Published in final edited form as:

J Cancer Educ. 2012 June ; 27(2): 299–305. doi:10.1007/s13187-011-0300-5.

The Role of Health Literacy on African American and Hispanic/Latino Perspectives on Cancer Clinical Trials

Kiameesha R. Evans, MPH, MCHES^{1,2}, M. Jane Lewis, DrPH, MA^{1,2}, and Shawna V. Hudson, PhD^{1,2,3}

¹Department of Health Education and Behavioral Science, UMDNJ – School of Public Health (683 Hoes Lane, Piscataway, NJ 08854)

²The Cancer Institute of New Jersey, UMDNJ-Robert Wood Johnson Medical School (195 Little Albany Street, New Brunswick, NJ 08903)

³Department of Family Medicine and Community Health, UMDNJ-Robert Wood Johnson Medical School

INTRODUCTION

Cancer is the second leading cause of death for all Americans. Almost 1.6 million new cancer cases are expected to be diagnosed in 2011, and more than 571,000 Americans are expected to die from cancer [1]. However, disparities in cancer incidence and mortality exist for some racial/ethnic minorities. African Americans have the highest mortality and shortest survival of any US racial and ethnic group for most cancers [1]. African Americans and Hispanics often have poorer access to care and an increased incidence of late diagnosis, resulting in more costly treatment and often poorer outcomes [1].

The National Cancer Institute estimates there were approximately 11.7 million cancer survivors alive in January 2007, an increase over the previous year [1]. Advances in cancer detection and treatment are due in large part to cancer clinical research and cancer clinical trials. Cancer clinical trials (CCTs) are research studies that measure the safety and effects of new treatments and procedures in human volunteers [2]. Participants in clinical trials: (1) often receive more comprehensive care and access to new drugs and therapies before they reach the greater market; (2) provide a valuable contribution to clinical research and (3) are often more knowledgeable about their cancer and health care needs [3–5]. For cancer research, the participation of people in clinical trials is imperative. However, adult participation is low at 3–5% and many individuals who are eligible for clinical trials do not actually participate in them [6–8]. For underrepresented groups, such as ethnic minorities, women, and the elderly, participation rates are estimated to be even lower [8]. Patient diversity in clinical research is essential, as it affects generalizability of trial results to these populations [9, 10].

Prior research has identified a variety of patient barriers and patient motivators to clinical trials participation. Motivators to participation include: the ability to help society [11–14]; a positive doctor-patient relationship and communication [12, 4, 14]; and the ability to gain access to new therapies [12]. Barriers to participation have also been identified in the literature, including: inconvenience of trial participation [11, 12, 4, 14, 13]; lack of

CORRESPONDING AUTHOR, Kiameesha R. Evans, MPH, MCHES, EvansKR@umdnj.edu, 732-235-9884 (voice), 732-235-9888 (fax).

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

awareness of trials [4, 14]; mistrust of the research process [12, 4, 13, 14]; concerns regarding issues such as randomization and disease progression [12, 4, 13, 14]; fear [12]; family considerations [4, 14]; and concerns regarding racism/discrimination [12].

The Institute of Medicine report on health literacy estimates that 90 million adults have literacy skills that test below high school, which has important implications for health care delivery and clinical trials research [15]. Health literacy is a “wide range of skills and competencies that people develop to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life” [16]. Zarcadoolas, *et al.* present a model of health literacy characterized by four domains: fundamental literacy, scientific literacy, civic literacy, and cultural literacy [16]. Fundamental literacy refers to skills related to reading, writing, speaking, and numeracy. Tools such as the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy Assessment (TOFLHA) are used to assess fundamental health literacy [17]. Scientific literacy refers to understanding science and technology, including the understanding that science is uncertain and that rapid change in previously accepted science is possible [16]. Research has shown that Americans have a poor understanding of science [18, 19], which can contribute to poor health outcomes. Civic literacy encompasses a range of skills that enable individuals to become aware of health issues and become involved in the decision-making process [20]. Finally, cultural literacy refers to the ability to recognize and use beliefs, customs, and social identity in order to interpret and act on health information [16]. In the health realm, culture can shape how individuals view illness, health messages, and the general medical system.

