



The influence of race and ethnicity on becoming a human subject: Factors associated with participation in research

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A B S T R A C T

Introduction: The purpose of this study was to explore factors associated with willingness of African Americans and Latinos to participate in biomedical and public health research and to delineate factors that influence the decision to become a human subject.

Methods: We present results from a 2010 random digit-dial telephone survey of 2,455 African American (N = 1191) and Latino (N = 1264) adults. We used standard measures to assess knowledge of research, terminology, informed consent procedures, previous participation in research, health care experiences, social support, risk perception, religiousness, and trust.

Results: Over 60% of both African Americans and Latinos reported they believed people in medical research are pressured into participating. Over 50% said that it was not at all important to have someone of the same race/ethnicity ask them to participate. In a sub-sample of 322 African Americans and 190 Latinos who had previously been asked to participate in a research study, 63% of African Americans and 65% of Latinos consented to participate in a study. Finally, both African Americans (57%) and Latinos (68%) reported willingness to participate in future research. Overall, the multivariate analysis explained 29% of the variability in willingness to participate in future research.

Conclusions: Results suggest that African Americans and Latinos have no automatic predisposition to decline participation in research studies. These results can inform culturally tailored interventions for ethical recruitment of minorities into research and clinical trials.

1. Introduction

Including racial and ethnic minorities in research is critical for generalizability of results and for providing equal opportunities to all people who may benefit from participation in research. Despite one article that suggests that minorities are overrepresented in Phase I drug clinical trials [1], evidence still confirms low participation in research [2–4]. Numerous studies seek to explain the reasons for the low participation in research [5–9], identifying both barriers and motivators/

facilitators to participation [5,6,10–13], and examining minority willingness to participate as a proxy for actual participation [12,14–17].

While these studies are varied, general consensus is that racial and ethnic minorities have generally positive attitudes toward research and are as willing as Whites to participate in research across different study types [9,12,14–17]. Not surprisingly, willingness to participate tends to depend upon the risks and level of invasiveness [15,18,19].

At the same time, however, researchers are documenting that there are significant differences in the numbers of minorities being asked to

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participate, far lower than would be expected based on minority representation in the country [9]. Additional studies suggest that minorities are less aware of research and research opportunities than Whites, and may rely more on their physicians or other health care professionals to provide information about research trials [12,20–22]. Yet, despite this need for communication about research studies, physician bias, both in treatment of minority patients and in the belief that minorities will not comply, may lead physicians to refrain from asking, thereby perpetuating the lower participation [1,23].

One approach for increasing minority participation in research has been to include “race matching” as a recruitment strategy. This approach has been adopted from research indicating greater patient satisfaction, longer visit times, and improved care in race matched physician-patient relationships [24,25]. While a few studies suggest that racially-matched minority researchers may increase willingness to participate, others highlight researcher characteristics other than race, such as honesty, openness and shared values, as more important contributors to recruitment success [20,26]. These studies are largely qualitative, and little empirical evidence exists to either support or refute the importance of race matching.

In an effort to further our understanding of minority willingness to participate in research and to elucidate some of the factors that influence the decision on joining a research trial, we conducted a unique study that included an all-minority sample of African Americans and Latinos who live in predominantly minority neighbourhoods. Via a random telephone survey, African Americans and Latinos responded to queries about their willingness to participate in different types of research, with different levels of invasiveness, motivations and barriers to participation, prior participation, perceived benefits of research, and attitudes toward their physician, researchers and research, in general. Analysis of the data allowed us to identify some key areas where researchers can tailor their recruitment strategies to help improve their inclusion of minorities in their research.

2. Methods

2.1. Study sample

ICF-MACRO, an international research firm, conducted the survey from June to December 2010 with 2455 African Americans (N = 1191) and Latinos (N = 1264).

