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# Variations in racial and ethnic groups' trust in researchers associated with willingness to participate in research

William T. Hu<sup>1✉</sup>, Stephanie M. Bergren<sup>1</sup>, Dana K. Dychtwald<sup>1</sup>, Yiming Ma<sup>1</sup> & Xinqi Dong<sup>1</sup>

Low enrollment in U.S. biomedical research by non-White adults has historically been attributed to mistrust, but few studies have simultaneously examined dimensions of trust in three or more racial/ethnic groups. Leveraging the racial/ethnic diversity of New Jersey, we prospectively recruited 293 adults (72% women, 38% older than 54 years of age) between October 2020 and February 2022 to complete two anonymous surveys in English or one of the common languages (e.g., Spanish, Mandarin Chinese). The first consisted of 12 Likert-scale questions related to trust in biomedical researchers (according to safety, equity, transparency), and the second assessed willingness to consider participation in eight common research activities (health-related survey, blood collection, genetic analysis, medication study, etc). Participants self-reported as Hispanic ( $n = 102$ ), Black ( $n = 49$ ), Chinese ( $n = 48$ ), other Asian ( $n = 53$ ), or White ( $n = 41$ ) race/ethnicity. Factor analysis showed three aspects related to trust in researchers: researchers as fiduciaries for research participants, racial/ethnic equity in research, and transparency. Importantly, we observed differences in the relationship between mistrust and willingness to participate. Whereas Chinese respondents' low trust in researchers mediated their low interest in research involving more than health-related surveys, Hispanic respondents' low trust in research equity did not deter high willingness to participate in research involving blood and genetic analysis. We caution that a generic association between trust and research participation should not be broadly assumed, and biomedical researchers should prospectively assess this relationship within each minoritized group to avoid hasty generalization.

<sup>1</sup>Rutgers Institute for Health, Health Care Policy, and Aging Research, New Brunswick, NJ, USA. ✉email: [William.hu@rutgers.edu](mailto:William.hu@rutgers.edu)

## Introduction

New Jersey has the third highest proportion of residents reporting as Asians nationally (11%, trailing Hawaii and California) and the second highest proportion of residents reporting as Hispanic east of the Mississippi (21.6%, trailing Florida). From 2010 to 2019, the number of older Asian and Hispanic adults who were 65 years of age or older in New Jersey also increased at much faster rates (83% and 64%) than non-Hispanic White (15%) and Black (31%) adults during the same time period (United States Census Bureau, 2021). This is a particular concern as the greatest increases are occurring in communities having disparate rates—at the national level—of uninsured status (18% Hispanic adults; Mahajan et al., 2021), healthcare access (18.2% of Asian and 18.9% of Hispanic adults have not seen a healthcare provider over the past 12 months; Mahajan et al., 2021), diabetes (35% in Asian Indian Americans ≥65 years of age; Shah et al., 2022), chronic hepatitis B (>10% in foreign-born Chinese Americans; Kowdley et al., 2012), and breast cancer incidence related to being foreign-born (three times the incidence in Asian Americans compared to native-born Asian Americans; Morey et al., 2019). Foreign-born Asian and Hispanic older adults may additionally face unique healthcare access issues due to work credits or waiting period necessary for Medicare enrollment (Lee et al., 2021; Pourat et al., 2010), on top of language (including understanding providers' accents; Rutgers Center for State Health Policy, 2014), cultural, and logistic barriers. However, health disparities in New Jersey extend beyond communities having large foreign-born members. The state hosts five of the top 15 worst-performing US cities (Newark, Camden, New Brunswick, Trenton, Paterson) according to poverty level, uninsured status, population change, and commute (Pasley and Wang, 2019). Black Americans represent 23–54% of residents in these five cities (vs. 15% in the state), giving rise to the greatest White-Black disparity in healthcare access (22 percentile points) in the northeastern states (Radley et al., 2021).

Consistent with national trends, all these healthcare disparities are paralleled by the exclusion of older minoritized adults from organized biomedical research (Milani et al., 2021; Occa et al., 2018; Shah and Kandula, 2020). Whether this phenomenon represents active gatekeeping by researchers, lack of participation by minority participants when invited, or both remains controversial (Fisher and Kalbaugh, 2011; George et al., 2014). One common approach to examine causes for racial/ethnic disparities involves surveys on willingness to participate in hypothetical research, which has modest correlation with subsequent actual participation (Halpern et al., 2001). Even though findings from small studies in New York City (NYC) or California may inform older minority adults' attitudes towards biomedical research and researchers, translating findings even from NYC to New Jersey may be confounded by differences in Asian and Hispanic subgroup composition, reason for immigration, and historical relationship with research institutions. According to the 2019 American Community Survey, Asian Indian adults outnumbered Chinese adults by more than 2:1 in New Jersey, but the opposite was true in NYC; older Dominican and Puerto Rican adults account for 66% of the older Hispanic population in NYC, but only 45% in New Jersey (United States Census Bureau, 2021). Analyzing research-related attitudes in aggregated racial/ethnic groups thus overlooks important cultural and country-of-origin distinctions. For example, perception of research among foreign-born US Chinese can be influenced by increasing mistrust of the medical establishment in China (Nie et al., 2018) and other sources of authority in East Asia (Ward et al., 2016), but experiences of discrimination in the U.S. and disease-related fear/fatalism among Asian Indians (Leader et al., 2018; Nicholson and Ahmmad, 2021). It is therefore important to disaggregate Asian

and Hispanic adults when assessing attitudes towards biomedical research to reflect the diversity in attitudes within the same metropolitan statistical area.