Low health literacy contributes to a number of problems such as: inappropriate or no use of health services; improper use of medications; financial drain on individuals and society; social inequity; and poor health outcomes [20]. Literacy levels are lower among members of racial/ethnic minority groups, the elderly and individuals with lower educational levels, groups for whom there is very low clinical trial participation [15]. Little research examines the intersection of health literacy and cancer clinical trials participation [21]. Decisions around participation in clinical research require an understanding of social, environmental, and systemic forces affecting health [22]. These and other skills that enable individuals to become aware of health issues and involved in the decision-making process are essential in an individual’s ability to judge and critique sources of health information [20]. Research also suggests that cultural beliefs contribute to an individual’s health decision-making [23, 24]. While there is limited research that examines the intersection of health literacy and cancer, almost no research has examined perceptions of clinical trials using a health literacy framework to understand individuals’ decisions regarding participation in cancer clinical trials. The current study explores African Americans’ and Hispanics’ perceptions about cancer clinical trials using Zarcadoolas, *et al.* multidimensional health literacy framework as a conceptual guide.

METHODS

Study Design and Population

This qualitative research study examined attitudes toward and willingness to participate in cancer clinical trials among African Americans and Hispanics/Latinos in New Jersey using focus group methodology. Institutional Review Board (IRB) approval was received from the University of Medicine and Dentistry of New Jersey.

Focus groups were conducted from January to May 2007 with African Americans and Hispanics/Latinos identified through faith- and community-based organizations throughout New Jersey. Eligibility requirements included understanding of spoken and written Spanish

or English and being over 18 years of age. Groups were conducted by racially/ethnically-matched moderators in community settings in northern (Newark, Morristown), central (Perth Amboy, New Brunswick), and southern New Jersey (Millville). Recruitment for Spanish-language sessions included the use Spanish-language flyers.

Each focus group consisted of a 90-minute session conducted by a trained facilitator, with 8 to 12 participants per group. Sessions were conducted in English or Spanish, and refreshments were provided at all groups. At the beginning of each group, the study procedures were explained, participants were assured anonymity, and informed consent was obtained. At the end of each focus group session, a fact sheet on clinical trials was provided to each participant to provide additional information. All participants completed a separate de-identified survey. Focus group participants received a \$35 gift card for their participation.

Focus Group Guide and Survey

The interview guide explored perceptions of cancer clinical trials among African Americans and Hispanics/Latinos and barriers and possible incentives for participation in them. Moderators were trained prior to implementation, including mock sessions to ensure consistency and understanding of the guide. Moderators were trained to encourage responses from all participants, but were not required to secure answers from every participant. Focus group discussions addressed awareness and understanding of clinical research, perceptions of benefits of participating in cancer clinical trials and barriers to participation, factors related to participation in cancer prevention and treatment trials, and perceptions of the importance of the racial/ethnic composition of the research team for participation. Probing was used to elicit additional information. Sample questions are presented in Table 1.

Focus group discussions began with questions to assess group members' awareness of cancer clinical trials and understanding of the clinical research process. Participants were asked to discuss their perceptions of benefits of participating in cancer clinical trials, and when given information about the lack of participation, they were asked to discuss why individuals, especially Blacks and Hispanics/Latinos, do not participate. Specific questions were introduced to discuss issues of trust as well as ascertain participant knowledge of the Tuskegee Syphilis Experiment and similar experiments, and if they believed this could happen again. Questions probed awareness of the Institutional Review Board (IRB) process and whether participants believed awareness of IRB protections would increase clinical trial participation as well as the potential problems caused by the lack of participation among their specific racial/ethnic group. Member checking was conducted throughout the focus group discussion as facilitators summarized comments provided by participants to ensure that participants were able to clarify responses if there was any misunderstanding.

