







# Willingness of Older Adults From Culturally Diverse Populations to Participate in COVID-19 Related Treatment Trials and Associated Factors

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## Abstract

This survey study aimed to assess the willingness of culturally diverse older adults to participate in COVID-19 research. The majority of the 276 participants were women (81%,  $n=223$ ) and Black/African American (62%,  $n=172$ ) or White Hispanic (20%,  $n=56$ ). A key finding from the survey was less than 1 of 10 respondents would be likely to participate in COVID-19 related research if given the opportunity. There were no differences observed by gender, race or ethnicity. Implications of these findings are considered. These study findings indicate continued effort and better messaging strategies are required to increase awareness that COVID-19 related research needs to include culturally diverse older adults to ensure vaccines and treatments are efficacious in different populations.

## Keywords

health services research, health care disparity, survey, methodology

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## Introduction

The underrepresentation of older adults and minorities in clinical trials is certainly not a new problem (Lockett et al., 2019), although there has been some improvement over time (Turner et al., 2022). The National Institutes of Health (NIH) has taken steps “To ensure that findings will be relevant for all people, clinical trials must include participants who reflect the diversity of the U.S. population” (United States Code, Public Health Service Act, 1993). Importantly, the 2017 NIH mandated for all proposal/applications to include a plan for “Inclusion Across the Lifespan” of study participants (National Institutes of Health, 2017). Specific to older adults, the National Institute of Aging (NIA) and other federal agencies developed the “Recruiting Older Adults in Research (ROAR) Toolkit” focused specifically on educating and increasing awareness of adults with dementia and care partners about dementia related research (National Institute of Aging [NIA], 2019).

Unfortunately, low enrollment in clinical trials for older adults persists. In a National Poll on Health Aging

only 12% of respondents report being very likely to participate in a dementia prevention trial (Cox et al., 2023). These results did not vary by race or ethnic group. However, Milani et al. (2021) found non-Hispanic Black individuals were less likely to participate in most research studies compared with non-Hispanic Whites. The unwillingness of older minority adults, specifically African Americans, to participate in research cannot be addressed without acknowledging the historical roots

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that led to mistrust in the healthcare system including the federal funded Tuskegee Syphilis Study.

As scientists sought to develop effective vaccines to combat SARS-2, the virus that causes COVID-19, Black and Asian participants were underrepresented and Hispanic or Latino were overrepresented in prevention trials (i.e., vaccine or diagnosis studies) (Xiao et al., 2023). Early in the pandemic, Black people accounted for 21% of the deaths from COVID-19 but only made up for 3% of participants enrolled in vaccine trials (Warren et al., 2020). Additionally, other studies have found racial and minority groups (Flores et al., 2022) and oldest old adults were underrepresented in clinical trials for new drugs (Lau et al., 2022) and vaccine trials (Flores et al., 2022).

Older adults from culturally diverse backgrounds had the highest COVID-19 related death rates in the United States (Hill & Artiga, 2022). Throughout most of the pandemic the age-adjusted case and death rates due to COVID-19 for Black, Hispanic and American Indian or Alaska Native people living in the United States has been disproportionately higher in comparison to White people (Hill & Artiga, 2022). In a 2020 systematic review of literature both the Hispanic and African/American populations were found to experience disproportionately more COVID-19 infections and increased risk for hospitalizations (Mackey et al., 2021).

There is limited data to assess the willingness of minority, culturally diverse older adult population to participate in COVID-19 related research. Thus, information regarding factors associated with older adults' willingness to participate in COVID-19 related research is necessary to improve recruitment and representation of an at risk culturally diverse populations. Therefore, the objectives of our study were to assess willingness of older culturally diverse adults to participate or not in COVID-19 research on vaccine or treatment.

## Method

### Participants and Procedures

For this current cross-sectional descriptive study, participants were persons 60 years old or older who participated in the parent study "*Florida Statewide Registry for Aging Studies*" and agreed to participate in focus groups and survey completion. The study protocol was approved by the *Florida International University Institutional Review Board* # IRB -20-0119-AM09.

Details regarding the study are available (Gaillard, Shambley-Ebron, Garcia et al., 2022). Briefly, the study recruited culturally diverse older adults and a family member. Persons self-identifying as "Black," "African American," "Hispanic," "Latino," or from the Caribbean, being at least 25 years old, were invited to participate. The *Florida Statewide Registry for Aging Studies* focused on statewide outreach to reach a high percentage of diverse adults. Participants were recruited using several outreach strategies from one of the three participating

*Florida* universities including word of mouth, community partnerships, social media announcements, and through *our community advisory board, the Floririda Statewide Aging Governance Engagement Council (FL-SAGE)*. In addition, flyers were distributed that provided a dedicated 800 number. Eligible persons were informed about the study, completed an informed consent using the Research Electronic Data Capture (REDCap) platform. Data analyzed in this report are from August 2021 through March 2022.