2.2. Eligibility criteria

Prospective participants completed a telephone screener to assess their eligibility, which consisted of the following five questions: 1. Are you 18 years of age or older? 2. Are you of Hispanic or Latino background? 2A. Which one of these groups best describes your own ethnic identification? (e.g., Mexican/Chicano, Puerto Rican, Cuban); 3. What is your race? (e.g., African American/Black, Asian, Caucasian/White, Native Hawaiian/Pacific Islander); 4. Would you consider your racial background to include Black or African American ancestry?

Prospective participants were randomly selected based on telephone exchanges associated with geographic areas of high concentrations of African Americans and Latinos. To identify the exchanges, directory-listed telephone numbers were mapped and assigned to a specific geographic location (census block group, census tract, or zip code); those exchanges with an estimated concentration of African Americans and Latinos of at least 40% were used. Four geographical regions were identified with a substantial sample size (> 250) for each region -Northeast, Midwest, South, and West (See Table 1 for the distribution of study respondents by region). The overall response rate was 20.3%, which is consistent with response rates from other current random-digit-dial surveys [27,28]. Sampling weights were calculated and stratified sampling was conducted to select telephone numbers for five strata defined by the estimated concentration of African Americans and

Table 1
Distribution of respondents by region.

	Frequency N	Percent %	Cumulative %.
Northeast	319	13.7	13.7
Midwest	294	12.62	26.32
South	1011	43.41	69.73
West	705	30.27	100

Latinos within exchanges. The resulting sample represents African American and Latino populations who live in predominantly African American/Latino neighbourhoods. The survey took an average of 30 min to complete and it was offered in both English and Spanish. University of Pittsburgh Institutional Review Board approved the study and the free and informed consent of all participants was obtained.

2.3. Measures

Socio-Demographics: Eight socio-demographic variables were measured: race, ethnicity, gender, age, education, marital status, health insurance, and income. We collapsed education into below college and college or above, and marital status into married or living with a partner and other. Income was collapsed into below \$36,000, \$36,000 to \$76,000 and above \$76,000. Participants' health status was measured on a 5-point Likert scale (1 = poor to 5 = excellent).

Additional survey questions covered the topics of: willingness to participate, previous participation in research, value of human subjects research, motivations for participation, patient-provider interactions, beneficiaries of research, attitudes about research, researcher honesty, experimentation, race matching, and knowledge about the Tuskegee Study [29]. Questions and potential responses are shown in Table 2, including how some of the variables were constructed.

2.4. Analyses

A two-way chi-square was first performed to examine racial/ethnic differences on categorical variables. All effect sizes were small, i.e., Cramer's V \leq 0.135. An independent samples *t*-test was performed on all other variables by race/ethnicity. Cohen's *d*, an effect size, is reported for each analysis.

Three factors were extracted from the items on willingness to participate in a future study by risk level, using maximum likelihood extraction method with direct oblimin rotation. There were five items loading on the first factor (Cronbach's alpha of 0.78), labeled “Risk Level: Do”. These items were: 1) survey, 2) education program, 3) group interview, 4) limited/restricted diet, and 5) exercise. The second factor, labeled “Risk Level: Take”, consisted of three items with a Cronbach's alpha of 0.81: 1) medicine by mouth, 2) new drug, and 3) medication by needle. Lastly, the third factor, labeled “Risk Level: Give”, consisted of three items with a Cronbach's alpha of 0.75: 1) give blood, 2) DNA test, and 3) give urine. There were moderate to large correlations among the three factors. The factor scores were computed by averaging the items on each factor (Table 3).

A logistic regression was performed on each outcome variable: 1) willingness to participate in future medical research, and 2) ever participated in a research study. For the “ever participated” outcome, analysis was limited to participants who responded yes to “ever asked” (N = 518). The predictors used for each outcome variable were: socio-demographic variables, value of human subjects research, previous participation, motivations for participation, patient-provider interactions, beneficiaries of research, researcher honesty, experimentation, race matching and the Tuskegee Syphilis Study [29]. Two-way interactions between race and each covariate were tested for the moderating effect of race on covariate-outcome association. Stepwise forward

Table 2
Survey questions.