Participants were asked about their perceived cancer risk and led through a series of hypothetical situations to learn whether type of treatment (new vs. standard) or doctor recommendation were factors that would affect their decision to participate in a treatment trial. There was also focused discussion on randomization to assess participant attitudes and awareness regarding this concept.

To gain an understanding of participant beliefs regarding prevention trials, a section of the focus group was devoted to delving into this issue. Participants were asked to discuss factors that may influence participation, such as compensation for participation, cancer type, required tests and procedures, and time constraints of participation. The remainder of the discussion focused on the importance of the racial/ethnic composition of the research team for participation.

At the close of the focus group sessions, participants completed a brief survey regarding demographic information and health-related information. The survey included closed- and open-ended questions regarding age, gender, education, race/ethnicity, attitudes and beliefs regarding cancer clinical trials (treatment and prevention), and factors that potential participants may consider prior to enrollment.

Analysis

All focus groups were audiotaped. English-language focus groups were transcribed by research assistants at the University of Medicine and Dentistry of New Jersey – School of Public Health. Spanish-language focus group sessions were translated and transcribed by an external, independent company which uses a three-step process for translation. Transcripts were coded for the presence of themes (KRE) using ATLAS.ti 5.2 qualitative software [26] and coded transcripts were reviewed by a second member of the project team (MJL). Additional codes were added and sections recoded as necessary [25]. Differences in interpretation of the data were resolved through discussion. For coded text where there was discrepancy between the coder and code reviewer, determination of final code assignment was achieved through discussion and group consensus; we therefore achieved 100% agreement in terms of inter-coder reliability for coded text segments. ATLAS.ti reports of coded text were examined for major themes, and representative quotes were selected to illustrate themes. Themes were identified using deductive and inductive methods, reflecting themes previously derived from the literature and others that arose through reading of the transcripts. Themes were analyzed within the health literacy framework of three health literacy domains (cultural, scientific, and civic). Frequencies from survey data were analyzed using SPSS 18.0 quantitative software.

RESULTS

Participant Characteristics

Demographic characteristics for focus group participants are presented in Table 2. Their mean age was 43.3 (range 23–64) and the majority of participants were female (77.2%). Among Hispanic/Latino focus groups, 75% lived in the United States for five years or less. Groups were held in community settings in the northern, central, and southern part of the state, with group size ranging from 8 to 12. Across all groups, few members (30%) had previously heard of clinical trials, and fewer participants (8%) knew someone or personally participated in clinical trials. Only 6% of participants had ever had cancer, but 38% had an immediate family member with cancer.

Themes that participants described included: 1) scientific literacy issues regarding limited and incorrect understanding of scientific information and perceptions of clinical trials as uncertain and fear; 2) limited civic literacy in terms of trust, perceptions of participants as guinea pigs, and perceptions of IRB protections; and 3) cultural literacy challenges regarding use, importance and healing power of home remedies for health; for Hispanic/Latinos the need for health care professionals to be conversant in their language, and the importance of race/ethnicity among health care professionals. Table 3 presents quotation(s) that illustrate major themes derived from focus group discussions.

Scientific Literacy

Although many participants were not aware of clinical trials, almost all groups had members with at least some knowledge of clinical trials. However, misconceptions regarding clinical research and health information were prevalent. When asked whether they would participate in a prevention trial, one participant (group 1) said that participating in a prevention trial would result in being injected with a virus, “like the flu shot.” Also, some participants

mistakenly believed that all clinical trials utilized a “placebo versus new treatment” design and were concerned that they could have cancer and receive no treatment if they chose to participate: “...in some cases they [participants] don’t know if they getting the real treatment or placebo, so it’s like you’re getting my hopes up but how do I even know that you’re really treating me....” (group 3)