Directly assessing older minority adults' knowledge of and attitudes towards biomedical research may identify the root causes of minority older adults' exclusion from participation, but findings can be biased by the small number agreeable to participate, requirement to speak English, or not simultaneously assessing general and race/ethnicity-specific issues. Prior qualitative studies have highlighted the importance of young and middle-aged adults (e.g., adult children in Asian and Pacific Islander communities and *promotores* in Hispanic communities) as potential facilitators in engaging older minority adults to participate in research (Garza et al., 2020; Giarelli et al., 2011; Ka'opua et al., 2004; Nguyen et al., 2005). Including younger and middle-aged adults in assessing research-related attitudes can thus be informative towards recruiting older adults of similar racial/ethnic backgrounds. To do this, we leveraged the diverse population in NJ to address attitudes towards research and researchers across the age spectrum in five racial/ethnic groups, as one prior review found only one study that included four racial/ethnic groups (Hispanic, Black, White, and Asian Americans; George et al., 2014). Based on extant literature in assessing barriers for research participation among Black (Thompson et al., 2021; Williams et al., 2010), Hispanic (Davis et al., 2012; Wilets et al., 2003), Chinese (Giarelli et al., 2011; Limkakeng et al., 2013), and Asian Indian (Menon et al., 2014) respondents, we focused on the relationship between multiple mistrust concepts and willingness to participate in research (Moreno-John et al., 2004). We hypothesized that using the same quantitative trust scale in a diverse population will be more informative than cross-study comparisons to identify shared and unique trust-related factors leading to low participation research participation rates among minoritized groups.

To test this, we prospectively conducted two surveys among adults from diverse racial/ethnic backgrounds during the period of 2020–2022. To explore trust and trustworthiness, we first assessed whether survey respondents agreed with positive and negative characterization of biomedical researchers. This was followed by a short survey on each individual's willingness to participate in hypothetical research activities, which varied in anonymity, duration, risks, and inconvenience. We further hypothesized that willingness to participate in some research activities but not others may differ between racial/ethnic subgroups, and this work assessing how potential research participants conceptualize different procedures may improve study design and recruitment strategies.

## Methods

**Participants.** This study qualified for Common Rule Exemption 2(i) as it did not obtain personally identifying information such that identity of the human Subjects could not be readily ascertained, directly or indirectly through identifiers linked to the subjects. An exemption was granted by the Rutgers University Institutional Review Board.

From October 2020 to February 2022, 437 adults were approached at community presentations and events attended by the Rutgers Institute for Health, Health Care Policy, and Aging research staff throughout the state of NJ to simultaneously complete two anonymous surveys (Table 1). In addition to health-related presentations, events, and health fairs (six fairs at two public libraries; two hosted by New Jersey Black Women Physicians Association) targeting the general community in Central and Southern New Jersey, cultural events (e.g., civic

**Table 1 Demographic information of the 293 survey respondents.**

	N (%)	Mean trust in researchers score (SD)	Categories of research activities in which to participate (SD)
Age			
18-24	68 (23.2%)	28.2 (6.8)	3.8 (2.1)
25-34	44 (15.0%)	27.9 (6.6)	3.7 (2.4)
35-44	25 (8.5%)	29.4 (6.8)	4.8 (2.4)
45-54	44 (15.0%)	29.2 (6.5)	4.3 (2.1)
55-64	51 (17.4%)	28.0 (6.5)	4.3 (2.3)
65-74	45 (15.4%)	29.4 (6.2)	5.0 (2.1)
75-84	16 (5.5%)	25.2 (4.3)	4.7 (2.1)
Gender			
Men	81 (27.6%)	27.1 (7.0)	4.3 (2.3)
Women	211 (72.0%)	28.7 (6.6)	4.3 (2.2)
Other	1 (0.3%)	21	1
Race/ethnicity			
Hispanic <sup>a</sup>	102 (34.8%)	28.6 (6.5)	5.2 (2.3)
White	41 (14.0%)	30.9 (5.4)	4.6 (2.0)
Black	49 (16.7%)	25.9 (8.0) <sup>b</sup>	4.1 (2.3) <sup>d</sup>
Chinese	48 (16.4%)	28.8 (6.7) <sup>b</sup>	3.3 (1.6) <sup>d</sup>
Non-Chinese Asian	53 (18.1%)	26.8 (6.3)	3.4 (2.0) <sup>d</sup>
Education			
High school or less	83 (28.3%)	26.8 (6.4)	4.9 (2.5)
Some college	87 (29.7%)	27.3 (6.8)	3.8 (2.0) <sup>c</sup>
College	66 (22.5%)	29.9 (6.4) <sup>c</sup>	3.9 (2.1) <sup>c</sup>
Graduate degree	57 (19.5%)	29.7 (6.8) <sup>c</sup>	4.6 (2.1)

<sup>a</sup>Mexican (43), Central American (8), South American (19), Caribbean (7), did not specify (25).

