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Socioeconomic determinants associated with willingness to participate in medical research among a diverse population

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Abstract

Introduction—Although it is federally-mandated that racial/ethnic minorities be included in research studies, recruiting diverse populations remains a challenge. This is particularly difficult when research involves children. The purpose of this study was to assess attitudes and beliefs toward medical research among a racially and socioeconomically diverse population of parents of school children.

Methods—A cross-sectional parent-report survey was conducted in New York City public elementary schools using stratified random selection to obtain a diverse population. Fear of medical research and likelihood to participate in medical research were assessed using a validated questionnaire. Differences in fear/likelihood to participate in research across race/ethnicity and socioeconomic characteristics were evaluated.

Results—In general, parents were afraid of their child “being treated as a guinea pig”, but were willing to allow their child to participate in research if asked by their own doctor. Factors associated with a lower score on fear towards research were; primary language other than English (OR=0.59), access to an interpreter (OR=0.73) and access to medical service within a day (OR=0.51). Latinos had the highest fear score (OR=1.87) compared to Whites. Asians were the ethnic group most likely to participate in research (OR=1.71). Low education level (OR=2.18) and public health insurance (OR=1.37) were associated with a higher score for likelihood of allowing one’s child to participate in medical research.

Conclusion—Minority parents reported more fear allowing their children to participate in medical research, but were as likely to consent their children’s participation, especially if asked by their own physician.

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Keywords

clinical research; minority health; parental consent; recruitment and health disparities

INTRODUCTION

A common challenge to the study of disease among minority populations is the ability to enroll patients in medical research [1, 2]. The NIH Revitalization Act mandates that minorities should be included in all federally-funded research studies [3]; however recruitment of these populations remains an ongoing struggle [4–7]. The persistent underrepresentation of racial/ethnic minorities, however, limits the ability of researchers to generalize findings and this is particularly important for pediatric populations which are already underrepresented in many research studies [8, 9]. Several barriers to participation in research have been identified, such as lack of time, inconvenient location and limited awareness [10]. In addition to these commonly acknowledged barriers [10], it has been suggested that beliefs about medical research stemming from socio-cultural and attitudinal factors are important factors in lack of participation from certain populations. For example, it has been said that African-Americans are generally less trusting of medical research, [11, 12] perhaps because of the impact of the 1932 Tuskegee Syphilis Study in which federally-funded researchers withheld available treatment from affected African-American males [11–13]. Studies have illustrated a difference in trust in medical research between racial/ethnic groups [3, 5, 14, 15], however, findings have not been consistent [16, 17]. Other studies have acknowledged that, while minorities may be less trusting of medical research, they are no less willing to participate in research than Whites [4, 16, 18, 19].

While race/ethnicity may be associated with willingness to participate in medical research [2, 12, 18, 19] other factors may modify attitudes and behaviors regarding participation in medical research. For instance, it has been documented that patient access to medical care is a predictor of patients' trust in physicians [15, 16, 18]. Conversely, lack of continuity of care has been proposed to have a greater impact on trust than race, gender, education or income [20, 21].

Recruitment of minority population for pediatric medical research poses a unique challenge [22–24]. Children are considered to be a vulnerable population and parental consent is required for children to participate in medical research [22]. Despite the need for pediatric studies and parental consent being crucial for children's participation [9], literature examining parental consent is limited. A few studies that do examine determinants of parental consent in minority populations cite transportation, child care and time away from work as barriers to participation [25]. Additionally, it was suggested that understanding of the child's disease, severity of disease and a parental history of research participation were associated with consent to child participation [26]. Parental consent may also be driven by altruism; that is, parent's wish to contribute to the medical knowledge of pediatric health and disease [27]. However studies indicating altruism as a determinant of parental consent were based on homogenous populations wherein diverse socioeconomic factors were not considered.

The present study assesses attitudes and beliefs among parents toward medical research, parents' willingness to let their child participate in research studies, and whether these vary by race/ethnicity, socioeconomic, access-to-care and acculturation factors.

METHODS

Sample population

A cross-sectional parent-report survey was conducted in New York City public elementary schools located in Queens, New York. Sample selection of schools was conducted using multistage stratified random sampling based on racial, ethnic and socioeconomic characteristics. The project was approved by the Mount Sinai Institutional Review Board, by the Mount Sinai Health Insurance Portability and Accountability Act (HIPAA) Privacy Office, and by the Proposal Review Committee of the New York City Department of Education Division of Assessment and Accountability.