Measure	Survey Question(s)	Possible Responses
Willingness to Participate	If you were asked to be a subject in a medical research study, do you think that you would or would not agree to participate?	4. Definitely would 3. Probably would 2. Probably would not 1. Definitely would not Dichotomized to yes/no (yes = probable would, definitely would no = probably would not, definitely would not)
	How likely are you to participate in a medical study if the study required you to (INSERT ITEM)? a. Take a survey b. Participate in an education program c. Participate in a group interview d. Limit or restrict your diet e. Do exercises f. Take medicine by mouth g. Take a new drug as part of a test h. Receive medication by a needle (e.g. shot) i. Give blood j. Take a DNA test k. Give urine	4. Very likely 3. Somewhat likely 2. Somewhat unlikely 1. Very unlikely
Previous participation in research Value of human subjects research	Have you ever been asked to participate in a medical research study?	Yes/no
	Have you ever participated in a medical research study? How do you feel about medical research involving people?	Yes/no 5. Very positive 4. Somewhat positive 3. Neutral 2. Somewhat negative 1. Very negative
Motivations for participation	How important to do feel medical research is?	3. Very important, 2. Somewhat important 1. Not important at all
	If you were asked to be a subject in a medical research study that involved drawing blood, what would make you more likely, less likely, or have no effect on your agreeing to participate? a) money b) curiosity c) close friends or relatives encouraging your participation d) close friends or relatives also participating e) a close friend or relative has or had the disease being studied f) having the disease that is being studied in the research g) feeling that the researchers were honest about the risks h) free medical care i) free transportation j) the idea of helping others k) helping you (yourself)	3. More likely 2. Less likely 1. Would have no effect Variable constructed: Assessed with eleven items (a-k) measuring what would make them more likely, less likely, or have no effect in their decision to participate on a medical research study. Response items were recoded as -1 = Less likely, 0 = have no effect, and 1 = more likely. Scale was calculated by the average of 11 items, ranging from -1 to 1.
Patient-provider interaction	If your doctor wanted you to participate in research, you trust he/she would fully explain it to you.	Yes/no
	Your doctor would not ask you to participate in medical research if he/she thought it would harm you.	Yes/no
Beneficiaries of Research	How much would (INSERT) benefit from medical research? a. Scientists b. Your community c. Your family or friends d. You, yourself e. The general public	4. A great deal 3. A moderate amount 2. Only a little 1. Not at all
	Variable constructed: Assessed with five items measuring how much participants believed the following groups benefited from medical research (a-e).Scale was calculated by the average of all items, ranging from 1 to 4.	
Attitudes about research	How often, if ever, do you think participants in medical research are pressured into participating?	5. Always 4. Most of the time 3. About Half of the time 2. Only occasionally 1. Never
Researcher honesty	Researchers are always honest with the people they want to participate in their studies.	Yes/no
Experimentation	How likely is it that you, or people with the same race or ethnicity as you, might be used as guinea pigs in research studies without your consent?	3. Very likely 2. Somewhat likely 1. Not likely at all
Race matching	How important would it be to you to have a researcher or research staff who looks like you ask you to participate in a study	3. Very important 2. Somewhat important 1. Not important at all
Knowledge about the Tuskegee Study	How much have you heard or read about the Tuskegee Syphilis Study?	4. A great deal 3. A moderate amount 2. Only a little, or 1. None at all

Table 3
Factor loadings for type of medical research study by risk level.

Items	Risk Level: Do	Risk Level: Take	Risk Level: Give	Communality
Take a survey	0.565			0.577
Participate in an education program	0.761			0.453
Participate in a group interview	0.745			0.453
Limit or restrict your diet	0.450			0.641
Do exercises	0.457			0.713
Take medicine by mouth		0.712		0.457
Take a new drug as part of a test		0.789		0.372
Receive medication by needle		0.775		0.407
Give blood			0.494	0.613
Take a DNA test			0.844	0.329
Give urine			0.660	0.467
Correlation				
“Do”	1.000			
“Take”	0.357	1.000		
“Give”	0.609	0.477	1.000	
Cronbach's alpha	0.78	0.81	0.75	

regression was conducted to select significant interactions of race and each covariate included in the model. Several models were tested in order to develop the most parsimonious set of predictors. McFadden pseudo R² is reported for each model.