<sup>b</sup>*p* < 0.05 compared to White respondents.

<sup>c</sup>*p* < 0.05 compared to HS or less.

<sup>d</sup>*p* < 0.05 compared to Hispanic respondents.

activities, traditional holiday celebrations, immigrant organization gatherings hosted by Trenton Health Team, Robert Wood Johnson University Hospital—Community Health Promotion, New Brunswick Tomorrow, RWJBH Center for Asian Health, and Korean Community Center) geared towards four non-White groups were selected to enhance the participation of Black, Hispanic, Chinese, and non-Chinese Asian adults. All participants 18 years of age or over were included.

Participants were asked to complete the two short anonymous surveys (on paper or online) in addition to providing their gender, self-reported race/ethnicity (Hispanic, White, Black, Asian subgroup, Native American/Alaska Native subgroup, Pacific Islander subgroup), age category (by decades), and education level. Both surveys were available in English, Spanish, Chinese (simplified), Korean, Tagalog, Urdu, Gujarati, and Hindi, with all non-English surveys having undergone forward and backward translation by different native speakers of the corresponding non-English language. Participants had the option of completing the surveys on their own or, when a staff fluent in the language preferred by the participant was available (usually the practice at events geared towards minority adults), verbally with the questions and answer options read to the participant. 293 adults (67%) agreed to participate and completed the surveys in English, Spanish, Mandarin, Chinese, and Korean. There were no partially completed surveys.

**Measures.** Participants were asked to complete the two short anonymous surveys. The first, “Trust in Research”, contains 12 Likert-scale questions assessing beliefs of biomedical researchers’ motivations and behaviors (Online Resource 1; Hall et al., 2006; Mainous et al., 2006; Margaret Smirnoff et al., 2018). Participants were asked on a 5-point Likert scale if they agreed with each statement (1 = Strongly disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly agree). Seven negative statements were reverse coded such that higher scores meant greater confidence in

researchers being trustworthy, fair, and transparent. The second, “Research Activities”, contains eight yes-no questions on each respondents’ willingness to participate in a study involving anonymous health surveys, review of medical records, blood draws, genetic analysis, a medication, a piece of equipment, an overnight stay, or a remuneration derived from the CTSA Sentinel Network (Liu et al., 2019; Varma et al., 2020).

**Statistical analysis.** Statistical analysis was performed using SAS version 9.2. After reverse coding of seven questions, a total Trust in Research score was generated by summing the responses to each question (range 12–60). For the 12-item perception survey, descriptive analysis, correlation, reliability test, factor analysis were conducted on the whole sample.

As the total Trust in Research score may represent an uneven summation of multiple subdomain scores, we further used Factor Analysis to characterize the number of constructs or latent variables represented in the survey. This is especially important as three of the questions focused on minority participation, which we might expect to differ between racial/ethnic groups. Exploratory factor analysis (EFA) was performed using the principal factor method and an orthogonal factor rotation using the Varimax method. Criteria for determine the number of factors to retain includes Kaiser’s criterion (eigenvalue greater than one; Nunnally, 1978), Cattell’s scree test (“elbow” in the plot) less prone to over-dimensionalization (Cattell, 1966; van der Eijk and Rose, 2015), and overall interpretability of conceptual meaning (Cattell, 1966).

Confirmatory factor analysis (CFA) was conducted to confirm the latent structure identified in EFA. Criteria to an acceptable model fit includes comparative fit index (CFI) and root mean square error of approximation (RMSEA). CFI larger than 0.9 is an acceptable model fit (Hu and Bentler, 1999). RMSEA less than or equal to 0.06 is considered a good fit, and less than or equal to 0.08 is also acceptable (Hair et al., 1998). EFA and CFA were

**Table 2 Trust in Research factor loading.**

Domain	Trust in Research statements	Factor 1	Factor 2	Factor 3
Researchers as fiduciaries	2. Researchers would not involve me in research that might be harmful.	<b>0.61081</b>	0.15788	0.04963
	3. It's safe to be in a medical research study.	<b>0.68009</b>	0.20404	0.02548
	1. My attitude towards research is positive.	<b>0.53449</b>	0.09182	0.20039
Trust in research transparency	9. Researchers only care about what is best for each patient.	<b>0.43826</b>	0.13386	0.04888
	6. Researchers tell their patients everything they need to know about being in a research study.	0.29120	<b>0.67681</b>	0.15718
	7. People who participate in research are like human guinea pigs.	0.18036	<b>0.49457</b>	0.22652
Equity in research	4. Researchers sometimes involve patients in research without their knowledge or permission.	0.15854	<b>0.69902</b>	0.07231
	11. Researchers unfairly select minorities for their most dangerous research.	0.07513	0.35692	<b>0.52061</b>
	12. I would be more comfortable having research explained to me by a researcher with a racial or ethnic background similar to mine.	0.01849	0.05676	<b>0.46953</b>