The uncertainty of clinical trials appeared as a theme, and some participants characterized randomization as “unfair” and a “loophole” during group discussions. Others felt that informed consent could only be *informed* if the patients knew which drug they would be receiving upon agreeing to participate in the trial: “[so]...you understand that you’re randomly assigned...and if you agree to that, and they have you sign that little paper and now they can give you whichever [treatment]...and, you sign the paper...knowing that you...can’t come back on them with that.” (group 1)

Fear was identified by all groups as a factor in the decision to participate in treatment trials. Regarding treatment trials, this fear was expressed in various ways, including fear of the unknown, of side effects, and of getting sick or dying. Participants were also very concerned that clinical trials do not provide a guarantee of success, and in some cases, may ultimately result in a person’s worsened condition or death: “If it fails, what happens with you then?” (group 2)

Civic Literacy

Focus group members identified trust as a factor in an individual’s decision to participate in clinical trials, even though the examples they gave were not cancer related. For example, the legacy of the Tuskegee Syphilis Experiment was well known in the African American groups, even if the specifics were unclear. Although Hispanic groups were not aware of Tuskegee, they also shared similar stories of discrimination or mistreatment that they had personally encountered or had heard from others: “[In Mexico]...they are placing women that have children, after delivery they place an intrauterine device so that they don’t get pregnant again....” (group 5) According to Hispanic group members, a lack of trust in American doctors and the medical system often leads those they know to seek medical treatment back in their native country: “They don’t think that doctors here are like theirs in their own country. Almost all Dominicans go to the Dominican Republic to see doctors there, and there is no electricity there, and there’s no water...therefore it doesn’t make sense that you go from here, where there is electricity in the hospitals, to go there, but almost everyone does it.” (group 4)

The perception of cancer clinical trial participants as “guinea pigs” appeared in all groups, and often with a negative tone. One participant referred to the guinea pig as “the sacrificial lamb.” (group 1) Even after receiving an explanation of IRB protections, many participants, while acknowledging that these protections may exist, were skeptical that they were being enforced as intended, or even at all: “I don’t think they do it [enforce IRB protections] at all. I think once you participate, [it is] at your own risk; you take your own life in your own hands, whatever the results are.” (group 2) However, one participant thought knowledge of IRB protections would help: “... even after being educated they still might decide not to participate, but at least I think it would, I think more people would participate...upon learning about these regulations than would...participate if they didn’t know.” (group 1)

Cultural Literacy

Members of both African American and Hispanic/Latino groups mentioned home remedies as options in their culture to cure illness and maintain health: “...they don’t even go to a doctor, always look for home remedies...not look for it in science, in doctors, much less be

in a study which will...be published....” (group 4) The role of language in educating and recruiting for clinical trials was also identified through Hispanic/Latino group members. Hispanics/Latinos, in general, felt that speaking their language was important: “Let an American come but they should speak our language.” (group 5) Among Hispanic/Latino members in our focus groups, a positive doctor-patient relationship was viewed as important: “There are doctors in a town where we lived, which is small and the doctor knows the whole family, knows many people, so that is the reputation we are looking for.” (group 4)

When asked whether the race or ethnicity of the doctor or researcher makes a difference in the decision to participate, members were divided. Some believed that health care professionals in their cultural groups would be most appropriate, whereas others believed that it did not make a difference. One man familiar with Tuskegee shared, “...that woman [nurse researcher] was black too and she was working with the white people to mislead the black[s] so I wouldn’t...necessarily trust a black person neither cuz they got some kind of ulterior motive going on....” (group 1)

