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A Paradigm for Understanding Trust and Mistrust in Medical Research: The Community VOICES Study

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Abstract

Background—To promote justice in research practice and rectify health disparities, greater diversity in research participation is needed. Lack of trust in medical research is one of the most significant obstacles to research participation. Multiple variables have been identified as factors associated with research participant trust/mistrust. A conceptual model that provides meaningful insight into the interplay of factors impacting trust may promote more ethical research practice and provide an enhanced, actionable understanding of participant mistrust.

Methods—A structured survey was developed to capture attitudes towards research conducted in emergency situations; this paper focuses on items designed to assess respondents' level of trust or mistrust in medical research in general. Community-based interviews were conducted in English or Spanish with 355 New York City residents (white 42%, African American 29%, Latino 22%).

Results—Generally favorable attitudes towards research were expressed by a majority (85.3%), but many respondents expressed mistrust. Factor analysis yielded four specific domains of trust/mistrust, each of which was associated with different demographic variables: General Trustworthiness (older age, not disabled); Perceptions of Discrimination (African American, Latino, Spanish language preference); Perceptions of Deception (prior research experience, African American); and Perceptions of Exploitation (less education).

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Conclusions—The four domains identified in the analysis provide a framework for understanding specific areas of research trust/mistrust amongst disparate study populations. This model offers a conceptual basis for the design of tailored interventions that target specific groups to promote trust of individual researchers and research institutions as well as to facilitate broader research participation.

Keywords

research trust; research mistrust; race; ethnicity; disability; limited English proficiency

Introduction

In response to concerns over health disparities and a lack of diversity among research participants, the National Institutes of Health (NIH) mandated the inclusion of women and minorities in clinical research (1993, 2001). The mandate is rooted in the principle of justice with a goal to promote fairness in the research process by fostering access and inclusiveness (Tilburt et al 2007). In the years since the policy was first initiated, there has been a 15.4 fold increase in the number of minority participants in NIH-funded clinical research studies, but this still represents only a modest increase in the percentage of NIH clinical research participants who are minorities (27.8%) (DHHS 2010). Even with renewed recruitment efforts and the increase in minority research participation, health disparities experienced by minorities persist in both incidence (new cases) and prevalence (all existing cases) (Schmotzer 2012). To identify more effective therapeutic interventions for groups disproportionately affected by particular health conditions, research on group-specific and subgroup-specific treatment effectiveness is needed.

Research Trust / Mistrust

Over the last decade, there has been considerable research into the barriers and facilitators associated with minority under-representation in research. A consensus has been reached that participant trust in research and research institutions is one of the most, if not the most, significant factors associated with research participation. This consensus is represented in an extensive literature that has been synthesized and summarized in four major systematic literature reviews; two focused on general clinical research and one each for emergency research and psychiatric research (Schmotzer 2012; George et al. 2014; Limkakeng et al. 2014; Brown et al 2014). Combined, these meta-analyses include dozens of studies conducted in geographically diverse locales, involving thousands of participants across multiple racial/ethnic groups, and each affirms the role of trust/mistrust as a primary determinant of research participation. Common trust-related themes identified in these studies involve being mistreated or taken advantage of (by specific research practices like randomization, or being used “like guinea pigs”) and unintended consequences (involuntary admissions, side effects or stigmatization) (Schmotzer 2012; George et al. 2014; Limkakeng et al. 2014; Brown et al 2014). It is not known if the respondent attitudes in these studies derive from personal experience of research.

A greater understanding is needed of the complexities involved in research trust. Referencing the literature on attitudes to doctors and healthcare, people distinguish between

global trust in healthcare institutions and specific trust in their individual physician; specific trust in the latter is usually higher for all population groups (Hall 2006a). Global trust is typically based on institutional reputation and status, while specific trust is often based on the quality of the personal interaction. Armstrong et al. (2008). found that mistrust among minorities towards the healthcare system is based on mistrust of values more than mistrust of clinical competency. Similarly, most research participants distinguish their relationship with “the researcher” from their relationship with the institution or study sponsor, with the individual relationship carrying greater weight (McDonald et al. 2008).