Questions 4, 7, 11, and 12 here were reverse-scored so a more positive score reflected greater trust, and loadings  $\geq 0.30$  are bolded. Questions which did not load strongly on any factor included: to get people to take part in a study, researchers usually do not explain all of the dangers about participation (reverse coded); researchers are more interested in helping their careers than in learning about health and disease (reverse coded); researchers act differently toward minority research participants than toward white participants (reverse coded).

done recursively until a solid structure was identified. Items that (1) were moderately correlated with other items, or (2) have relatively low loading factors, or 3) cross-load on two factors, were dropped (Costello and Osborne, 2005). Statements 5, 8, and 10 (provided in supplementary material) each cross-loaded onto two factors 5, 8 onto fiduciary and transparency; 10 onto transparency and equity), and were removed before EFA was repeated to derive the most independent factors.

After factor structure was established, factor scores were generated for each participant to make subgroup comparisons. Compared to the sums of two or more ordinal questions underlying each construct, the continuous factor scores do not assume equal weight for each question (DiStefano et al., 2009). As factor scores were shown normally distributed, ANOVA test was used to examine statistical differences across race and ethnicity subgroups, gender, education, and age. Post-hoc analysis was then used to examine statistical difference between various pairs of subgroups for those measures found to differ by ANOVA. Disaggregating Hispanic respondents by country-of-origin did not reveal any between-group differences (Online Resource 2), and they were treated as a single group for subsequent analyses.

To identify patterns of research participation among survey respondents, dichotomous responses to participate in different research activities were analyzed by hierarchical cluster analysis. The Ward minimum-variance method was used as it performed best among four methods tested for dichotomous variables (Finch, 2005). Pseudo *F* statistic and pseudo *t*<sup>2</sup> statistic determined two main clusters appropriate for this dataset, and proportion of each racial/ethnic group in each research willingness cluster was compared by Chi-squared test. A total research willingness score was also generated by summing answers to research activities, which differed between the two clusters. This total research willingness score was used as the dependent variable in a regression-based mediation analysis to determine if different trust in research constructs mediated racial/ethnic differences in willingness to participate in research.

**Results**

Complete responses were collected from 293 adults (Table 1), with 38% reporting ages of 55 years or older (ranging from 17% in non-Chinese Asian adults to 60% in Chinese adults). Women represented the majority of respondents, and this did not differ between racial/ethnic groups (range of 64% in non-Chinese Asian to 76% in White adults). There was a difference in education between the major racial/ethnic groups: whereas 51% of Hispanic adults have completed high school or less, 62% of Chinese and

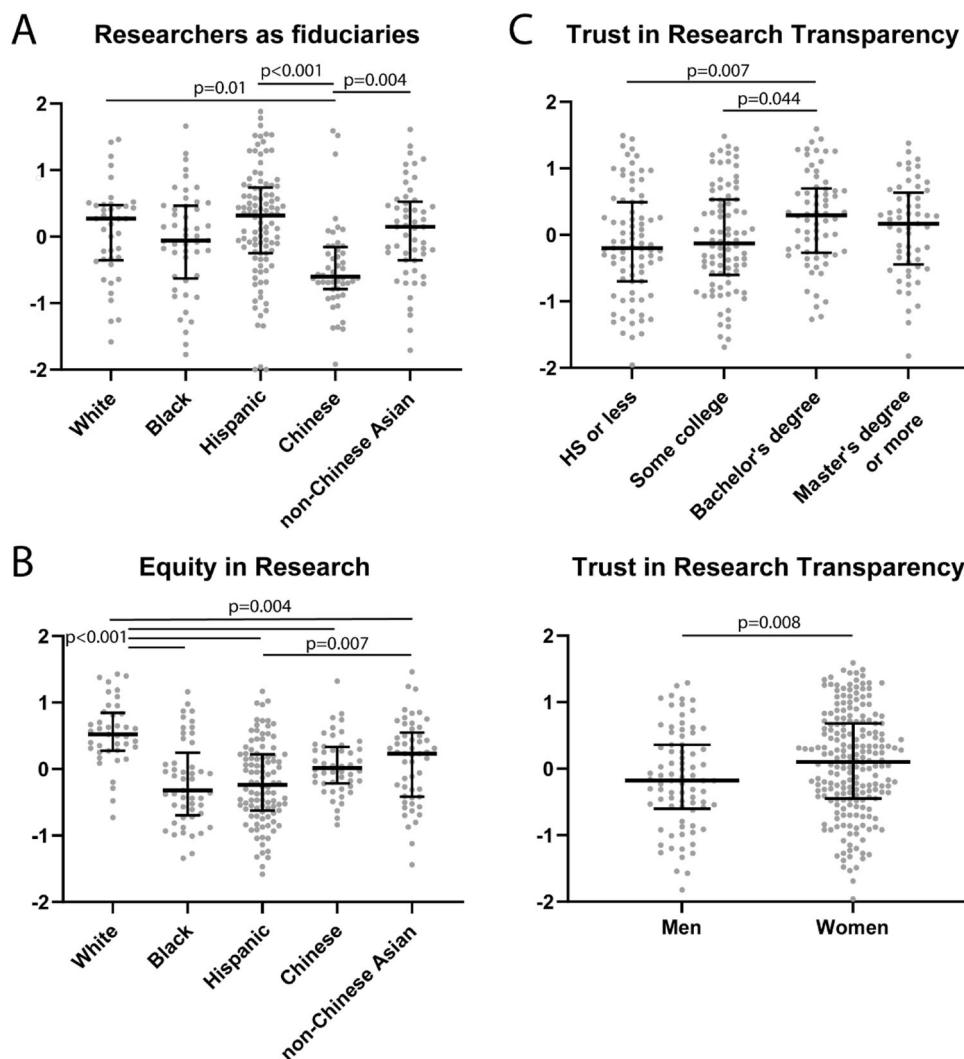
71% of White adults have completed college or more education ( $p < 0.001$ ).