The borough of Queens was selected for this study because, according to the 2010 US Census, it is the most ethnically diverse county in the nation [28]. In addition, there is significant economic diversity not only between but within the various racial and ethnic groups that inhabit this borough. Whereas many research studies are limited by economically homogeneous (low-income) minority populations, the present study aimed to represent and analyze the unique socio-demographic variability in Queens. In Queens, some minority populations have attained socioeconomic status equivalent to middle class, surpassing the average median income of the same racial/ethnic group in other boroughs of New York City. To capture this variability in our study population, in first stage sampling, Census data were used to collect population demographics for children 5–14 years by residential ZIP codes. All residential ZIP codes reporting greater than 50% Black population or greater than 50% White population in the 5–14 age range were identified for inclusion. Sixteen (16) ZIP codes were identified, 11 with a high Black population and 5 with a high White population. These ZIP codes were then stratified into high (> \$50,000), median (\$35,000–\$50,000), and low (< \$35,000) income groups based on median ZIP code income. This grouping resulted in six strata representing combinations by minority race/ethnicity and income status in order to study the influence of race/ethnicity and income on likelihood of participation in research.

In the second stage sampling, one public elementary school (grade K-5) was randomly selected in each ZIP code based on the New York City Department of Education enrollment and demographic population data. Because there were only two High White/High Income ZIP codes, we sampled one additional school among these ZIP codes to ensure representativeness. Magnet schools and other schools of choice were not included because children attending these schools often do not live in the same neighborhood as the school. Overall, 17 schools from 16 ZIP codes were selected for participation but one school refused, which resulted in a total of 16 schools sampled. This school was not significantly different in demographic characteristics from schools selected to represent the strata.

Response rates

Within each school, all K-5 classrooms were visited and delivered an interactive health-focused presentation as previously described [29]. In brief, the staff visit in each classroom consisted of a 10 to 15 minutes presentation promoting children's interest in science and engaging students in the process of data collection. The presentation involved description of the respiratory system, and invitation for students to be "scientist helpers" and an age-appropriate description of the questionnaire. All students were then given questionnaires to be brought home and completed by a parent/guardian. Children and teachers were given nominal incentives, consisting of school supplies, to encourage participation. A total of 4,640 parents responded to this questionnaire which represents a response rate of 67.5%, after adjusting for absenteeism. Out of the group of parents who responded to the questionnaire, a total of 294 (6%) parents did not respond to the fear and willingness items

on the questionnaire, and were excluded from the analysis. This group had a similar proportion of minority children, but was less educated and had lower household income, more children covered by public insurance and more foreign-born parents and children, compared to the rest of the respondents. The final sample consisted of 4,346 respondents, which represents a response rate of 62.6%. Some respondents provided complete data on the fear and willingness items but provided missing data on important socio-demographic characteristics. Nevertheless, these respondents were included in the analysis because of crucial information on fear and willingness items. In the descriptive analysis, all missing values on other selected covariates were included in the denominators of the weighted percentages (Table 1). All missing values are excluded from the multivariate regression.

Questionnaire

The questionnaire was composed of items validated in previous studies, including the National Health Interview Study Health Care Access and Utilization Module, the National Survey of Children's Health, the Tuskegee Legacy Project Survey, and our previously developed Children's Health Survey [29]. It consisted of items on family and child demographics, measures of socioeconomic status including household income, parental education level, insurance status, prevalence of childhood morbidities, health care utilization, access to healthcare, and parents' beliefs about their child participating in medical research.

Children's race/ethnicity was reported based on the parents' classification using both primary categories (Black, Latino, White, Asian, American Indian, Pacific Islander) and secondary categories (e.g. Puerto Rican, West Indian, Eastern European, etc.) to best capture the diversity of respondents. If more than one primary category was selected, children were classified as "multiracial/multi-ethnic". Combinations of Latino ethnicity with other races were handled as "multiracial/multi-ethnic". Final classification resulted in the following group of non-Latino Black, Latino, non-Latino White and Asian. Children classified as American Indian, Pacific Islander were very few (less than 10) and were therefore consolidated with the category of "multiracial/multi-ethnic". Questionnaires were available in English, Spanish, Korean, and Chinese and were anonymous to ensure confidentiality. Questionnaires were translated by professional translators and field-tested with native speakers with similar demographics as the study participants.

Fear and likelihood to participate in research were assessed using the scales developed by Katz *et al.*, [30]. In brief, five questions addressed fear to participate in research: fear of their child being treated as a "guinea pig", fear of disease, fear of results not being private, fear of having to pay for medical services and lack of trust in research. The answers to these five questions were summarized into a Guinea Pig Fear Factor (GPFF) scale.