Definitions of Research Trust / Mistrust

Although several authors have defined medical trust by its behaviors or characteristics such as fidelity, loyalty, honesty and competence (Hall 2006a), a Cochrane review (McKrisny et al. 2006) defines medical trust in terms of the classical doctor-patient relationship: “Patient trust is the belief that a doctor is working in the patient’s best interests.” Similarly, Armstrong et al. (2008) define trust as “the belief that an entity will act in one’s interest in the future,” in contrast to distrust, or “the belief that an entity will act against one’s interest in the future.” The terms *distrust* and *mistrust* are often used interchangeably, but distrust is most correctly based on a specific experience or information, while mistrust expresses a general sense of unease toward someone or something. Authors also make a distinction between mistrust/distrust and absence of trust because the former imply a more malignant state that may be critical to racial and ethnic disparities. For these reasons, in our discussion, the opposite of trust is mistrust, rather than distrust or lack of trust.

Clinical research trust is defined in this study as the belief by the study participant that his/her interests (e.g. full disclosure, balance of risk/benefit, prudent data usage) are considered before the interests of the study or the researcher. This would be reflective of Wright’s (2010) view, that a trustworthy researcher acknowledges the value of the trust that the participant vests in them and uses this to rationally decide how to act. Conversely, research mistrust is defined as the belief by the study participant that his/her needs are subordinate to those of the study or the researcher as evidenced by conditions such as withholding important information, risks that outweighs benefit, or data used to damage individuals or communities.

Measurement of Trust

The literature on trust has informed the development of several tools for measuring trust and mistrust in clinical research (Corbie-Smith et al. 2002; Mainous 2006; Hall et al. 2007; Braunstein 2008) This paper describes the development and use of an interview instrument to assess research trust/mistrust and discusses the findings and implications of a survey using this instrument conducted in diverse communities in New York City. The survey was part of the Community VOICES Study (Views on Informed Consent in Emergency Situations). *Emergency research* refers to research performed in emergency situations that cannot realistically be done in controlled, clinical situations; e.g., development of new, effective treatments for cardiac arrest when the intervention must be initiated immediately and there is no time to obtain traditional informed consent. There is specific guidance on the proper conduct of research in emergency situations (USDHSS 1996). The Community VOICES

Study utilized mixed methods to examine the operational, ethical, educational, and social implications of the Exception from Informed Consent (EFIC) for Emergency Research regulations (USDHSS 1996) and guidance (USDHSS 2000, 2006, 2011; Richardson 2005). Since EFIC studies present special issues of trust and mistrust of medical researchers, the Community VOICES team was interested in assessing whether community members' trust and mistrust of research in general influenced their attitudes towards EFIC studies.

Methods

IRB Review

The Community VOICES Study was reviewed by the Icahn School of Medicine at Mount Sinai Institutional Review Board and was deemed to be exempt from review.

Population

Study participants were recruited from a stratified sample of 35 residential buildings in New York City that had participated in the Public Access Defibrillation Trial (Ornato et al. 2003; The PAD Trial Investigators 2004) one of the earliest NIH-funded multicenter EFIC trials. A representative sample of buildings was obtained using a diversity score developed for the study. Buildings were categorized according to the average age, socioeconomic status (SES) and racial/ethnic composition of residents. A stratified random sampling procedure using these categories was used to obtain a representative sample of buildings.

Recruitment

The research team contacted the management of the residential buildings for permission to conduct active, on-site recruitment of residents for this study. Flyers posted in common areas and letters distributed to each apartment informed residents about the study. The interviews required no appointment and were conducted, in English or Spanish, at the point of contact, on-site, either in quiet public spaces in the buildings or in participants' apartments.