**Trust in Research/researchers survey.** We first assessed the proportion of respondents with overall positive perception of researchers (agree or strongly agree to the statement “My attitude towards research is positive”). Most respondents (235/293, 80.2%) agreed or strongly agreed with this statement. At the same time, a similar proportion of respondents (219/293, 74.7%) expressed at least one negative perception of researchers (a response of 1 or 2 on the Likert scale for any question), with the most common perception that researchers acted differently toward minority research participants than toward White participants (87/293, 30.0%). There was no difference in age, gender, race/ethnicity, and education between those who had no negative perception of researchers or at least one negative perception.

We next performed factor analysis to identify constructs associated with the trust in Research survey. Factor analysis revealed three main factors related to Researchers as Fiduciaries (statements 1, 2, 3, 9), Equity in Research (statements 11, 12), and Transparency in Research (statements 4, 6, 7; Table 2). The first two factors were strongly influenced by race/ethnicity. Chinese respondents were much less likely to believe that researchers would safeguard study participants’ safety than White ( $p < 0.001$ ), Hispanic ( $p < 0.001$ ), and non-Chinese Asian ( $p = 0.004$ , Fig. 1A) respondents. At the same time, all non-White groups were less likely to believe that researchers treated participants of all racial/ethnic backgrounds similarly ( $p < 0.005$ ) with Black and Hispanic respondents having the lowest scores (Fig. 1B). Finally, people with a bachelor’s degree (only) had greater belief that researchers conduct their work with transparency than people with a high-school diploma or less ( $p = 0.007$ ), and women had greater such belief than men ( $p = 0.008$ , Fig. 1C).

We additionally examined responses to three questions which did not align with the above factors. Whereas we expected one statement to reflect Researchers as Fiduciaries (“*Researchers are more interested in helping their careers than in learning about health and disease*”), its responses correlated with education ( $p < 0.001$ ) but not the factor score. Responses for “*To get people to take part in a study, researchers usually do not explain all of the dangers about participation*” were influenced independently by Researchers as Fiduciaries ( $p < 0.001$ ) and Transparency in Research ( $p < 0.001$ ), and only Black respondents showed greater agreement with the statement “*Researchers act differently toward minority research participants than toward white participants*” ( $p < 0.001$ ).





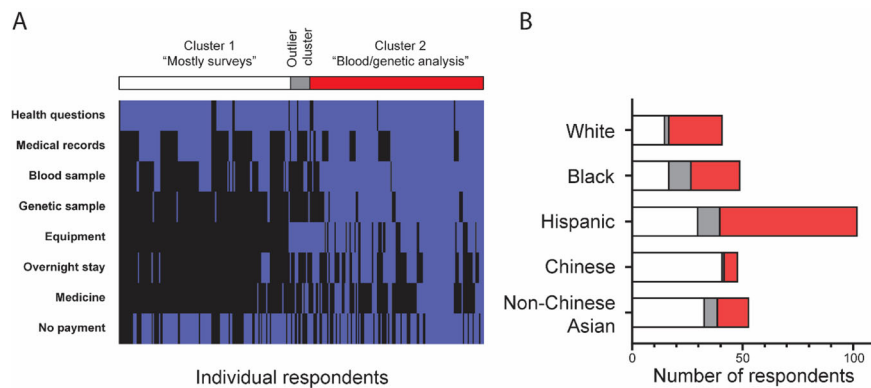
**Fig. 1 Normalized factor scores related to trust in research/researchers according to demographic grouping.** Chinese respondents had the lowest factor scores for trust in researchers to act as their fiduciaries (A), while all non-White respondents had lower factor scores for trust in researchers to act equitably across racial/ethnic groups (B). There was also a lower perception of transparency in research among those with lower education and among men (C).