Likelihood to participate in research was assessed using seven questions as described by Katz *et al.*, [30]. Parents were able to answer how likely it was for them to let their child participate in medical research depending on who asked them: their own doctor, a medical school, the government, a community-based organization, drug company or an insurance company. The answers to these seven questions were summarized into a Likelihood of Participation (LOP) scale.

Data Analysis

All data were weighted to represent the number of children that attend public elementary schools within each selected ZIP code, adjusting for absenteeism. Survey procedures in STATA (STAT Corporation, College Station, TX) were used to account for the sampling

design of: 1) stratification by income and race/ethnicity distribution and 2) clustering by school.

Descriptive statistics were calculated for demographic characteristics and significant differences were evaluated by race/ethnicity using chi-square test. Similar to the analysis performed by Katz *et al.*, [30] a chi-square test was performed to evaluate significant differences in self-reported fear and likelihood of participation in research across race/ethnicity and socioeconomic status. This was done by evaluating each question independently: the 5-point LOP scale was converted into two category responses; “Likely” (LOP ≥ 4 includes: 5 = Very likely, 4 = Somewhat likely,) and “Unlikely” (LOP < 4 includes: 3 = Not quite sure, 2 = Somewhat unlikely, 1 = Very unlikely) and the 5-point GPFF scale was converted into the following categories; “At least some fear” (GPFF ≥ 3 includes: 5 = Totally, 4 = A great deal, 3 = Some) and “A little or no fear” (GPFF < 3 includes: 2 = A little, 1 = Not at all).

Another level of analysis was added with a logistic regression analysis for both of the 5-point Likert scales (GPFF and LOP scale), using the median score as cut-off level. The median score was calculated by first adding the score on the 5-point Likert scales (GPFF and LOP scale). In our population the scales ranged from 5 to 25 points for the GPFF scale and from 7 to 35 points on the LOP scale. The median for each scale was calculated. The median score for GPFF was 18 and the median score for LOP scale was 14. Therefore, the primary outcome in the logistic regression model was the likelihood of having a score above the median (GPFF > 18 or LOP > 14).

Selected factors were evaluated for significant association with the GPFF and LOP scales. These factors were related to access to medical care (type of insurance, regular physical exams, having a primary physician, access to medical care during evenings/weekends, access to care within a day, usual place of care, visits to emergency department (ED)), having at least one documented chronic illnesses (nervous disorder, diabetes, obesity, asthma, cancer, allergies, autism, learning disability, ADHD, mood problems, and developmental delay) and factors associated with acculturation (primary language, US born vs. foreign born, being able to speak to a physician in the same language, having access to an interpreter). All the variables with $\alpha < 0.05$ in the bivariate analysis were introduced in a multivariate logistic regression, with each scale as the dependent variable and race/ethnicity as the primary independent variable.

RESULTS

The sampling resulted in 4,346 respondents of which 52.4% were Black, 11.9% Latino, 17.6% White, 8.8% Asian and 7.8% were of “multiracial/multi-ethnic” race/ethnicity (Table 1). This sample represents children from diverse racial/ethnic and socio-economic background attending public elementary schools. Our sample had a somewhat larger proportion of minority children (80.9%) when compared to the proportion of minority children reported to the Department of Education by the 16 schools surveyed (77.5%). Respondents who provided missing data to the fear and willingness items represented 6% (n=294) of the sample. Compared to the rest of the respondents, they were similar within a $\pm 10\%$ in the following characteristics: sex (50% females) and minority population (81% vs. 84%). They were different to the rest of the respondents in terms of lower education level and household income. Among this group, there were also more foreign born parents and children, and more children covered by public health insurance.

The “multiracial/multi-ethnic” group represented 7.8% of the whole sample and did not show notable trends in fear or willingness to participate. Due to this group being very

culturally diverse and not representing a particular race/ethnic group, their results are only shown in the descriptive analysis. In terms of income, more than 50% of the households sampled earned less than \$50,000/year, and the majority (67.2%) had at least some college education. Fifty-two percent of all respondents had private health insurance, with the highest percentage among Whites (79.8%). The highest percentage of parents and children born outside of the US and a primary language other than English spoken at home was among Asians and Latinos.

In general, the vast majority of the respondents (85.9%) indicated that their child had a primary care physician. Fewer Latinos (73.7%) reported having a primary care physician and also had the highest percentage reporting at least one visit to the Emergency Department (ED) within the previous 12 months (26.9%). A sizeable group of all respondents (14.9%) considered a community clinic/health clinic to be their usual place of care. Latinos and Blacks were more likely to report community clinic/health centers (19.5% and 18.3%) or the ED (2.7% and 4.0%) as their usual source of health care compared to Whites (community clinic: 2.5% and ED: 0.3%). Forty percent of the children had at least one diagnosed chronic illness and this occurrence was more common among Latinos (43.9%) and multiracial/multi-ethnic (49.9%).