Instrument Development

Using purposive sampling, based on gender, race, and ethnicity, of residents and employees from the cohort buildings, focus groups were conducted in English and Spanish to inform the development of the interview instrument. The interview instrument was pilot tested on a sample of building residents prior to study initiation. The interview instrument was translated into Spanish by native Spanish speakers then back translated by someone naive to the instrument and reconciled with the original to assure accuracy. The Community VOICES interview elicited information in several domains including: informed consent for research, definition of community, research risks/benefits/burdens, previous experience with research and with emergencies, knowledge of the previous study (PAD Trial), and medical mistrust.

The trust/mistrust questions on the interview were derived from the Group-Based Medical Mistrust Scale (GBMMS) (Thompson et al. 2004), a measure developed to evaluate attitudes towards cancer screening among African American and Latina women. The instrument is "group-based" because it attempts to assess trust through the prism of group identity. It utilizes a 12-item Likert scale to measure suspicion of mainstream healthcare systems,

healthcare professionals, and the treatments they provide to members of the respondent's ethnic or racial group. The instrument has been tested in groups of minority women and men and found to be both reliable and valid (Shelton et al. 2010; Thompson et al. 2004). Based on a review of the literature and focus group comments, the VOICES research team modified the GBMMS to address group based concerns about medical research and researchers. This synthesis yielded a 10-item Likert scale to measure research trust/mistrust that was embedded within the larger 8-item VOICES interview. This paper presents the results obtained from the interview questions concerning research trust/mistrust (Table 3) and seventeen demographic questions. Findings from other sections of the interview have been published elsewhere (Ragin et al. 2008).

Interview Administration

All participants were screened for eligibility prior to the interview. Eligible participants were at least 18 years old, and were either building employees who had worked in the participating building for at least 3 months prior to the survey or building residents who had lived in the building for a minimum of 3 months. All participant responses were anonymous and no participant identifiers were collected. Interviewers obtained verbal informed consent from each participant prior to the interview and advised them that they were not obliged to answer any question that made them uncomfortable or which they did not wish to answer. Participants were given the choice of being interviewed in either English or Spanish by bilingual study coordinators and each received their choice of a \$20 New York City Metrocard (public transportation fare card) or a \$20 phone card upon completion of the interview. Interviews were about 40-minutes long and were conducted during both daytime and evening hours, on both weekdays and weekends. Interviewing was initiated in January 2005 and completed in March 2006.

Data Analysis

All analyses were conducted using SAS v.9.2. Descriptive information (means, standard deviations, etc.) was obtained using the UNIVARIATE procedure. The factor analysis utilized a principal components solution with an oblique rotation (using the promax criterion). A General Linear Model approach was taken to assess the predictors of the Trust factors. Post-hoc tests of mean differences employed the Tukey-Kramer adjustment for multiple comparisons.

Results

Management from thirty-one of the 35 selected buildings agreed to participate in the Community VOICES study. Two declined to participate and two sites did not respond despite repeated outreach attempts. Interviews were obtained from 288 residents and 68 employees for a total of 355 interviews. (One participant was both a resident and employee in the same building). The mean number of interviews per building was 11.5, ranging from 2 to 25 per building. The interviews were conducted in English (312 participants, 88%) and Spanish (43 participants, 12%).

Demographic Characteristics

The majority of participants were female (64%) and over 60 years of age (53%) (less than 25 years: 4%; 25–45 years: 21%; 46–60 years: 21%; 60–75 years: 23%; greater than 75 years: 30%). The largest single racial/ethnic group was White (42%) followed by Black (29%), Latino (22%) and other (6%). Other demographic factors, including household income and level of education, are shown in Table 1. A summary of participant responses to the 10 trust items are shown in Table 2.

Factor Analysis Results

Survey responses were reviewed by the investigators and into four factors:

- “General Trustworthiness” included two positively worded statements focused on whether participants felt positive about research and whether researchers would subject participants to harm.
- “Perception of Deception” included three negatively worded statements about doctors/healthcare workers hiding and withholding information, or taking action without permission.
- “Perception of Exploitation” included two negatively worded statements which suggested that researchers “used” participants for their own personal gain or devalued the participants as individuals.
- “Perception of Discriminatory Treatment” included three statements about awareness of differences in treatment and research practices among racial/ethnic groups.