**Willingness to participate in research.** We then examined the general pattern of respondents’ willingness to participate in hypothetical research projects (Online Resource 3). Respondents to the survey were willing to participate in a median of four research types, with a very small number wanted to participate in none of the eight research types ( $n = 5$ , 1.7%). As respondents may elect to participate in one or more research types due to the research activities’ characteristics, participants’ own characteristics, or both, we used cluster analysis to determine if there existed patterns of research participation. This revealed two main clusters with a smaller third cluster (Fig. 2A). Cluster 1 (“mostly surveys”,  $n = 136$ ) consisted of people highly willing (95%) to participate in survey-based questions regarding their health, but these respondents were less willing to participate in research involving medical record review (47%), a blood draw (26%), genetic analysis (4%), or an overnight stay (7%). In contrast, respondents in Cluster 2 (“blood/genetic analysis”,  $n = 128$ ) were willing to participate in research involving a blood draw (99%) and genetic analysis (93%), as well as health-related surveys (98%), medical record review (83%), and an overnight stay (62%). Cluster 3 (“equipment”,  $n = 29$ ) was characterized by willingness to participate in research involving a piece of equipment (100%, vs. 80% in Cluster 2 and 0% in Cluster 1). Less than half of the

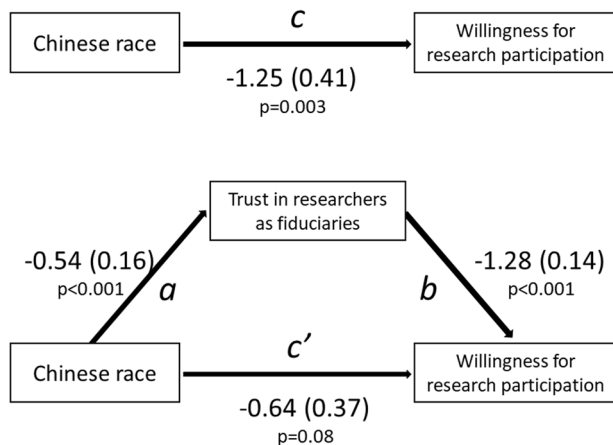
respondents expressed willingness to participate in research involving medications (2% in Cluster 1, 45% in Cluster 2, and 31% in Cluster 3), and respondents in the clusters did not significantly differ in willingness to participate in a research study without a payment or remuneration to the participants (64% in Cluster 1, 72% in Cluster 2, and 52% in Cluster 3).

We further examined the relationship between race/ethnicity and willingness to participate in research (Fig. 2B). Chinese respondents were most likely (85%) to belong to the Mostly Surveys cluster, while Hispanic (61%) and White (58%) respondents were most likely to belong to the Blood/Genetics cluster. Black participants were more evenly distributed across the three clusters, and non-Chinese Asian respondents had a profile most similar to Chinese respondents.

**Relationship between trust in researchers, race/ethnicity, and willingness to participate in research.** As trust in researchers and willingness to participate in research both differed according to race/ethnicity, we next analyzed whether trust in researchers mediated the effect of race/ethnicity on potential research participation. A total research willingness score was calculated by adding total affirmative responses to questions, which differed



**Fig. 2 Cluster analysis of willingness to participate in different research activities.** Respondents' willingness or refusal to participate in hypothetical research activities formed two large clusters, with each horizontal row reflecting one respondent's affirmative (indigo) or negative (black) response for the eight research activities (A). Cluster 1 (white) included people largely only willing to participate in anonymous health surveys, while Cluster 2 (red) included people willing to consider blood/genetic analysis as well as non-biological activities (survey research, medical record review). A small outlier cluster (gray) preferred equipment-based studies, and the relative distribution of cluster membership differed between racial/ethnic groups (B).



**Fig. 3 Mediation analysis of the association between Chinese ethnicity and willingness to participate in research activities.** Introduction of trust in researchers to act as fiduciaries as a mediator reduced the direct association between Chinese ethnicity and willingness to participate in research ( $c \rightarrow c'$ ), in keeping with a significant mediation effect.

between the clusters (range 0–6, excluding willingness to complete health-related surveys and studies without payment/remuneration). Univariate analysis showed lower willingness among Chinese respondents ( $p = 0.003$  vs. White respondents) but greater willingness among Hispanic respondents ( $p = 0.026$  vs. White respondents). Only Chinese race/ethnicity was associated with Researchers as Fiduciaries scores ( $B = -0.54$ , 95% CI  $-0.85$  to  $-0.23$ ,  $p = 0.0007$ ), with the mediation model (Sobel  $Z$  of  $-3.22$ ,  $p < 0.001$ ,  $\kappa^2 = 0.13$ ) showing a direct effect of  $-0.64$  (95% CI  $-1.36$  to  $0.08$ ,  $p = 0.08$ ) and indirect effect of  $-0.69$  (95% CI  $-1.06$  to  $-0.32$ ,  $p = 0.001$ , Fig. 3) from Chinese race/ethnicity on participation willingness. We interpreted this as low trust in researchers as fiduciaries among respondents to mediate the relationship between Chinese race/ethnicity and low willingness to participate in various research types. No other mediation effect was found.