Respondents across all race/ethnic groups, were most fearful of their child being “used as a guinea pig” (82.4%) and of contracting a disease as a result of participating in a research study (76.5%) (Table 2). In contrast, respondents were less fearful of research data not being private (70.5%) and of the costs incurred from participation (55.2%), although Latinos reported more fear towards data not being private (73.5%) and fear of the costs (63.5%) (p -value<0.01). Compared to other race/ethnic groups, a higher number of Black (75.2%) or Latino (75.0%) parents reported lack of trust in research. After adjusting for socioeconomic (income), acculturation (primary language, place of birth) and access-to-care factors (health insurance status, having a medical home), Latinos and Asians remained more likely than Whites to have a GPFF score above the median (OR=1.87 and OR=1.41, respectively; p -value<0.01 (Table 4), indicating a higher level of fear of participating in research related to race/ethnicity.

When comparing the groups by income status, respondents with an income of \$25,000–\$50,000 had the highest percentage reporting fear (Table 3). In contrast, parents with an income of less than \$25,000 had the lowest percentage of reporting fear of their child being “treated as a guinea pig” (72.2%) or fear of disease (70.4%). Across education levels, the proportion of respondents reporting fear was highest among those with some college education and lowest among respondents with less than high school education (p -value<0.001). In the multivariate analysis, participants with income \$25,000–\$50,000 remained more likely to have a GPFF score above the median, compared to other income levels (OR=1.44; p -value<0.05) (Table 4). In contrast, participants speaking a language other than English at home (OR = 0.59), not being able to communicate with the physician in your own language (OR=0.55) and having access to an interpreter (OR = 0.73) were less likely to have a GPFF score above the median (p -value<0.01). Also, responders that had access to a doctor within a day were less likely to have a GPFF score above the median (OR=0.51; p -value<0.01).

In general, all responders were most willing to let their children participate in research if their own doctor (35.9%) asked them to participate (Table 2). Across race/ethnic groups a significant percentage of Latinos and Asians reported willingness to let their child participate in research if asked by a medical school or hospital (31.2% and 34.1%). After adjusting for other factors, only Asians remained more likely to have an LOP score above

the median compared to Whites (OR=1.71; p-value<0.001), indicating a greater willingness to participate in research than Whites (Table 5).

Across income status and education levels, parents with an income of less than \$25,000 and less than high school education were most willing to participate in research, if asked by the institutions listed (Table 3). Lower educational attainment remained significantly associated with an LOP score above the median after adjusting for other factors related to medical care, access to medical care and acculturation (Table 5).

Other factors that remained significantly associated with an LOP score above the median were having public health insurance (OR = 1.37; p-value<0.01) and having access to an interpreter if needed (OR=1.48; p-value<0.05). In contrast, factors that were associated with a lower LOP score included having access to medical advice during evenings/weekends (OR=0.59), and being born in the US (parent: OR = 0.77, and child: OR = 0.62) (p-value<0.05).

DISCUSSION

Minorities had more fear of research but were as willing as non-minorities to let their child participate in research

The results demonstrate that a majority of the respondents across all race/ethnic groups were most fearful of their child being “treated as a guinea pig”, as previously found by Corbie-Smith *et al.*, [13]. It was also found that a higher proportion of Blacks and Latinos reported lack of trust in research compared to other race/ethnic groups, which may be a consequence of mistrust in the health care system [14, 20]. Latinos also feared incurring costs when agreeing to participate in medical research. This may be attributed to predominance of Latinos in our sample who fell within the lowest income bracket (44%).

There is little information in the literature concerning Asians’ perceptions about participating in medical research. We found that this group was significantly more willing to participate in research. This is consistent with a qualitative study of South Asians, which reported no evidence of antipathy to the concept of clinical trials or medical research [31]. We found that Blacks and Latinos were as willing to let their child participate in medical research studies as Whites and Asians, which is consistent with other studies [18, 30, 32–34]. All of the ethnic/racial groups, showed a high likelihood to participate in research when they were asked by their own doctor or by a medical school/hospital. Interestingly, a significant proportion of minority respondents were more willing to participate if asked by a community organization compared to Whites. This finding is consistent with studies reporting more successful recruitment when including community members and leaders in the recruitment team [2, 24] as a strategy for successful recruitment of minorities [4, 35].