These factors were subject to further statistical analysis. Each Likert-type question had a score range of 1–5. These were summed to create a score range for the factor category. For example, on a factor with 3 items, the total score ranged between 3 and 15. Mean scores for each category and the demographic variables that were associated with significant difference in scores are shown in Table 3. (Please note: in the following sections, we present the means and a t-test for domains in which all of the explanatory variables are categorical; for domains in which any of the significant explanatory variables are continuous, the F ratio is presented for all of the significant variables in that domain.)

For the domain of General Trustworthiness, not being disabled ($F(1, 340) = 4.74$; $p = 0.0301$) being older ($F(1, 340) = 4.42$; $p = 0.0362$) and/or having children living at home ($F(1, 340) = 10.73$; $p = 0.0012$) were associated with viewing researchers as trustworthy. Perception of Discriminatory Treatment was associated with totally different predictors. Those participants who preferred to be interviewed in Spanish (mean = 10.24) versus English (mean = 9.23; $t[1,339] = 1.98$; $p = 0.04$) were more likely to perceive discriminatory treatment. African-American participants (mean = 10.51) and Latinos (mean = 10.23) were marginally ($t(1,339) = 2.49$; $p = 0.0627$) were more likely to think that researchers were discriminatory compared to Caucasians.

Educational background was the only significant ($F(3,342) = 4.14$; $p = 0.0066$) factor associated with Perceptions of Exploitation. Those reporting high school education or less

(mean = 5.97) were significantly ($t[1,342] = 3.10$; $p = 0.011$) more likely than others to say that researchers exploit participants.

There were three predictors of Perceptions of Deception. Those who had some experience with research were significantly ($t[1,344] = -2.52$; $p = 0.0122$) more likely to say that researchers are deceptive (mean 9.72) compared to those without research experience (mean = 9.00). Respondents who were divorced or separated were ($t[1,344] = -2.71$; $p = 0.0358$) more likely to say that researchers are deceptive (mean = 9.71) compared to those who were married or living with a significant other (mean = 8.82).

African Americans were marginally ($t[1, 342] = 2.37$; $p = 0.0846$) more likely to say that researchers deceive (mean = 9.97) compared to Latinos (mean = 9.12) and compared to participants of other races (mean = 8.69; $t[1,342] = 2.33$; $p = 0.0935$).

Correlation between factors

Correlation between the questions grouped in a single category supported the validity of grouping. There was a weakly negative correlation between the general trustworthiness scale and the factors which described perceptions of doctor/researcher behaviors that may negatively affect trust (correlation). This suggests that participants who felt a greater general sense of trust in researchers were less likely to see them as deceptive, exploitative, or treating patients differently according to race/ethnicity. Conversely, there were weakly positive correlations between trust and beliefs that researchers exploit, researchers deceive, and researchers treat people differently (correlations). Those who did not think that researchers are exploitative were also less likely to think they deceive or treat people differently (correlation). Conversely, those who thought researchers are exploitative were more likely to say they deceive research participants and that they treat people differently (correlation).

Discussion

Sensitive evaluation tools are needed for measuring the complex relationships of race, ethnicity, and trust in the research setting. It is important to evaluate and disentangle aspects of both specific interpersonal trust (a participant's personal relationship with a researcher) and global trust (a participant's relationship with the medical research enterprise as a whole) as well as capturing determinants of trust in research that are specific to racial/ethnic identity. This study aimed to explore these influences on attitudes towards medical research participation and create a paradigm for greater understanding.

Conceptual Model: Domains of Trust

While confirming others' findings, our study adds a new element to the literature with the identification of four domains that conceptualize the phenomenon of research trust/mistrust. In a racially and ethnically diverse cohort, these factors were differentially associated with socio-demographic variables, some of which have not previously been fully considered.