A multiple regression was performed with the factors extracted from the items on willingness to participate in a future study by risk level as the outcome variables (Do, Take and Give), using the same predictors in Table 5 and same procedures as stated under logistic regression. All analyses were conducted using STATA 14.2.

3. Results

Descriptive statistics for demographic, research participation, patient-provider, and other selected variables are reported by race/ethnicity in Table 4. Most effect sizes were small: Cramer's V ≤ 0.10 and Cohen's d ≤ 0.20. More African Americans than Latinos had been asked

Table 4
Descriptive statistics by race and ethnicity.

Variable	Category	African Americans	Latinos	Cramer's V
		N (%)	N (%)	
Gender	female	801 (68%)	782 (63%)	0.056
Education	college or above	656 (56%)	564 (45%)	0.108
Marital Status	married	579 (50%)	792 (63%)	0.135
Health Insurance	yes	966 (82%)	922 (74%)	0.106
Income	< \$36,000	573 (56%)	612 (56%)	0.011
	\$36,000 - \$76,000	276 (27%)	292 (27%)	
	> \$76,000	172 (17%)	194 (18%)	
Willingness to participate	Yes	668 (57%)	856 (68%)	0.114
Prior Participation: Ever been asked to participate in a medical research study	Yes	324 (27%)	194 (15%)	0.146
Prior Participation: Ever participated in research	Yes	204 (63%)	125 (65%)	0.014
Researcher honesty	Yes	380 (34%)	524 (44%)	0.102
Experimentation: Doctors given treatment w/o permission	Yes	228 (20%)	206 (17%)	0.040
Patient-Provider: Trust fully explain it to you	agree	927 (79%)	917 (73%)	0.069
Patient-Provider: Not ask to participate if harm you	agree	903 (78%)	950 (76%)	0.018
Attitude: Pressured to participate	never	219 (19%)	260 (22%)	0.066
	only occasionally	406 (36%)	461 (38%)	
	about half of the time	285 (25%)	279 (23%)	
	most of the time	180 (16%)	150 (12%)	
	Always	41 (4%)	58 (5%)	

to participate in research (27% vs 15% respectively), although Latinos were more willing to participate in future research. African Americans were more skeptical of medical research studies than Latinos, based on their responses to the experimentation items. In addition, both groups felt medical research was somewhat to very important (Mean (SD) = 2.87(.37) for African Americans and 2.87(.35) for Latinos).

3.1. Pressured to participate

Just over a third of African Americans and Latinos thought that participants were occasionally pressured into participating. An additional 25% of African Americans and 23% of Latinos believed that participants were pressured half of the time. Furthermore, 20% of African Americans and 17% of Latinos felt participants are pressured most of the time or always (Table 4).

3.2. Race matching

In response to the question about importance of race-matched researchers, over half of both groups replied “not at all important” (57% and 51%, African Americans and Latinos, respectively) and 30% of Latinos and 28% of African Americans said it was somewhat important. Less than 20% of each group indicated it was very important.

3.3. Motivations for participation

The top reasons for deciding to participate in a study were: 1) helping others; 2) helping yourself; 3) having the disease being studied; 4) having a relative or close friend with the disease being studied; and 5) researchers' honesty about risks. Responses were comparable across the two groups (Data not shown).

3.4. Research participation

Participants reported a high level of willingness to participate in numerous types of research studies especially those in the “Do” factor. There were no statistically significant differences between groups on these items. For the “Take” factor, 50% of African Americans and 53% of Latinos stated they would be willing to take medicine as part of a research study. In addition, 30% of African Americans and 36% of Latinos said they would take a new drug. These differences between

Table 5
Odds ratio and coefficients for participation in research risk level.