Respondents with low education and low income levels were willing to consent to their child participating in research

Our data show that people with low educational attainment were more likely to consent to participation in research studies when compared to those with a higher educational attainment. This result is consistent with another study that reported very high willingness to participate in research in an economically disadvantaged population that responded with very high enrollment and retention rates (85%) [24]. This finding may be explained by the benefits received by participating in a study, such as monetary compensation or access to free medical care which can be especially attractive to low income participants [27]. Another explanation may be that populations with low educational attainment may have a low perception of risk [36] involved in medical research and therefore, would be more inclined to participate in research.

Most respondents would let their child participate in research when asked by their own physician

The usual place of care has a strong impact on a participant's attitude towards medical research. Respondents who considered a community clinic/health center to be their usual place of care, or had visited the emergency department during the previous year, had more fear regarding their child's participation in a study. In contrast, we found that respondents tended to be more willing to participate when their own doctor asked them to participate, which is consistent with previous studies [15, 18, 37–39]. A sustained relationship with a primary care physician offers patients the opportunity to become familiar with the many facets of the healthcare system. As a result, the patient may develop trust in his or her physician and the medical system as a whole, including the medical research community [15, 37, 39]. Our findings suggest that collaboration with primary care physicians may be a strategic and beneficial recruitment strategy.

Interestingly, more Latinos and Asians were willing to let their child participate in medical research if asked by a medical school/hospital rather than by the child's own physician. It is important to recognize that more Latinos, when compared to other race/ethnic groups, reported that their child did not have a regular primary care physician. Consequently, this population lacks the sustained relationship with a medical provider, which would aid in establishing trust of medical personnel [15, 20, 21].

In addition to access to primary care providers, accessibility to medical services may contribute to willingness to participate in medical research. This study found that respondents who were able to receive medical care within one day were more willing to let their child participate in research. These results suggest that past experience with medical care can be associated with parents' consent for their child to participate in medical research. Moreover, our results emphasize the importance of increasing access to care in minority populations. Though it is widely recognized that lack of access to care contributes to health disparities [1, 17, 40–42], we are suggesting that such barriers to care may hinder the ability of researchers to obtain diverse populations and consequently provide results that are generalizable to racial and ethnic subgroups.

Respondents with a primary language other than English or who were foreign-born were more willing to let their child participate in research

Our results suggest that people who speak a primary language other than English at home have less fear towards participating in medical research. Similarly, it was also shown in another study that non-English speakers were more likely to participate and stay enrolled over time compared to those who spoke English as a primary language [24]. Positive results in recruitment efforts have been obtained when recruiters are of the same race/ethnicity as the respondents, which helps to establish trust and overcome language or dialect barriers [35, 43]. Our results also suggest that the inclusion of an interpreter in medical care can have a positive impact on attitudes towards medical research. A multicultural and culturally-competent research team can help improve the participation of minorities, specifically those who speak other languages [44, 45].

Our study also found that participants born in the US had more fear and were less willing to participate in medical research. The same pattern was identified by Sexton *et al.*, [24] wherein a Black foreign-born population demonstrated higher enrollment compared to those born in the US. A multi-site epidemiological study on diverse populations, suggested that recruiting foreign-born populations was facilitated by having several resources for translation and interpretation [44].

Parental consent of children participating in research may be influenced by medical experience

Overall, the percentage of parents willing to let their child participate in medical research was lower compared to a similar study on adults [30]. It is possible that parents are more reluctant to consent to their children's participation in research than they would be for their own participation. A qualitative study on parent's decision to enroll their child in a vaccine study reported that parents had a tendency to uphold more strict criteria on what they would allow for their children than what they would allow for themselves [46]. The familiarity with science and medicine also seems to have an important influence on parents' decision to enroll their child in medical research. It has been suggested that parents with experience in science and medicine either professionally or as a consumer are less frightened by the idea of their child participating in a study, whereas parents with less experience seem to need more assurance [46]. It has also been suggested that parents who consider their child to have a severe disease would be more willing to enroll their child in a medical research study [26]. These results further speak to the idea that familiarity with the medical field can improve trust in medical research, which may ultimately help to increase participation in clinical studies.