DISCUSSION

The ability to make a decision to participate in clinical trials is based on a combination of skills, including patients having an understanding of research and science, patients being able seek out and evaluate health information, and providers giving messages that are appropriate for the populations served. Moreover, literacy in one domain can assist in the development of skill in another domain, and can compensate for competency deficiencies in another domain [20]. Health professionals generally agree that low health literacy contributes to poor understandings and can contribute to an array of poor health behaviors and outcomes [20]. Particularly around scientific literacy, focus group discussions in this study underscored that health literacy is important for understanding and revealed inaccuracies and misconceptions of information necessary for an individual to understand the clinical research process (e.g., study designs, risk and benefits, and how to contact study protections such as investigators and Institutional Review Board). Clear understandings of the science and its purpose are imperative for *informed* consent. Results from these discussions highlighted concerns regarding the uncertainty of clinical trials, a fear of participation, and the perception of participants as guinea pigs; these factors must be considered and addressed in the development of any interventions to increase clinical trials participation.

A main tenet of civic literacy is the ability for individuals to evaluate and judge the sources of health information [20]. African American and Hispanic groups were critical of the medical system, the research environment, pharmaceutical companies, and the government. All these partners are involved in the clinical trials process. Trust is an important factor that affects how individuals view clinical trials and contributes to whether they ultimately are willing to participate. Any interventions to increase accruals must consider the importance of trust and have components to address potential concerns while building a participant’s civic literacy.

Participants in our focus groups reported positive and negative experiences in the health care system both within and outside of their racial/ethnic group. The domain of cultural literacy speaks to the communicator’s skill in “framing health information to accommodate powerful cultural understandings of health information, science, and individual and collective action” [20]. As highlighted by our groups, developing interventions that incorporate building cultural literacy in these populations must include the communicator having a comprehensive understanding of the populations they serve.

Our study has a few limitations. Although efforts were taken to obtain feedback from residents throughout the northern, central, and southern parts of New Jersey, focus group participants were selected from a pool of participants who expressed interest in the topic and may not be representative of others who did not volunteer. Therefore, the generalizability of our findings is limited. Second, we recruited from community-based settings such as houses of worship which while building rapport and gaining trust, may have resulted in more socially cohesive groups. Finally, while focus group moderators were trained to encourage and elicit responses from all group members, there were some respondents whose responses may have swayed the opinions of others who may have had divergent views.

Despite these limitations, this study suggests the decision to participate in a cancer clinical trial is determined by a multitude of factors. This study's use of health literacy as a framework provides a unique perspective on barriers to clinical trials participation. Data from our study suggest that using a health literacy framework for the development of programs to educate the lay community about cancer clinical trials may be beneficial. Educational interventions regarding cancer clinical trials should target the importance of scientific literacy, cultural literacy, and civic literacy in a person's decision-making, and future research should evaluate interventions to increase clinical trials accrual that address these domains.

Acknowledgments

This research was partially supported through grants from The Cancer Institute of New Jersey and the National Cancer Institute (P30 CA072720, K01 CA131500). We would also like to thank Olivia Wackowski, MPH, PhD at the University of Medicine and Dentistry of New Jersey-School of Public Health for her contribution on this manuscript.

References

1. Siegel R, Ward E, Brawley O, Jemal A. Cancer statistics, 2011: the impact of eliminating socioeconomic and racial disparities on premature cancer deaths. *CA Cancer J Clin.* 2011; 61(4): 212–236. [PubMed: 21685461]
2. Center for Information and Study on Clinical Research Participation. African Americans and Clinical Research. http://cisrcp.org/patient/educ_materials/brochures/cisrcp_AA_brochure_web.pdf. Accessed July 2011.
3. National Cancer Institute. Should I Participate in a Clinical Trial?. <http://www.cancer.gov/clinicaltrials/education/should-I-take-part>. Accessed July 2011.
4. Ford LG, Minasian LM, McCaskill-Stevens W, Pisano ED, Sullivan D, Smith RA. Prevention and early detection clinical trials: opportunities for primary care providers and their patients. *CA Cancer J Clin.* 2003; 53:82–101. [PubMed: 12691266]
5. U.S. National Institutes of Health. Understanding Clinical Trials. <http://clinicaltrials.gov/ct2/info/understand#Q06>. Accessed July 24, 2011.
6. National Cancer Institute. Cancer Clinical Trials: The Basic Workbook. Bethesda, MD: 2002.
7. Newman LA, Kim Roff N, Weinberg AD. Cancer clinical trials accrual: missed opportunities to address disparities and missed opportunities to improve outcomes for all. *Ann Surg Oncol.* 2008; 15(7):1818–1819. [PubMed: 18425554]
8. Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: race-, sex-, and age-based disparities. *JAMA.* 2004; 291:2720–2726. [PubMed: 15187053]
9. U.S. National Institutes of Health. NIH Guidelines on the inclusion of women and minorities as subjects of clinical research. <http://grants.nih.gov/grants/guide/notice-files/not94-100.html>. Accessed July 24, 2011.
10. Sadler GR, Gonzalez J, Mumman M, Cullen L, LaHousse SF, Malcarne V, Conde V, Riley N. Adapting a program to inform African American and Hispanic women about cancer clinical trials. *J Canc Educ.* 2010; 25:142–145.