Variable	Willing to Participate	Ever Participated	Risk Level: Do	Risk Level: Take	Risk Level: Give
	OR (95% CI)	OR (95% CI)	B (SE)	B (SE)	B (SE)
Race/Ethnicity					
African American (Ref.)					
Latino	6.55 (2.69, 16.0)	1.39 (0.69, 2.78)	-0.38 (0.9)	0.52 (0.11)	-0.63 (0.14)
Gender					
Males (Ref.)					
Females	0.76 (0.59, 0.98)	0.86 (0.53, 1.38)	0.03 (0.03)	-0.21 (0.04)	0.02 (0.04)
Age	1.02 (0.99, 1.05)	1.02 (1.00, 1.03)	-0.003 (0.001)	0.01 (0.01)	0.002 (0.001)
Education					
Below college (Ref.)					
College and above	0.72 (0.54, 0.95)	0.92 (0.54, 1.56)	0.04 (0.03)	-0.17 (0.04)	-0.40 (0.11)
Marital Status					
Other (Ref.)					
Married or living with partner	1.07 (0.83, 1.39)	1.14 (0.70, 1.83)	0.04 (0.03)	0.03 (0.04)	0.02 (0.04)
Health Insurance					
No (Ref.)					
Yes	1.02 (0.74, 1.40)	0.85 (0.46, 1.56)	-0.04 (0.03)	0.03 (0.05)	-0.02 (0.04)
Health Status					
Income (< \$ 36,000) (Ref.)					
\$36,000 - \$76,000	1.47 (1.08, 2.00)	0.97 (0.49, 1.94)	0.02 (0.03)	-0.04 (0.05)	0.10 (0.04)
> \$76,000	1.71 (1.18, 2.47)	1.37 (0.61, 3.08)	0.04 (0.04)	-0.11 (0.06)	0.04 (0.05)
Ever been asked to participate in research					
No (Ref.)					
Yes	1.65 (1.21, 2.26)		0.07 (0.03)	0.12 (0.05)	0.05 (0.04)
Value of human subjects research					
Motivations for participation in Research	1.45 (1.29, 1.63)	0.88 (0.70, 1.12)	-0.03 (0.04)	0.18 (0.02)	-0.02 (0.05)
Patient-Provider: Trust MD fully explain research					
Disagree (Ref.)					
Agree	1.92 (1.44, 2.56)	2.17 (1.16, 4.04)	0.11 (0.03)	0.15 (0.05)	0.17 (0.04)
Patient-Provider: MD would not ask if research harms you					
Disagree (Ref.)					
Agree	0.95 (0.70, 1.27)	0.75 (0.42, 1.35)	-0.07 (0.03)*	-0.01 (0.05)	-0.04 (0.04)
Beneficiaries of research					
Researcher are always honest with people	2.76 (2.23, 3.41)	1.70 (1.11, 2.60)	0.19 (0.02)	0.16 (0.03)	0.17 (0.03)
No (Ref.)					
Yes	1.56 (1.20, 2.03)	1.02 (0.63, 1.66)	0.07 (0.03)	0.24 (0.04)	0.05 (0.04)
Experimentation: used as guinea pigs					
How Important: Race Matching	1.07 (0.90, 1.28)	0.97 (0.71, 1.33)	0.04 (0.02)	0.01 (0.03)	-0.003 (0.02)
Knowledge: Tuskegee Syphilis Study	1.33 (1.12, 1.58)	0.88 (0.65, 1.21)	0.03 (0.01)	0.13 (0.03)	-0.22 (0.07)
Race × Age	1.13 (1.00, 1.28)	0.99 (0.80, 1.22)	0.03 (0.01)	-0.01 (0.02)	-0.02 (0.02)
Race × Education	0.98 (0.97, 1.00)				0.20 (0.07)
Race × Health status				-0.11 (0.03)	
Latino × Income (\$36,000-\$76,000)		0.62 (0.21, 1.87)			
Latino × Income (> \$76,000)		0.23 (0.07, 0.75)			
Race × Value of human subjects research			0.09 (0.02)		0.10 (0.03)
Race × Motivations for participation in research	0.40 (0.18, 0.86)				
Race × How Important: Race Matching					0.12 (0.05)
R ² (full model)	0.29	0.10	0.23	0.26	0.20

Boldface indicates statistical significance.