The results of this study should be interpreted taking into consideration a few limitations. The proportion of respondents who provided missing data (6%) may represent potential selection bias. In spite of this limitation, this group had a similar proportion of minority children, but was less educated and had lower household income than the rest of the participants. As second limitation, this study asked for identification by the parent of the child's health and/or ethnicity. This construct addresses the sociodemographic categories and not biological markers of health. Additionally, children of multiple races and/or ethnicities were included in the "multiracial/multi-ethnic" and may have differed from other methods of reporting race separate from ethnicity category. It may have resulted in an underestimation of the true Latino sample size and consequently impeded our ability to identify significant results within the Latino subgroup. Another limitation is that our survey did not collect information on gender of the parents, which limited the possibility to identify differences between genders. BeLue *et al.*, [47] found that men have a tendency to require information on funding issues, financial benefit and impact of research, whereas women wanted to be treated respectfully when approached about research participation. Finally, our study did not distinguish between types of studies in which parents were willing to let their child participate. Previous research has found that willingness to participate in research also depends on the invasiveness of the study protocol [18]. Despite these limitations, this study brings important results on race/ethnic and socioeconomic factors that may influence parents' decisions to let their child participate in medical research.

This study has strengths worth highlighting. Our sampling design allowed us to achieve a sample of school children from diverse racial/ethnic and socioeconomic background attending public elementary schools. The study design also permitted to survey among populations with diverse racial and economic background which allowed examining economic differences within minority populations. This study is also one of a handful studies focused on factors affecting parental consent and, to our knowledge, the first study which, in addition to race/ethnicity, also evaluates the effect of socioeconomic, access-to-care and acculturation on parental consent.

CONCLUSION

The results of this study may be used to address specific barriers that are most important to overcome for the successful recruitment of diverse populations in health and/or medical research. The majority of participants reported fear of their child being treated as a "guinea

pig". It is important that researchers are aware of potential fears and doubts that may exist among different populations. It's key to inform parents about existing guidelines for research on human subjects that requires respectful treatment of participants. Most of the respondents indicated likelihood of participation in research when their own doctor or medical school/hospital runs the study, indicating the importance of established relationships of trust. Despite parents' fear of medical research, this study shows that minorities are as willing as Whites to allow their children to participate in medical research. Willingness to participate in medical research can be improved by addressing specific factors such as familiarity with medical providers that concern specific populations. A better understanding of these factors will ultimately strengthen investigators' abilities to recruit representative populations and allow for the generalization of research findings.

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Abbreviations

GPFF	Guinea Pig Fear Factor
LOP	Likelihood of Participation

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Table 1

Weighted percentages^a of socio-demographic and access-to-care characteristics, overall and by race/ethnicity.

	Total sample (N =4346) ^b	Black (n =1591) 52.4%	Latino (n =529) 11.9%	White (n =1167) 17.6%	Asian (n = 658) 8.8%	Multiracial/Multi-ethnic (n=344) 7.8%
Annual Household Income *						
Less than \$25,000	25.1	28.6	44.3	6.8	20.1	19.5
\$25,000–\$50,000	32.9	40.7	22.9	18.5	35.0	28.1
\$50,000–\$75,000	15.3	13.5	11.2	22.8	12.5	21.9
More than \$75,000	20.3	13.1	12.5	43.6	27.4	22.6
Education *						
Less than high school	7.6	6.9	19.3	2.3	7.3	6.4
High school diploma/GED	22.4	25.4	21.8	20.0	15.2	17.1
Some College/trade school	29.2	33.1	28.1	25.9	17.6	28.7
College/graduate degree	38.0	32.6	25.5	50.7	58.1	43.9
Type of Insurance *						
Private	52.2	48.2	33.7	79.8	41.9	61.8
Public	46.4	50.2	64.9	19.4	57.5	37.3
Parent Born in US *						
No	47.5	48.9	52.4	31.9	86.1	24.4
Yes	51.6	50.3	46.9	68.0	13.0	73.8
Child Born in US *						
No	9.3	9.7	11.8	4.5	16.6	4.6
Yes	89.7	89.4	87.0	95.0	82.7	94.6
Primary Language used at home *						
English	81.2	96.2	51.4	76.1	32.7	93.2
Other than English	13.3	2.1	38.8	14.8	51.3	3.1
English & other	5.0	1.4	8.6	8.7	15.7	3.5
Primary Care Physician *	85.9	87.9	73.7	88.5	82.6	89.7
One or more well-visits	86.7	87.3	80.3	92.1	80.6	90.2
One or more visits to the Emergency Department *	17.7	19.4	26.9	11.1	8.8	18.1

	Total sample (N =4346) ^b	Black (n =1591) 52.4%	Latino (n =529) 11.9%	White (n =1167) 17.6%	Asian (n = 658) 8.8%	Multiracial/Multi-ethnic (n=344) 7.8%
Usual place of care [*]						
Physician's office	76.6	70.2	71.2	95.1	83.8	81.7
Community clinic center	14.9	19.5	18.3	2.5	10.1	11.3
Emergency Department	2.1	2.7	4.0	0.3	0.4	1.1
Other place of care	5.0	6.2	5.1	1.4	4.2	5.2
Diagnosed disease [*]	40.2	40.9	43.9	34.8	34.0	49.9

^aMissing values were included in the denominators of all calculated percentages.