The General Trustworthiness factor was developed by other authors. Hall (2006a) has written extensively about the concept of global trust and reports that even where conceptual

domains of trust are explored and measured, they are often indivisible from a global sense of trust. The current study identifies three other factors, which may be more properly described as determinants of trust.

Race and Ethnicity as a Predictor of Mistrust

The results of this study related to race and ethnicity may be particularly valuable as our participants closely approximated the racial/ethnic profile of the New York City target population: (white: NYC 44% vs. VOICES study 42%; black: NYC 25.5% vs. study 29%; Latino: NYC 28.6% vs. study 22%) (Census 2010). As a microcosm of NYC, and perhaps other urban areas, these data may offer insight into attitudes of trust/mistrust towards research of a swath of the national population, more than two-thirds of which lives in urban areas (Census 2010).

We found that although participants were generally more trusting than mistrusting, African-American race and Latino ethnicity were variables associated with Perceptions of Discrimination and Perceptions of Deception. This is a finding consistent with the work of other authors (Hughes et al. 2015; Moreno et al. 2015; Lang et al. 2013; Brandon et al. 2005; Braunstien et al. 2008; Corbie-Smith et al. 2002; Hall 2006b; Mainous et al. 2006). The U.S. history of racism towards blacks, illustrated by memories of the Tuskegee Syphilis Study, make our findings of Perceptions of Discrimination and Deception unsurprising in this group. Discrimination against the Latino community, with its own unique historical experiences, is well described (Moreno-Jones 2004); in our survey Perceptions of Discrimination were also voiced by Latino respondents, an effect seen most strongly among those who chose to be interviewed in Spanish. Not just a historical memory or part of an extensive oral history, for many members of minority communities, their lived experience with the current healthcare system reinforces perceptions of injustice and discrimination on a daily basis (Brandon et al. 2005; Corbie-Smith et al. 2007; Moreno-Jones et al. 2004; Scharf et al. 2010). These results also highlight the importance of not over-simplifying the effect of race/ethnicity on trust, especially by erroneously grouping all racial/ethnic minorities together. It is important to explore and address the roots of mistrust among different minority communities separately. The specific domains of mistrust that emerged from our data offer possibilities for targeted interventions. To alter Perceptions of Discrimination, evidence-based strategies that take into account the culture and diversity of a population to help health care providers give high-quality clinical care, might prove to be just as effective among investigators and research staff. Similarly, much of the current work on identifying and neutralizing implicit bias in the workplace might be transferrable to the research setting. Targeted interventions to alter Perceptions of Deception should focus on openness and transparency; researchers should actively seek to demonstrate that they are trustworthy. Among blacks, this may require that groundwork to build relationships with the community being researched precede specific research projects (Yarborough 2013). Such relationships and the expectation of reciprocity between community and researcher are of particular importance in many minority communities (Corbie-Smith et al. 2007; Kagawa-Singer 2000; McDonald 2008).

Neither race nor ethnicity was significantly associated with Perception of Exploitation; it was less education that predicted this domain, suggesting that more education mitigates feelings of susceptibility to exploitation among all racial and ethnic groups. The fact that the Community VOICES Study respondents included a range of educational and income levels within each racial and ethnic group allowed us to observe the distinct impacts of race/ethnicity and socioeconomic status on the various domains of trust.

At the same time, previous research experience was associated with Perception of Deception. This suggests something in the personal research experience may imbue an expectation of deception; whether this is due to a misunderstanding of certain research processes such as blinding or randomization or it is the result of actual deceptive acts by researchers is unclear. Furthermore, as in this study, other authors have noted that older age has greater association with trust than race does (Farmer 2007). Feelings of trust may be related to older adults' more frequent contact with the healthcare system.