African Americans and Latinos for the “Take” factor were statistically significant. For the “Give” factor, there were statistically significant differences for giving blood and giving DNA, but not for giving urine. Over 70% of both groups reported they would take a DNA test (Data not shown).

Table 5 shows the odds ratio and regression coefficients for predicting willingness to participate, ever participated, and risk level of research study. Overall, 29% of variability in the willingness to participate in a future medical research study was explained. Compared to Latinos, African Americans tend to have higher odds of participating in a medical research study as age (OR = 0.98) or motivation (OR = 0.4) increases. Female participants with low-income level or high education level were less likely to participate than low-income participants. Factors that increased likelihood of participation were: 1) value of human subjects research; 2) previously asked to participate; 3) Trust MD fully explain research; 4) Researchers are honest; 5) belief that people benefit from research; 6) Race Matching; and 7) Knowledge: Tuskegee

Syphilis Study. In order to develop the most parsimonious model, other predictors listed in Table 4 were left out of the models (Table 5) if R [2] increased by less than .01.

The second column in Table 5 provides the odd ratios for “ever participated.” About 21% of participants (n = 518) reported having been asked to participate in a medical research study (27% of African Americans vs. 15% of Latinos). Of those asked to participate, 63% of African Americans and 65% of Latinos participated. Older respondents were more likely to have participated than younger respondents, as were those with higher motivation for participation, who believed others benefitted from research, and had greater trust in doctors. Compared to Latinos, African Americans in high-income levels tend to have higher odds of ever participated.

In Table 5, columns 3–5 show the beta coefficients for the risk level factors. The demographic variables were highly significant for what the participants were willing to “Take”: 1) females were less likely than males, 2) older respondents were more willing than younger

respondents, and 3) college educated individuals were less willing than those with no college education. Compared to African Americans, Latinos were less willing to “take” as health status improves. For willingness to “Do”, older participants were less willing than younger participants. Latinos were more willing to “Do” than African Americans as they agree with the value of human subjects' research. For willingness to “Give,” only income was significant. Compared to African Americans, Latinos are more willing to give as their education levels, valuing of human subjects' research, or importance of race matching increases. There were similar predictors that were significant for the willingness to participate in a future research study and the factors of the different levels of risk, including 1) being more influenced by motivational factors, 2) Trust MD fully explain research, and 3) believing people benefitted from research. For willingness of “Do” and “Take”, predictors of 1) ever been asked to participate in research, and 5) feeling researchers were honest (only for “Take”) have significant positive impact. Few predictors were significant for one type of risk level factor of a research study but not others.

4. Discussion

This is one of the few studies to investigate differences between African Americans and Latinos on factors associated with participation in research. Key results include several issues that have not yet been covered in the literature using empirical data: 1) the importance of race matching, 2) differential willingness according to three novel levels of study risk, and 3) a normative belief that individuals are frequently pressured into research.

One reason identified in this study for continued underrepresentation of minorities in research is that participants are not being asked to participate. In our study, only 27% of African Americans and 15% of Latinos were ever asked to participate in medical research. Of those who were asked, over 60% did participate, indicating a willingness to participate that supports the findings of several previous studies [6,9,30,31]. Thus, one way to overcome the underrepresentation of minorities may be, simply, to ask. Particularly with regard to clinical trials, many minorities would not only be willing to participate if asked by their doctor, but also expect that the information about research should come from their physicians [32,33]. Researchers outside the clinical environment might consider partnering with community physicians as a way to improve their recruitment efforts. Some studies suggest that researchers' preconceived ideas about minorities' unwillingness to participate leads them to not ask, believing the response will be no [23]. With recent evidence suggesting that minorities are indeed willing to participate, researchers may need to examine their own biases, and if present, overcome them [5,13,34]. Therefore, research training may be helpful. Quinn and colleagues found that training on recruitment of racial and ethnic minorities was associated with the use of a greater number and more diverse recruitment strategies, and other studies support that varied recruitment strategies are effective for recruiting minorities into research [34].