^bTotal numbers of each race/ethnic group may not add up to the total sample because 57 participants did not classify themselves in any of the race/ethnic categories.

^{*} p-value<0.001, χ^2 -test of significance across race/ethnicity.

Table 2

Weighted percentages^a of parent report of fear and willingness to let their child participate in medical research by race/ethnicity.

	Total sample (N =4346) ^b				
	Black (n =1591) 52.4%	Latino (n =529) 11.9%	White (n =1167) 17.6%	Asian (n =658) 8.8%	
“At least some fear”					
GPFF score 3^c					
Fear of being a “guinea pig”	82.4	82.1	82.1	76.6	
Fear of disease	76.5	77.2	77.5	74.6	
Lack of trust in research [*]	74.0	75.0	69.0	72.2	
Fear of results not private [*]	70.5	73.5	66.8	70.4	
Fear of having to pay ^{**}	55.2	63.5	52.9	57.9	
“Very likely”					
LOP score 4^c					
Your own doctor ^{***}	35.9	29.2	44.3	25.2	
A medical school/hospital ^{***}	24.6	31.2	20.9	34.1	
Government ^{***}	13.8	18.9	10.1	24.7	
Community-based organization ^{***}	13.8	15.4	10.2	20.3	
Non-profit foundation ^{**}	13.4	15.7	11.0	18.2	
Insurance company ^{**}	13.4	16.0	9.2	21.3	
Drug company ^{**}	8.0	10.2	7.0	14.0	

^aMissing values were not included in the denominators of all calculated percentages.

^bTotals of each race/ethnic group may not add up to the total sample because 57 participants did not classify themselves in any of the race/ethnic categories.

^cGPFF score 3 includes respondents who reported “some, a great deal, or totally” to the different barriers. LOP score 4 includes respondents who reported “very likely or somewhat likely” to let their child participate in medical research.

* p-value<0.05

** p-value<0.01

*** p-value<0.001

Weighted percentages^a of parent report of fear and willingness to let their child participate in medical research by income and education.

“At least some fear”		Total sample (n = 4346) ^b	Less than \$25,000 (n = 942)	\$25,000–\$50,000 (n = 1331)	\$50,000–\$75,000 (n = 699)	More than \$75,000 (n = 1093)
GPEF score 3^c						
Fear of being a “guinea pig”	***	82.5	72.2	85.1	86.4	86.8
Fear of disease	***	76.7	70.4	80.3	76.7	78.5
Lack of trust in research	**	74.2	71.7	79.6	70.5	71.4
Fear of results not private	*	70.5	68.5	73.7	68.2	69.7
Fear of having to pay	**	54.8	53.4	61.4	51.0	49.1
“Very likely”						
LOP score 4^c						
Your own doctor	**	35.7	30.7	35.1	39.2	39.8
Medical school/hospital	***	24.8	31.2	24.7	20.2	21.7
Government	***	13.9	21.5	14.2	9.2	8.7
Community-based organization	***	14.2	20.6	13.7	10.6	10.9
Non-profit foundation	***	13.7	18.3	13.3	11.2	11.5
Insurance company	***	13.5	22.3	14.1	9.1	6.6
Drug company	***	8.3	12.3	8.8	6.0	5.0
		Total sample (n = 4346) ^b	Less than high school (n = 296)	High school diploma/GED (n = 897)	Some College/trade school (n = 1197)	College/Graduate degree (n = 1852)

	Total sample (n =4346) ^b	Less than \$25,000 (n =942)	\$25,000–\$50,000 (n =1331)	\$50,000–\$75,000 (n =699)	More than \$75,000 (n = 1093)
Fear of having to pay ^{**}	55.4	53.1	60.0	57.6	51.6
“Very likely”					
LOP score 4^c					
Your own doctor ^{***}	35.9	13.7	35.8	38.6	38.1
Medical school/hospital ^{***}	24.6	42.8	27.2	20.3	23.3
Government ^{***}	13.8	32.7	18.5	11.4	9.9
Community-based organization ^{***}	13.8	26.1	15.3	11.3	13.0
Non-profit foundation ^{**}	13.4	21.8	15.6	10.7	13.0
Insurance company ^{***}	13.4	33.8	18.5	10.6	9.4
Drug company ^{**}	8.1	14.7	11.3	6.3	6.7

^aMissing values were not included in the denominators of all calculated percentages.

