



Translational Science April 2017, Washington, DC

RESEARCH OVERVIEW

Barriers to participation in clinical trials in general and particularly in African Americans and other racial and ethnic minorities include lack of awareness about trials, economic factors, mistrust and issues related to lack of communication.

There is growing interest to improve study participant experiences for minorities. However, few studies have examined research participant satisfaction and its relationship to racial diversity.

OBJECTIVES/GOALS

The objectives of this study were: 1. To examine research participant levels of satisfaction, experiences and perceptions; and, 2. To determine best practices for researchers for engaging research volunteers in clinical trials, and thereby reducing barriers to participation.

Participants Satisfaction Survey Questionnaire

A: Research Staff Delivery of Care

- I was treated well by the research staff
- During my research visit my privacy was respected
- I felt comfortable asking questions of the staff
- I felt my questions were answered to my satisfaction
- The staff was helpful in scheduling my future appointments & upcoming visits

B: Environment

- I was able to get to the research clinic/center easily
- I was greeted courteously when I arrived
- The waiting room was clean & comfortable
- I was attended to by the staff in a timely manner
- The exam room was clean

C: Center Operation

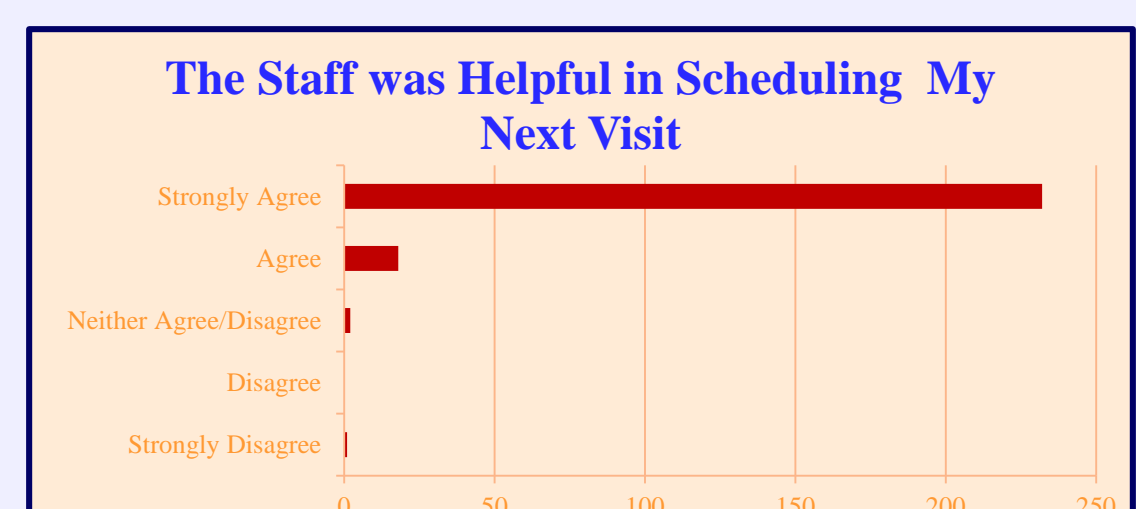
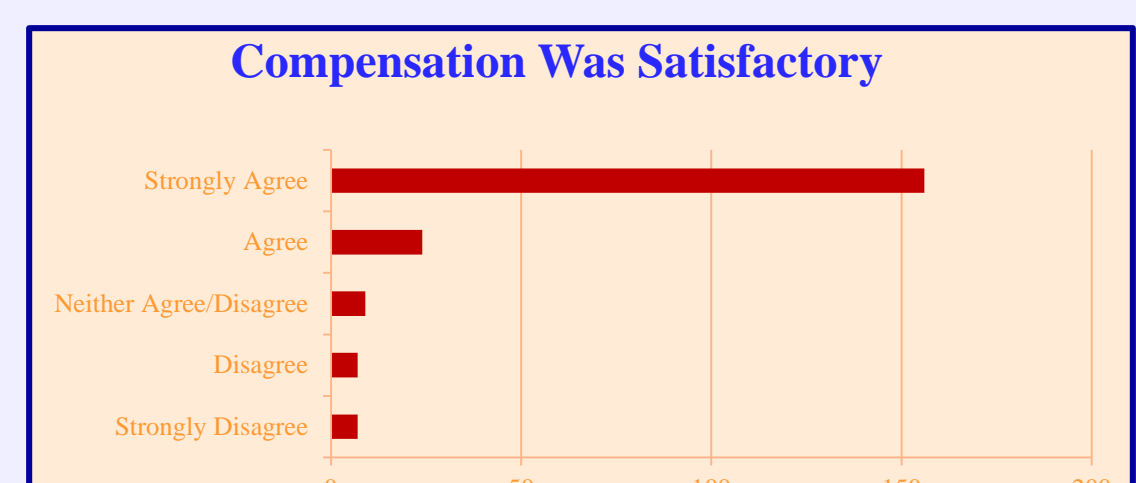
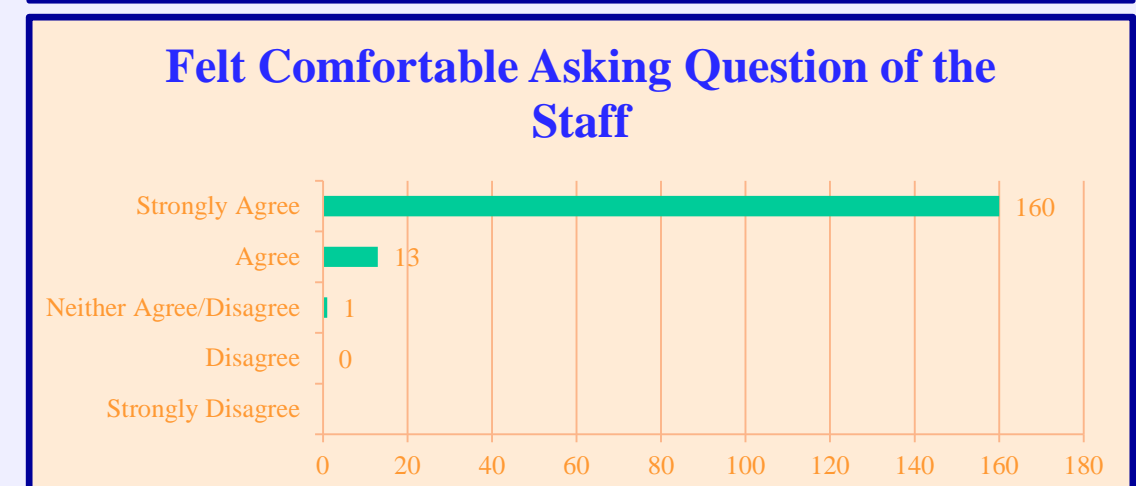
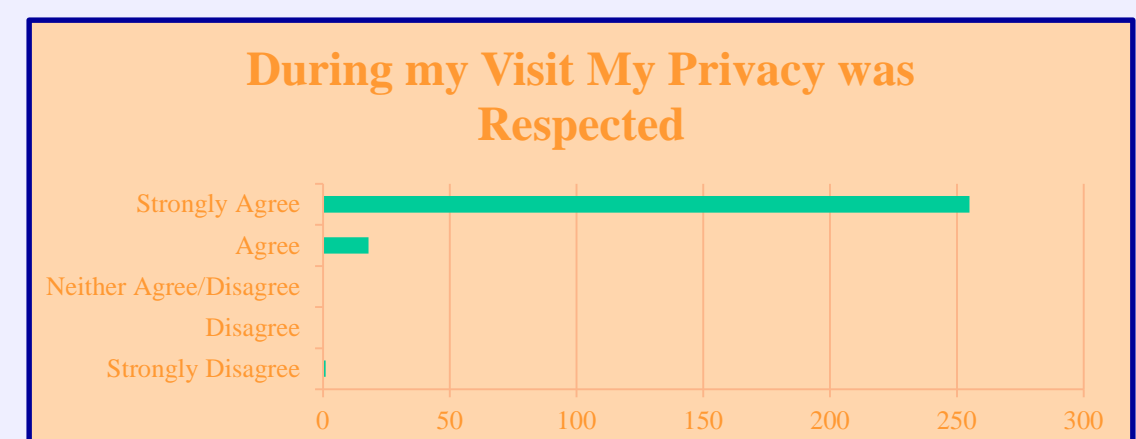
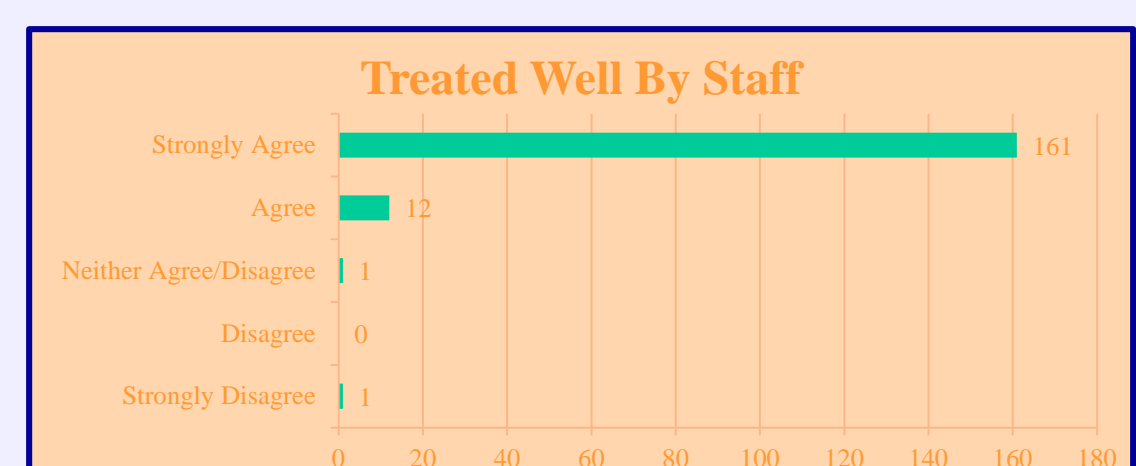
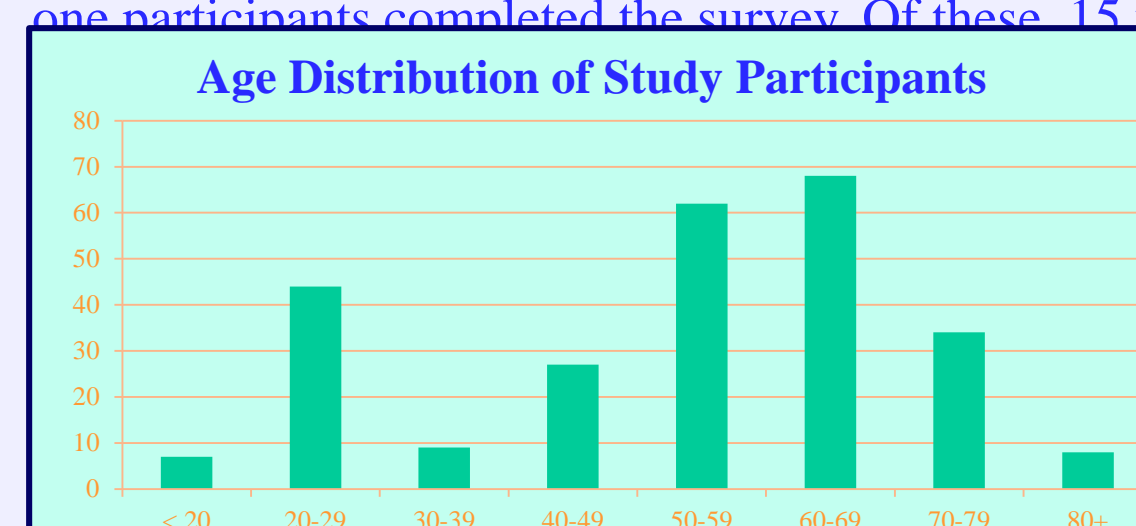
- I felt the research staff was knowledgeable
- I felt today's visit was completed in a timely manner
- If you had a procedure today, rank your satisfaction with the process
- I felt the staff had the necessary skills to perform the research procedures