Previous studies reported several motivations for minorities to participate in research, including altruism, money and others [15,20,35]. In our research, four of the top five motivators for participation (e.g., helping others, helping yourself, have the same disease being studied, relative/close friend have the disease being studied) are supported by the literature. In our study, however, money ranked only seventh, behind the belief that researchers were honest about the risk. The finding that researcher honesty is an important motivator for participation reinforces the need for careful attention to making the informed consent process a true conversation in which trust is established between the participant and the researcher [36].

Race matching of research staff to potential participants is used by many researchers for recruitment [20,26,34]. For example, Quinn et al. [34] found that almost 80% of “comprehensive researchers” reported matching the race and ethnicity of the recruiter to the target

population. Yet we found that more than 50% of participants reported that it was not important. While the temptation to simply ‘match’ by race is strong, it neglects the more complicated issues of class, education, individual personality, and institutional reputation that can also affect recruitment. Although race matching could be critical in some cultures and contexts, in our study, researcher honesty and shared values were more important than racial concordance.

Previous literature has differed on the association between level of risk and willingness to participate. We found that African Americans and Latinos are not automatically predisposed to decline participation in research, including potentially controversial research involving DNA. This is consistent with a recent study in which African Americans were likely to report interest in participation across an array of studies including giving blood and providing biological material for a DNA sample, although in that study, African Americans and Latinos were least willing to take a medication as part of a study, which differs considerably from our results [37]. We empirically identified three novel factors illustrating the level of risk, named “Do”, “Take” and “Give”, which did not differ by race/ethnicity. Our results provide evidence of minority willingness to participate across risk levels, which is useful for researchers who may have been reticent to recruit minorities for higher risk studies such as clinical drug trials or potentially sensitive genomic research. The question of risk of a specific study is an important consideration for participants, and yet it is not an insurmountable obstacle to recruitment.

An interesting and novel finding that emerged from our study was the issue of being pressured into participating in research. Despite the current human subjects protections in place today and individuals' willingness to participate, we still found that 60% reported they believed people in medical research are pressured into participating and over 17% felt individuals are pressured most or all the time. Respondents who believed people are pressured into participating in research did not differ on the variables of: ever being asked, ever participated, race/ethnicity or level of risk. There was, however, a moderate correlation between level of risk and pressure. This reinforces the need to create an open and honest dialogue between researchers and potential participants, both by providing community education about research, and by enhancing the capacity of researchers to effectively engage participants in a dialogue during the informed consent process [36].

4.1. Limitations

To our knowledge, this study is the first to utilize an all-minority sample to examine willingness to participate in research and the largest sample size of minority respondents in any survey assessing attitudes and willingness to participate in research; however, this study did not include a White referent group, which may be considered a limitation by some investigators. In addition, our sample is not representative of all African American and Latino populations but of those who live in predominantly African American and Latino neighbourhoods.

4.2. Conclusion and future research

Our results provide evidence that despite their underrepresentation in research trials, minorities are willing to participate in a wide array of research studies and risk levels. Concurrently, respondents indicated concern about researcher honesty and pressure, suggesting a need for more educational or outreach efforts to minority populations, which would include a general discussion of the value of research, acknowledge past abuses, increase understanding of human subjects protections today, and empower individuals to make an informed decision about participation. Further training for researchers, focused on specific recruitment of racial and ethnic minorities, could assist investigators in developing greater skills and confidence in their abilities to successfully recruit racial and ethnic minorities in their studies.

Conflict of interest statement

The authors have no conflicts of interest to report. Also, the study sponsor (National Institutes of Health) did not have any role in study design; collection, analysis, and interpretation of data; writing the report; and the decision to submit the report for publication.

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