11. Bieniasz ME, Underwood D, Bailey J, Ruffin MT. Women's feedback on chemopreventive trial for cervical dysplasia. *App Nurs Res*. 2003; 16(1):22–28.
12. Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med*. 1999; 14:537–546. [PubMed: 10491242]
13. Jones JM, Nyhof-Young J, Moric J, Friedman A, Wells W, Catton P. Identifying motivations and barriers to patient participation in clinical trials. *J Canc Educ*. 2006; 21:237–242.
14. Wright JR, Whelan TJ, Schiff C, Dubois S, Crooks D, Haines PT, DeRosa D, Roberts RS, Gafni A, Pritchard K, Levine MN. Why cancer patients enter randomized clinical trials: exploring the factors that influence their decision. *J Clin Oncol*. 2004; 22:4312–4318. [PubMed: 15514372]
15. Nielsen-Bohlman, L.; Institute of Medicine (U.S.). Committee on Health Literacy. *Health literacy : a prescription to end confusion*. Washington, D.C.: National Academies Press; 2004.
16. Zarcadoolas C, Pleasant A, Greer DS. Understanding health literacy: an expanded model. *Health Promot Int*. 2005; 20(2):195–203. [PubMed: 15788526]
17. Baker DW. The meaning and measure of health literacy. *J Gen Intern Med*. 2006; 21:878–883. [PubMed: 16881951]
18. National Science Board. *Science and Engineering Indicators 2004*. 2004. <http://www.nsf.gov/statistics/seind04/pdf/c07.pdf>. Accessed July 2011.
19. Gansler T, Henley SJ, Stein K, Nehl EJ, Smigal C, Slaughter E. Sociodemographic determinants of cancer treatment health literacy. *Cancer*. 2005; 104:653–660. [PubMed: 15983986]
20. Zarcadoolas, C.; Greer, DS.; Pleasant, A. *Advancing Health Literacy: A Framework for Understanding and Action*. Wiley, John & Sons, Inc.; 2006.
21. Krieger JL, Parrott RL, Nussbaum JF. Metaphor use and health literacy: a pilot study of strategies to explain randomization in cancer clinical trials. *J Health Commun*. 2011; 16(1):3–16. [PubMed: 21128152]
22. Paskett, ED.; Katz, ML.; Degraffinreid, CR.; Tatum, CM. Participation in Cancer Clinical Trials. In: Miller, SM., editor. *Handbook of cancer control and behavioral science : a resource for researchers, practitioners, and policy makers*. Washington, DC: American Psychological Association; 2009. p. 103-112.
23. Shaw SJ, Huebner C, Armin J, Orzech K, Vivian J. The role of culture in health literacy and chronic disease screening and management. *J Immigr Minor Health*. 2009; 11(6):460–467. [PubMed: 18379877]
24. Berkman ND, Davis TC, McCormack L. Health literacy: what is it? *J Health Commun*. 2010; 15(Suppl):9–19. [PubMed: 20845189]
25. Crabtree, BF.; Miller, WL. *Doing qualitative research*. 2. Thousand Oaks, CA: Sage Publications; 1999.
26. ATLAS.ti. Version 5.2. Berlin: Scientific Software Development; 2006.