## Discussion

Low participation rates among non-White volunteers in biomedical research have often been attributed to mistrust, but few studies have included a sufficiently diverse cohort to identify

differences between different racial/ethnic groups. Here, we show in a diverse (86% from minority background) NJ-based group of survey respondents unique characteristics related to trust according to race/ethnicity. Specifically, Chinese respondents showed low trust in researchers to serve as their fiduciaries, and this mediated the low willingness in this group to participate in research involving more than health-related surveys. Hispanic and Black adults' willingness to participate in largely minimal risk research (blood draw, genetic analysis) was not diminished by their belief that researchers would treat subjects differently according to race/ethnicity. These findings call for community/subgroup-specific approaches to enhance biomedical research participation among non-White adults.

While theoretical willingness was examined in several previous settings, there were few studies, which included sufficiently diverse participants beyond two or three major racial/ethnic groups. In the CTSA Sentinel Network, over 17,000 adults at six national sites (Liu et al., 2019) were examined including 485 Asian participants (over 90% from three sites: UC Davis, University of Michigan, and University of Florida). Similar to the current study, Asian adults to have the lowest willingness to participate in multiple research activities. At the same time, their proportion of Asian adults willing to undergo blood sample collection was much higher than ours (62% vs. 37%,  $p < 0.001$  by Chi-squared test), and this pattern extended to research involving genetic analysis (57% vs. 22%), medical equipment (54% vs. 23%), overnight stay (39% vs. 16%), or medicine (31% vs. 12%). Black—but not Hispanic—respondents in our study were also less likely to participate in different research activities than those assessed in the CTSA study (e.g., 81% vs. 45% for genetic analysis, 57% vs. 20% for medicine). These differences can result from different ethnic composition and local history between the CTSA sites and our recruitment area, but we cannot discount the potential impact of the COVID-19 pandemic on trust in biomedical research in the NY/NJ area. It is simultaneously difficult to predict how *theoretical willingness to participate* translates into actual participation. While theoretical willingness correlates with actual participation in clinical trials, actual participation rates are generally lower except donating excess biofluids or tissue during the course of medically necessary treatment (UK Biobank, 2006; Bryant et al., 2008; Ford et al., 2006; Halpern et al., 2001; Nyasani et al., 2018). Future work on trust in researchers and willingness to participate in research in different racial/ethnic groups should thus assess the relative cost (time, involvement) and benefits (personal illness,

family history) of participation to identify potentially modifiable barriers as well as facilitators.

Whereas we did not identify subgroup differences among Hispanic respondents, our finding of especially lower trust among US-based Chinese respondents than other Asian and non-Asian respondents confirms prior studies of mistrust in strangers among those from Chinese societies than those from Japan, Australia, and US (Fukuyama, 1996; Ward et al., 2014). While China overtook Mexico as the primary country of origin of immigrants entering the US in 2018, the understanding of research-related attitudes (including trust) in Chinese as well as other Asian subgroups has not kept pace. In the first part of this century, research assessing US Chinese's attitudes towards medical research has been largely qualitative (Fuller-Thomson et al., 2011; Hastings et al., 2015; Jose et al., 2014). One study in Seattle and one study in Manhattan Chinatown showed limited understanding of clinical trials among US-based Chinese (most born outside of US; Lin et al., 2005; Tu et al., 2005), and the Manhattan study further found older Chinese immigrants to consider clinical trials only when sick. Both studies and a third in Boston of mostly immigrants from China and Hong Kong (Brugge et al., 2005) showed older Chinese immigrants to be more likely influenced by a trusted one (e.g., adult children, physician) to participate in research. Subsequent work showed similar overall levels trust in medical researchers among Asian American subgroups but also culture-specific perceptions (e.g., symbolic association of blood among Chinese immigrants; Dang et al., 2014; Saadi et al., 2020). Survey-based studies related to blood banking have examined culture-specific factors (such as belief in not parting with one's blood among Chinese) may also lend some insight into blood as a specific biofluid in a different context. However, studies from as early as 2002 have shown a rise in blood donation rates in China [Shan et al., 2002], and a recent study further found a majority of Chinese respondents to not believe donating blood in small amounts would have any major impact on their health—even among people who hold traditional beliefs about blood (Tison et al., 2007). Safety as the most significant concern among our Chinese respondents is also supported by follow-up qualitative interviews in focus groups (YP Jiang, private communication).