### Measures

A 30-item survey was developed that included demographic items (gender, age, race, ethnicity, education) and items focused on willingness of minority older adults to participate in COVID-19 related research. Guided by the theory of planned behaviors (Ajzen, 1985) we assessed the attitudes of likeliness to complete a behavior (i.e., to engage in COVID related research). Participants were queried:

- If given the opportunity, how likely are you to participate in a research study focused on testing a treatment for COVID-19?
- If given the opportunity, how likely are you to participate in a research study focused on testing a vaccine to prevent COVID-19?

The answers were based on a 4-point Likert scale (i.e., definitely not, maybe not, maybe, definitely). We created dichotomous variables for age (greater than 70 years old, 60 years to 70 years) and education (high school or more education, less than high school). There were other survey items not reported in this current report.

### Data Management and Analysis

Surveys were completed electronically, and the responses were immediately transferred and stored into REDCap. All analyses were conducted with SAS v. 9.4 (SAS Institute, Cary NC) software. Descriptive statistics assessed frequencies for continuous data and percentages for categorical data. Bivariate correlations with the Chi-square test were calculated with possible predictive factors and examined.

## Results

The 276 participants were culturally diverse, mostly older women (mean age  $72.2 \pm 35$ ). Table 1 provides demographic characteristics.

When queried participants how likely they were to participate in a research study focused on testing a vaccine to prevent COVID-19: 35% ( $n=95$ ) responded they would "definitely not" participate, 29% ( $n=79$ ) "maybe not," 28% ( $n=78$ ) "maybe," and only 7% ( $n=20$ ) responded they would "definitely" participate. When queried how likely they were to participate in a research

**Table 1.** Sample Characteristics.

Demographic Variables	n (%)
Women	223 (81%)
<i>Race/Ethnicity</i>	
Black Non-Hispanic	172 (62%)
White Hispanic	56 (20%)
Caribbean	31 (11%)
Other	17 (6%)
Education High School or >	221 (80%)
<i>Preferred language</i>	
English	235 (85%)
Spanish	38 (13.7%)

study focused on testing a COVID-19 treatment: 31.5% ( $n=86$ ) responded “definitely not,” 31% ( $n=85$ ) “maybe not,” 28% ( $n=77$ ) “maybe,” and only 9% ( $n=25$ ) responded they would “definitely” participate.

There were no significant differences in responses by race or ethnicity ( $p=.54$ ), age ( $p=.19$ ), or gender ( $p=.64$ ) in how likely survey respondents were to participate in a research study focused on testing a COVID-19 treatment. Participants with less than a high school education were significantly more likely to report they would “definitely not” participate in research focused on testing a treatment compared to persons with high school education or more education (Chi-Square=12.1918,  $p=.007$ ).

There were no significant differences in how likely participants were to participate in a study focused on testing a COVID-19 vaccine by race or ethnicity ( $p=.44$ ), education ( $p=.58$ ), gender ( $p=.08$ ), or primary language ( $p=.21$ ). Respondents >70 years were significantly more likely to “definitely not” or “maybe not” be interested in participating in a study to test a vaccine compared to younger respondents (Chi-Square=8.6410,  $p=.034$ ).

## Discussion

The primary finding from this survey of culturally diverse older adults is most of these older adults are not willing to participate in COVID-19 vaccine or treatment studies. This finding is of concern as older adults are at the highest risk for COVID-19 related morbidity and mortality (Wong et al., 2023). Furthermore, only a small percentage of participants report that they would definitely participate in a COVID vaccine prevention study or treatment study. This finding is consistent with related research (Cox et al., 2023; Milani et al., 2021).

Emerging variants with unknown lethality, case surges, and evolving vaccine recommendations have complicated patient health care decision making process. Therefore, it is not surprising people are hesitant to participate in COVID-19 related research. The pandemic has again demonstrated that it is critically important to increase diversity within clinical research to

better meet the health needs of historically underrepresented groups. As previously discussed, the need for innovative recruitment and retention methods to increase recruitment of culturally diverse participants across the lifespan, especially older adults, is not new nor unique to COVID-19 related research. In recent years, health care related information is often searched for online, commonly used digital recruitment tools including internet sites, social media, and television or radio (Frampton et al., 2020). Although, leveraging digital tools has been the focus of limited number of studies with minority and/or older adult populations to support study recruitment efforts (Frampton et al., 2020).

A strength of these study findings is that the participants are from a very hard to reach minority older adult population. However, there are a couple of limitations to be considered in interpreting these findings. First, these data are only from Florida and it is unknown if these findings are generalizable to other regions in the United States. However, hesitancy to participate in clinical trials among culturally diverse adults has been demonstrated in various communities throughout the US. Second, selection bias may have been a limitation as these participants were primarily women and willing to participate in research. Therefore, these findings may not be representative of individuals that would not be willing to participate in this current research study. Third, we do not know the reasons why participants were not interested in participating in COVID research, knowing this would provide a better understanding of the issue. Lastly, the generality of the queries regarding willingness to participate was a limitation, more details as to what type of study and what their involvement in research and requirements could make a difference in the responses.

In conclusion, the lack of inclusion of culturally diverse older adults in COVID-19 research focused on treatments and vaccines is an ongoing problem that needs further research and culturally responsive targeted solutions.

## Declaration of Conflicting Interests






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