Language Preference as a Predictor of Mistrust

The 12% of respondents who were more comfortable being interviewed in Spanish than in English had stronger Perceptions of Discriminatory Treatment compared to English language respondents. We did not explicitly assess English proficiency in our survey. While some of our respondents who chose to be interviewed in Spanish may be fluent in both languages, it is likely that most of those who were interviewed in Spanish had limited English proficiency. People who speak English "less than very well" are considered of limited English proficiency (LEP) and represent 8.5% of the total US population or 25 million people over the age of five, with higher rates in some regions, including New York City (Census 2013). Nationally, those with LEP are more likely to live in poverty, have poorer health outcomes (Fields 2016), be less educated (Zong and Batalova 2015), and be underrepresented in clinical research. This underrepresentation of significant portions of the population in clinical trials results in research that may not be generalizable to those excluded populations (Glickman et al. 2011).

To improve fair access to research participation and the resulting improvements in health and healthcare, interventions should be directed towards both the LEP and the research communities. Targeted linguistically and culturally fluent educational interventions geared towards LEP communities should be developed to explain the risks, benefits, and methods of clinical research. Sympathetic, culturally appropriate translations by native speakers rather than directly translated words, may avoid confusion due to discrepant meanings and cultural cues (Brown 2014). Systemically, federal guidelines and individual IRBs must reconsider policies that address language barriers, especially in the informed consent process, to facilitate research participation by LEP individuals (Resnik 2006; Glickman 2011; Livaudais-Toman 2014). Fear of deportation amongst undocumented immigrants related to research participation has been identified as a source of mistrust and fear (Brown 2014). As a corrective action, study policies on reporting of undocumented immigrants should be noted in each study protocol and explicitly described during participant recruitment.

Disability Status as a Predictor of Mistrust

People with disabilities, an often marginalized group, are a unique health disparities population (Healthy People 2020). Though they comprised only 4% of our cohort, 20% of all American adults are disabled and have disparate special health needs (CDC 2012). This group is often under-represented in research, just as they were under-represented in our survey, and have been described as having pervasive research trust issues (McDonald 2013). Correspondingly, respondents in this study who self-identified as disabled had significant concerns related to General Trust. More focused research is needed to identify specific issues of mistrust among this group and address health disparities amongst people with intellectual and physical disabilities. Researchers, with federal guidance, need to consider accommodations to special needs (physical plant access, readers for the blind) that would remove barriers, demonstrate respect, and promote fairness and inclusion in research.

Study Limitations

The Community VOICES Study was designed to explore attitudes towards a specific type of research (e.g. EFIC studies), not to investigate research trust/mistrust. The insights that can be gained from our data do, however, highlight important issues to consider in trying to understand and lessen mistrust in medical research of all types. Unfortunately, our survey did not include information about all groups that are underrepresented in research. One such group who may have special research trust issues that merit further study is the Lesbian, Gay, Bisexual, Transgender, and Queer/Questioning (LGBTQ) community and those who are Gender Non-Conforming. Often marginalized, members of sexual orientation and gender identity minorities encompass all genders, races, ethnicities, SESs, and educational backgrounds. There is published literature on LGBTQ attitudes towards research surrounding HIV/AIDS treatment and prevention, which shows high rates of mistrust, often strongly associated with fear of stigmatization (Berg and Ross 2014, Sevelius et al. 2016, Loutfy 2014).

However, it is not known if this mistrust is related exclusively to HIV-specific research or impacts general medical research participation, resulting in this broadly categorized group being underrepresented in clinical research findings.

Conclusions

Ethical research processes can help achieve greater participant diversity. This in turn results in research findings that are generalizable to broader segments of the population. Both lack of trust by participants and lack of access to research opportunities may contribute to underrepresentation by certain groups. This study offers a paradigm to understand the lack of trust in clinical research: domains of General Trustworthiness, Perception of Deception, Perception of Exploitation, and Perception of Discrimination. The empirical data collected by this study, supported by systematic literature reviews, suggests specific concerns of underrepresented groups and conceptualizes a framework of global issues. These insights can propel researchers towards effective strategies to promote greater participation by developing and testing group-specific targeted interventions, based upon empirical data. In

order to increase research participation among people from diverse racial, ethnic, and socioeconomic backgrounds, the sources of their mistrust will have to be addressed.