Table 1

Sample Focus Group Questions from Interview Guide

Sample Questions
What do you think the benefits of cancer clinical trials are?
Do you think that something like Tuskegee could still happen today?
Do you think that educating people about these protections may make people feel safer about going into a clinical trial?
This may be difficult to imagine, but <i>if</i> you had cancer, do you think you would participate in a treatment trial? What would it depend on?
[W]hat you think <i>your own</i> chances are of getting cancer – do you think you are more or less likely or just as likely to get cancer as other people? Why do you think that?
Do you think you would ever participate in a prevention trial? Why or why not?
Some African Americans/Hispanics say they might participate in a clinical cancer study if the research or the people that recruit them were African American/Hispanic; would that be true in your case?
Do you think recent immigrants would be treated differently than someone who was born in the United States? (Spanish-language focus group)
Do you think new immigrants would get the same benefits from clinical studies as the people that were born in the United States? (Spanish-language focus group)

Characteristics of Focus Group Participants (n = 50)

Table 2

Group #	Location	Number of Participants	Age			Language	% Female	% At Least Some College
			Mean	SD	Range			
1	South	10	46.1	9.62	32–63	English	70	70
2	Central	8	46.3	6.54	39–56	English	100	75
3	North	11	49 *	11.88 *	29–62 *	English	81.8	81.8
4	Central	9	33.3	6.25	23–43	Spanish	100	44.4
5	North	12	43.3	11.60	24–64	Spanish	40	16.7

* Two cases missing.

Table 3

Themes with Illustrative Quotes

Theme	Illustrative Quotes
Misconceptions of scientific information	“Green tea heals a lot of things....” (group 1) “It’s natural; it doesn’t have any [side] effects.” (group 5)
Uncertainty of clinical trials	“If it happened to me...I would not want to go with what they are trying out.... I want to go with what is certain.” (group 5)
Fear	“Is it going to make me worse than what I am right now? Is it gonna hurt me.... I wouldn’t want it to get any worse...I want it to at least help...longer life....” (group 2)
Trust	“...that happens in my family...in my Mother’s case...she prefers to save money and go to my country, Peru, find the best doctor and be treated there. She feels more secure. She doesn’t trust.” (group 4) “They are playing with you; they are doing what they want.” (group 5)
Guinea pig	“...I don’t wanna be a guinea pig either. I don’t want you to give me something and then say, well this might, you know, I don’t know how it’s gonna affect you, this might do this, I can’t really say, you know doctors always say that.” (group 3) “I think they are afraid, afraid of what will be done to them, afraid of being guinea pigs. Perhaps they think they don’t know what will be done and what the experiment is. Perhaps they will give me a medication but they will experiment on me and maybe they don’t know what the effects it might have are and what will happen to me?” (group 4)
IRB Protections	“I don’t think it [knowing of IRB protections] would make people likely to participate because I think on average people from the African American and Hispanic community are distrustful of government. And just because you tell them that they’re being protected by this agency, that they probably have never heard of before, and have no idea that it even may exist, they’re probably not going to believe you.” (group 2)
Home Remedies	“...you know cuz we have our home remedies, and things that we say this what we do to fix this, and so...I think it’s culture.” (group 3)
Language	“I don’t have any problems with English, but I think I would feel more comfortable speaking Spanish.” (group 4)
Race/Ethnicity of healthcare team	“If you’re trying to give me information on something that’s gonna help me, then you could be purple.” (group 2) “I don’t think that it should make a difference what color [a] person...is, but realistically most people are comfortable dealing with their own ethnic group....” (group 2)