^bTotals of each group may not add up to the total sample because 281 participants did not indicate their income level and 103 participants did not indicate their education level.

^cGPFF score 3 includes respondents who reported “some, a great deal, or totally” to the different barriers. LOP score 4 includes respondents who reported “very likely or somewhat likely” to let their child participate in medical research.

* p-value<0.05

** p-value<0.01

*** p-value<0.001

Table 4Likelihood of having a GPFF score ^a above the median, n=3039.

	Adjusted OR ^b	Above/below median (n/n)	CI 95%	P-value
Race/ethnicity ^c				
Black	1.11	551/531	0.94–1.32	0.199
Latino	1.87	198/155	1.61–2.17	<0.001
Asian	1.41	190/262	1.13–1.75	0.006
White	1.00	395/498	-----	
Income				
Less than \$25,000	1.13	288/308	0.74–1.73	0.532
\$25,000–\$50,000	1.44	496/478	1.07–1.95	0.021
\$50,000–\$75,000	1.04	257/298	0.79–1.36	0.789
More than \$75,000	1.00	417/497	-----	
Education				
Less than high school	0.71	61/90	0.47–1.06	0.087
High school diploma/GED	1.17	301/288	0.91–1.49	0.199
Some college/trade school	1.05	459/442	0.86–1.27	0.606
College/graduate degree	1.00	637/761	-----	
Primary language				
Other than English	0.59	179/307	0.47–0.73	<0.001
English & other	0.90	99/117	0.61–1.34	0.574
English	1.00	1180/1157	-----	
Physician speak the same language				
No	0.55	41/83	0.39–0.79	0.004
Yes	1.00	1417/1498	-----	
Access to interpreter				
No	0.98	107/110	0.82–1.18	0.837
Yes	0.73	119/212	0.59–0.90	0.007
Did not need one	1.00	1232/1259	-----	
Usual place of care				
Emergency Department	1.01	21/22	0.56–1.84	0.962
Community clinic/health center	1.21	183/171	1.00–1.45	0.049
Other	0.98	49/57	0.78–1.24	0.848
Physician's office	1.00	1205/1331	-----	
Access to doctor within a day				
Yes	0.51	1440/1568	0.35–0.74	0.002
No	1.00	18/13	-----	

^a Above median (> 18) vs. below median (< 18)^b All OR's are adjusted for race/ethnicity, income, parental education level, insurance status, place of birth (US born or foreign born) for parents and child, primary language used at home, being able to speak to a physician in the same language, access to an interpreter, usual place of care, ER visits in the past 12 months and access to care within a day.^c Results for "Multiracial/Multi-ethnic" (OR=1.04; CI 95%: 0.69–1.56)

Table 5Likelihood of having a LOP score^a above the median, n=2961.

	Adjusted OR ^b	Above/below median (n/n)	CI 95%	P-value
Race/ethnicity ^c				
Black	1.11	455/585	0.93–1.34	0.215
Latino	1.04	179/152	0.67–1.63	0.840
Asian	1.71	297/161	1.44–2.04	<0.001
White	1.00	338/535	-----	
Education				
Less than high school	2.18	97/42	1.51–3.16	0.001
High school diploma/GED	1.33	292/274	1.07–1.66	0.016
Some college/trade school	0.98	382/500	0.85–1.19	0.869
College/graduate degree	1.00	604/770	-----	
Type of insurance				
Public	1.37	648/551	1.13–1.66	0.004
Private	1.00	727/1035	-----	
Parent born in US				
Yes	0.77	630/959	0.62–0.95	0.018
No	1.00	745/627	-----	
Child born in US				
Yes	0.62	1233/1501	0.43–0.91	0.019
No	1.00	142/85	-----	
Access to interpreter				
No	1.07	105/103	0.79–1.46	0.635
Yes	1.48	221/109	1.04–2.10	0.031
Did not need one	1.00	1049/1374	-----	
Access to medical advice during evenings/weekends				
Yes	0.59	1233/1507	0.39–0.89	0.016
No	1.00	142/79	-----	

^a Above median (> 14) vs. below median (≤ 14)^b All OR's are adjusted for race/ethnicity, income, parental education level, insurance status, place of birth (US born or foreign born) for parents and child, primary language used at home, being able to speak to a physician in the same language, access to an interpreter, access to medical advice during evenings/weekends, usual place of care, ER visits in the past 12 months and having a primary care physician.^c Results for "Multiracial/Multi-ethnic" (OR=1.17; CI 95%: 0.91–1.51)