Each researcher, study, and study population is unique, requiring that protocols have tailored strategies for engaging the community and recruiting participants in ways that are responsive to these domains of concern. Suggestions for developing tailored and targeted interventions can be found in the extensive literature on community based participatory research (Corbie-Smith et al. 2015; Salsberg et al. 2015). However, ethical behavior is not achieved through regulation alone, it requires an ethical character of researchers and institutions. Frequently, researchers view their social contract with the community under study as having well-defined boundaries of time and scope. For many investigators the research relationship commences at informed consent and ends at the final study visit. In order to develop a sense of trust, the individuals and community being researched may require a research relationship with more expansive boundaries (Kerasidou and Parker 2014)

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Table 1

Demographic Characteristics of Study Participants N=355

Characteristic	Total % (n)	White	Black	Latino	Other
Gender:	355	42 (150)	29 (104)	22 (78)	6 (23)
Male	36	34	33	41	43
Female	64	66	67	59	57
Age:					
<60	45	31	70	45	55
>60	53	69	30	55	45
Household income					
<\$20K	32.15	29	19	63	10
\$20–60K	47.49	44	69	22	55
>\$60K	20.35	27	12	15	35
Educational level:					
High school or less	43.14	29	50	68	17
Some college	25.71	29	27	21	17
Bachelor's degree	13.43	16	13	8	22
Post-graduate degree	17.71	27	11	3	43
Female	64	66	67	59	57
Age:					
<60	45	31	70	45	55
>60	53	69	30	55	45
Household income					
<\$20K	32.15	29	19	63	10
\$20–60K	47.49	44	69	22	55
>\$60K	20.35	27	12	15	35
Educational level:					
High school or less	43.14	29	50	68	17
Some college	25.71	29	27	21	17

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	Total % (n)	White	Black	Latino	Other
Bachelor's degree	13.43	16	13	8	22
Post-graduate degree	17.71	27	11	3	43

Table 2

Research Trust/Mistrust Questions N=355

	Question as delivered in interview	% Agree or strongly agree
1	My attitude towards medical research can best be described as positive	85.3
2	Doctors and healthcare workers would not involve me in research that might be harmful	57.3
3	Doctors and healthcare workers sometimes hide or with-hold information from individuals	61.8
4	Doctors and healthcare workers sometimes involve patients in medical research without their knowledge or permission	44.6
5	Doctors and healthcare workers perform research on left-over blood from patients without their permission	27.5
6	People who participate in medical research are like human guinea pigs	43.9
7	I believe that medical researchers are often more interested in fame or making money than in helping people or saving lives	25.8
8	People from my racial/ethnic group are asked to participate in research <i>more</i> often than people from other groups	35.6
9	Within the healthcare system, people from my racial/ethnic group are treated differently than people from other groups	53.1
10	I would be more comfortable having research explained to me by a doctor or health care worker with a racial or ethnic background similar to mine	40.0

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Table 3

Factor Analysis

Factor (score range for factor)	Mean score for factor	Significant demographic variables	Mean Score demographic variable in this factor	P value
General Trustworthiness (2–10)	7.41	Age		
		>60	7.42	p <0.05
		<60	7.09	
		Children living at home		
		Children at home	7.59	P <0.01
		none	6.92	
		Disability status		
Not disabled	7.65	<0.05		
Disabled	6.86			
Deception (3–15)	9.34	Personal experience of research		
		experience	9.72	<0.05
		none	9.00	
		Marital status		
		Single	9.67	<0.05
		Married	8.82	
		Race/ethnicity		
Black	9.97	P= 0.08		
Latino	9.12			
Exploitation (2–10)	5.69	Educational attainment		
		High school or less	5.97	p=0.05
		Post grad	5.16	
Discrimination (3–15)	9.42	Language preference for interview		
		Spanish	10.24	<0.05
		English	9.23	
		Race/ethnicity		
		Black	10.51	Black vs White: p<0.01
		White	9.12	
Latino	10.23	White vs Latino: p =0.06		