D: Overall Experience (Major questions)

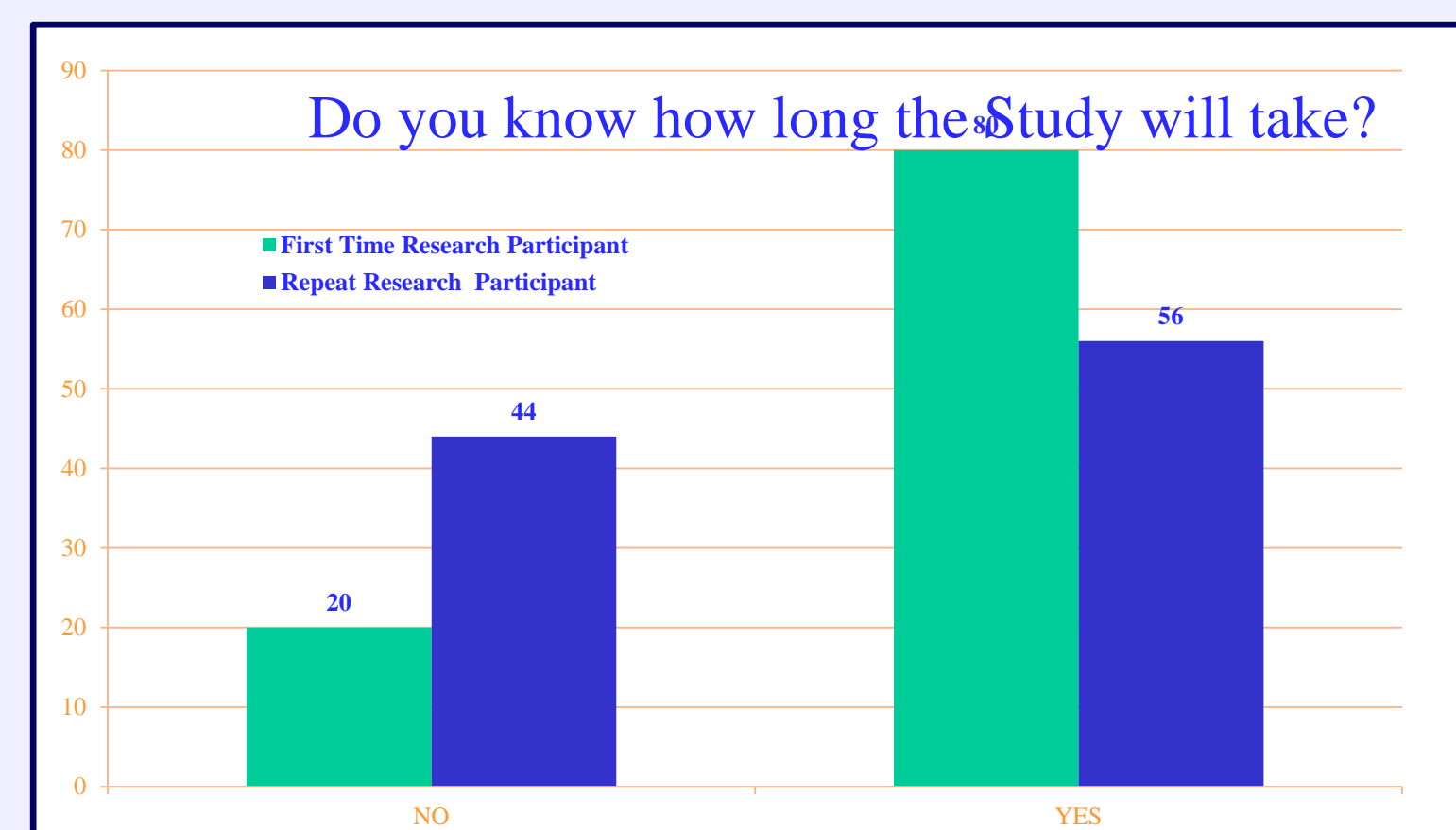
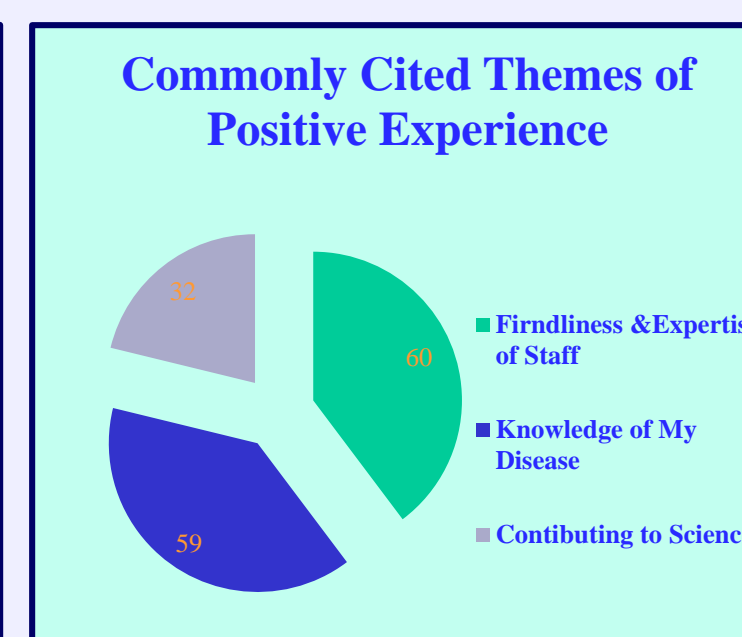
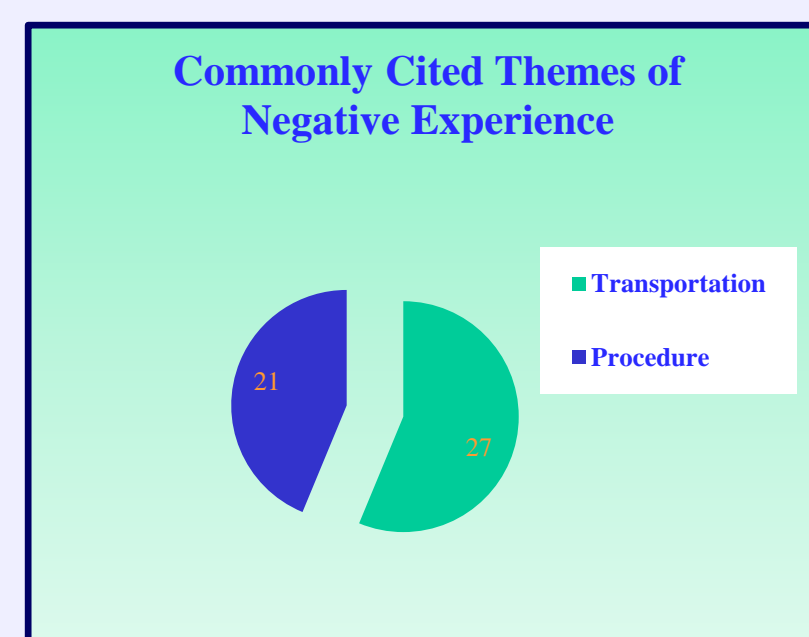
- Based on your experience what do you like most about participating in this research study?
- Based on your experience what do not like (like least) about participating in this research study?
- Were your expectations met during your participation in this study?
- Over all what is/was your experience during this research study?
- Would you be willing to participate in future studies?
- Would like recommend a friend or a family member to participate in a research