As factors other than mistrust in researchers as fiduciaries likely contribute to Chinese respondents' low enthusiasm for medical research, future efforts to enhance Chinese Americans' participation in research will need to more comprehensively consider personal vs. cultural belief, incentives (e.g., pride associated with owning a blood donation card; Yu et al., 2013), and role of the physician (Simon et al., 2014).

Also noteworthy is our replication of others' finding that mistrust in research equity doesn't necessarily lead to low willingness for research participation involving both blood collection and genetic analysis. Unlike a study in New York City (NYC) conducted in 2005–2006 (Smirnoff et al., 2018), we found greater perception of researchers treating participants differently according to race/ethnicity among Hispanic and Black respondents. Based on prior associations between perceived discrimination and medical mistrust (Bazargan et al., 2021; Sullivan, 2020), we might have expected these two groups in our study to show low interests in research participation. Instead, we found Black respondents to be equally interested as White respondents (in keeping with a prior NYC study; Murphy et al., 2009) and the greatest level of interests among Hispanic respondents. As there are increasing interests in examining aging-related health disparities among older Hispanic Americans as well as the mixed evidence for the Hispanic paradox (Quiroz et al., 2022; Tarrat et al., 2020), future work needs to examine the apparent dissociation of these high levels of enthusiasm from observational

and late-phase clinical trials but not the more risky phase I trials (Fisher and Kalbaugh, 2011; Javier-DesLoges et al., 2022; Lolic, Araojo, Okeke, and Temple, 2021).

While our study generated interesting findings, we acknowledge a number of key shortcomings. Survey research intrinsically creates a cohort not absolutely opposed to polls, and often involves more women than men (Curtin et al., 2000; Dunn et al., 2004; Glass et al., 2015). However, we observed a clear gradient of trust and theoretical willingness to participate in biomedical research among those willing to complete the surveys. We recognize that a measure on the willingness to participate in research may not correspond to actual participation due to factors such as personal illnesses, other motivators, or incentives, which cannot be easily simulated in a theoretical survey (Falk et al., 2023; Johnsson et al., 2010). The overall sample size was small with uneven subgroup distribution, but we had relatively high numbers of Hispanic and Chinese respondents to generate the above observations for future follow-up and limited subgroup analysis. We did not examine whether trust and willingness to participate in research were influenced by non-racial/ethnic drivers of disparities (e.g., LGBTQIA+ status, income level, disabilities, immigration status; Thompson et al., 2021), past experiences with researchers and research participation, and any potential effects from intersectionality. We did not anticipate a prolonged pandemic from the study's outset and work to characterize impact of COVID-19—including experiences of discrimination—is underway. In keeping with this, our convenient sampling at community-based events (including health fairs) during the pandemic where non-White adults gathered may have biased our samples towards respondents who are more health-conscious, more acculturated, less risk averse to COVID-19 exposures from community settings, or more willing to engage researchers. We also could not account for social desirability or Happy Migrant effect in the conduct of the survey (Garrett et al., 2008; Gnams and Kaspar, 2017) or the possibility that our Spanish or Mandarin translations would convey perception-related questions with gravity similar to English surveys. Finally, there were insufficient respondents identifying as common ethnic groups (e.g., Asian Indian, Puerto Rican, Dominican) beyond Chinese and Mexican Americans to allow for more detailed subgroup analysis. The low number of Asian Indian respondents relative to their population size reflects recent national trends when Asian research participants are disaggregated (Ethoan et al., 2019; Kwon et al., 2017; Lolic, Araojo, Okeke, and Woodcock, 2021), and work is on-going in New Jersey to understand reasons for low participation. Nevertheless, we conclude that a one-size-fits-all approach to enhance non-White adults' research participation likely risks further alienating those already under-represented in common observational studies and clinical trials. Instead, an evidence-based strategy with greater specificity for each subgroup (e.g., emphasis on safety in Chinese participants; less focus on explaining historical inequity in Hispanic participants) may better bridge the divide between community outreach and research participation.

#### Data availability

Dataset from this study has been deposited at Scholarly Open Access at Rutgers and will be available at <https://doi.org/10.7282/0000222>.

#### Code availability

Not applicable.



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## Competing interests

The authors declare no competing interests.

## Ethical approval

This study qualified for Common Rule Exemption 2(i) as it did not obtain personally identifying information such that identity of the human Subjects could not be readily ascertained, directly or indirectly through identifiers linked to the subjects. An exemption was granted by the Rutgers Institutional Review Board due to the anonymous nature of the survey and minimal risk of research activities.

## Informed consent

All participants provided consent to participate in the de-identified survey by reading the consent document and then agreeing or disagreeing to continue with the survey. Documentation of consent was waived, as it could be used to identify participants.

**Consent for publication**

Not applicable.

**Additional information**

**Supplementary information** The online version contains supplementary material available at <https://doi.org/10.1057/s41599-023-01960-z>.

**Correspondence** and requests for materials should be addressed to William T. Hu.

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