4 (22%)	16 (42%)	29 (25%)	13 (27%)	1 (25%)	4 (31%)	21 (23%)
Forget to sign up ^c	75 (23%)	7 (39%)	15 (40%)	26 (22%)	11 (23%)	2 (50%)	1 (8%)	13 (14%)
Don't think it makes a difference ^c	75 (23%)	5 (28%)	13 (34%)	26 (22%)	11 (23%)	1 (25%)	0 (0%)	19 (21%)
Don't trust the researchers ^c	65 (20%)	5 (28%)	11 (29%)	28 (24%)	7 (15%)	0 (0%)	2 (15%)	12 (13%)
Don't want to impact benefits ^c	64 (19%)	4 (22%)	7 (18%)	24 (20%)	10 (21%)	0 (0%)	4 (31%)	15 (17%)
Too many research opportunities ^c	50 (15%)	4 (22%)	6 (16%)	22 (19%)	5 (10%)	0 (0%)	1 (8%)	12 (13%)

Am. = American; Al. = Alaska; Haw. = Hawaiian; Pac. = Pacific.

^aItem responses range 0 to 4.

^bTotal scores range 0 to 40.

^cNumber and percentage who agreed or strongly agreed that each barrier would prevent them from participating is reported for each item.

or barriers to research participation among Asian or Latinx participants, Black participants reporting more frequent experiences with racial/ethnic discrimination reported significantly more barriers to research participation (e.g., concern that participation would impact benefits). Thus, discrimination based on race or ethnicity seems to impact some Veterans of color differently. Developing relationships with the participant community, conducting research that is important to the community (in collaboration with the community), and acknowledging power differentials between researchers and participants are key strategies in participatory action research, which aims to reduce social disparities through research partnership with marginalized communities.³⁰ These strategies are important in future health-related research with racially/ethnically diverse communities and may be especially important in work with Black Veteran communities. Incorporating culturally centered research processes will not only produce outcomes that are valuable to communities but also engender trust and promote research engagement. As examples, transparency about research procedures, risks, and benefits (for clinical trials, in particular); diversity and representation within one's research team; and face-to-face recruitment meetings in the community may be helpful.

This study aimed to reduce health disparities by identifying barriers to research participation and treatment engagement in a vulnerable, hard-to-reach sample. However, there were limitations. First, we recruited participants using an online research panel. Online participant recruitment has many strengths, including affordable access to hard-to-reach populations (in this case, Veterans) and better representation of the diversity of the United States.³¹ The quality of data collected also seems to converge with data collected via community recruitment.^{31,32} We chose Qualtrics panels over researcher-initiated internet recruitment to improve the diversity and ensure the integrity of the sample (e.g., to reduce the likelihood of repeat participants and falsified data).³³ However, internet recruitment also may have biased our sample (e.g., selection of experienced survey respondents with internet access),³¹ making it unclear how findings will translate to an individual healthcare setting. Data quality is also a concern with internet recruitment; however, we followed recommendations to ensure data integrity and removed unreliable responses from the sample.³¹ A second limitation is that not all racial/ethnic groups were equally represented. As such, it is unclear if findings will generalize to all racial/ethnic groups or if lack of associations in certain groups were due to lack of power. Gender differences in perceptions of priorities for and barriers to research may also exist within racial/ethnic groups and are encouraged for consideration in future research. Finally, we included White Veterans because Veterans in general tend to be a hard-to-reach population, in which case inclusion of Veterans of all races and ethnicities can inform future research. However, we discourage readers from viewing White Veterans as the "normative" comparison group, as this undermines multiculturalism and limits

understanding of the unique sociocultural experiences of each racial/ethnic group.^{7,34,35}

CONCLUSIONS

Veterans of all racial/ethnic groups are interested in participating in health-related research. As such, efforts to engage diverse samples should prioritize better research marketing, and lack of diversity may not be attributable to low participant willingness. Veterans identified psychological issues, particularly PTSD, as health-related research priorities in their communities. However, physical impairments (e.g., brain injury and pain) and social issues (e.g., access to quality care and social support) were also prioritized. Although perceptions of, motives for, and barriers to research were largely similar across racial/ethnic groups, experiences with discrimination were associated with barriers to research participation among Black Veterans only. Based on these data, the development of trusting relationships and respect may be especially important for the engagement and support of Black Veterans, who must be included in research to promote equity in treatment and healthcare.

ACKNOWLEDGMENT

None declared.

FUNDING

Investigator contributions to this project were supported by the National Institute on Alcohol Abuse and Alcoholism (K23AA026895, PI Miller; R21AA025175, PI Miller; T32AA013526, PI Sher), the National Institute of Nursing Research (R01NR017168, PI McCrae), and the Department of Defense (AR190047, PI McCrae).

CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to report.

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