METHODS/STUDY POPULATION

A self-administered IRB approved survey on satisfaction and perception in translational and clinical studies was developed. The study questions were validated by five key informants from each of the three research centers who were asked to provide constructive feedback on the clarity and relevance of the questions. The final survey was a 25-item questionnaire that used a Likert scale and focused on 5 domains to reflect satisfaction with "Staff delivery of care", "Environment", "Center Operations", "Study specific questions" and "overall experiences". Questions to reflect participant perceptions were open ended. A convenience sample of all participants currently enrolled in research studies at CTSA institutions (GU, HU & MHRI) was obtained. One hundred thirty one participants completed the survey. Of these, 15 were



RESULTS. Ninety-four (67%) were first time study participants. Over 90% of those surveyed strongly agreed that they were "treated well", that their "privacy was respected", and that they "felt comfortable asking questions of the staff". Eighty-four percent (84%) indicated they would participate in future studies while over 91% indicated they would recommend a family member or a friend. Only 46% of participants coming for their first research visit strongly agreed that the "compensation received was satisfactory". However, 74% of participants returning for follow-up or who had been enrolled in a previous study felt the compensation was appropriate. Seventy-four percent (74%) of those enrolled for the first time indicated "knowing the duration of this study" as compared to only 38% of repeat visitors. When asked what they liked most about participating in a research study their primary responses were "contribution to science" and "knowledge about their diseases".



DISCUSSION/SIGNIFICANCE OF IMPACT:

Qualitative Results

The results of this survey demonstrated that the majority of research participants rate their experience as highly favorable even among those who had never participated in clinical research previously. In some existing literature, it has been reported that financial compensation was a major motivation to participation in studies involving healthy volunteers. In this current study, however, financial compensation did not appear to be the primary motivation for participation. The participants' at all three sites stated that the main reason for their participation was the increased knowledge about their disease and the contribution to science. Negative experiences cited were primarily discomfort with blood draw, transportation and parking logistics. Most importantly, a majority of the participants stated they would participate in future studies and would recommend a family member or a friend for a clinical study. In our sample, there was no difference in the favorable ratings as determined by

Demographic Characteristics of Participants

Characteristic	Count	Percentage
Gender		
Female	143	(51%)
Male	125	(45%)
Ethnicity		
African American	153	(55%)
Non-Hispanic Whites	81	(29%)
Hispanics	6	(2.2%)
Asian	5	(1.8%)
Other	16	(5.8%)
Prefer Not to answer	6	(2.2%)
Education		
Elementary School	17	(7%)
Junior High School	5	(2.1%)
High School	69	(29%)
College	140	(58.6%)