

# FACTORS AFFECTING AFRICAN AMERICAN PARTICIPATION IN AIDS RESEARCH

SOHINI SENGUPTA<sup>1</sup>, RONALD P. STRAUSS<sup>2</sup>, ROBERT DEVELLIS<sup>2</sup>,  
SANDRA CROUSE QUINN<sup>2</sup>, BRENDA DEVELLIS<sup>2</sup>, WILLIAM B. WARE<sup>2</sup>

<sup>1</sup>Center for AIDS Prevention Studies, UCSF, USA; <sup>2</sup>University of North Carolina - Chapel Hill, USA

## ABSTRACT

**Background** This study examines a multidimensional construct of distrust and other factors that may affect willingness to participate in AIDS research.

**Methods** A total of 301 African Americans (ages ≥ 18) in Durham, North Carolina participated in a cross-sectional survey. In-person interviews, 20-25 minutes in length, were conducted with participants. Structural equation modeling was used to develop models exploring distrust and other factors affecting willingness to participate in AIDS research among African Americans.

**Results** Distrust was the strongest inverse predictor of willingness to participate in AIDS clinical trials. Distrust was not significantly associated with willingness to participate in AIDS surveys and educational interventions. Altruism, facilitators/barriers, religiosity, and economic group membership were also significantly associated with willingness to participate in AIDS clinical trials. Only altruism was significantly associated with willingness to participate in AIDS surveys and educational interventions.

**Conclusions** Distrust in research institutions is a significant barrier to recruiting African Americans in AIDS clinical trials. Issues of distrust need to be acknowledged by researchers to develop better recruitment and retention strategies when conducting AIDS clinical trials in African American communities.

## INTRODUCTION

- Blacks make up 13% of the U.S. population, but have the highest HIV prevalence compared to other racial minority groups, and accounted for 47% of persons diagnosed with AIDS in 1997.
- Blacks in the U.S. (African Americans) are under-enrolled in AIDS clinical trials, including preventive HIV vaccine trials.
- Historically, African Americans have been mistreated in research; the famous case is the Tuskegee Syphilis Study. Previous studies have demonstrated an association between their distrust in medical institutions and participation in research.
- This study developed a multivariate model explaining predictors of African Americans' willingness to participate in AIDS research. Institutional distrust was the primary variable affecting willingness to participate in AIDS research vis-à-vis other factors postulated.

## METHODS

### Sample

Convenience sample of 301 adults (ages ≥ 18) who self-identified as African Americans, and were living in Durham, North Carolina for at least a year, participated in the study.

- Nearly 75% of the sample were women.
- Nearly two-thirds of the sample were single.
- The mean age was 33 years.
- Income level and family size were used to divide participants into two groups: poor and non-poor; 102 participants were classified as poor and 199 as non-poor.
- HIV status was NOT asked and unknown in this sample.
- Participants were highly religious.

### Survey Instrument

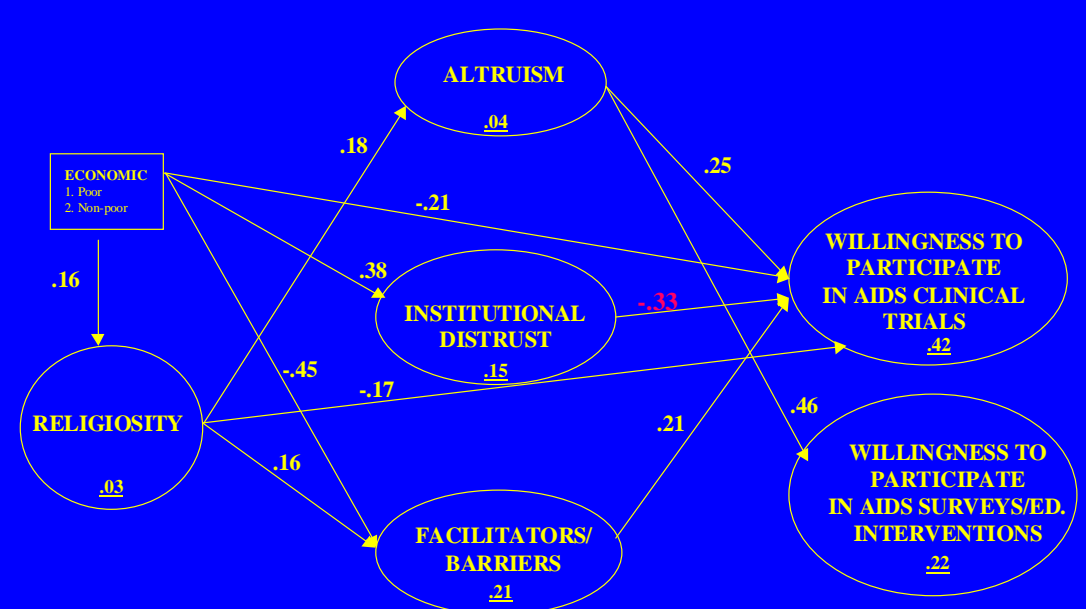
A new survey instrument was piloted and developed for this study. The final survey instrument consisted of 113 closed-ended questions. These included:

- Sociodemographic questions
- Factors believed to affect willingness to participate in AIDS research (from scientific literature): *institutional distrust, altruism, religiosity, and facilitators/barriers*
- Willingness to participate in AIDS research (12 questions)

## RESULTS

Respondents' Answers	%
Identified altruistic reasons as important	> 80
Identified as important:	
1) access to transportation	> 50
2) loss of current health care benefits	> 50
Frequent participation in religious activities	> 50
Strong religious beliefs	> 50
Agreed that Blacks are suspicious when research is done in their communities.	66.7
Disagreed with the U.S. government's involvement in AIDS research as being beneficial to the African American community.	> 50
Disagreed with statements referring to AIDS conspiracy theories.	> 50
AIDS scientists used poor people about the same as the Tuskegee Syphilis Study scientists.	> 50
AIDS scientists could be trusted about the same as the Tuskegee Syphilis Study scientists.	50
Would participate in survey-related research via the telephone, mail, or in person.	> 50
Would participate in both patient education programs and safer sex programs.	> 85
Would participate in therapeutic HIV vaccine trials.	> 66.7
Would not participate in AIDS clinical trials (including preventive HIV vaccine trials, drug treatment/prophylaxis trials).	> 50

### INSTITUTIONAL DISTRUST WAS THE STRONGEST INVERSE PREDICTOR OF WILLINGNESS TO PARTICIPATE IN AIDS CLINICAL TRIALS



NOTE: Economic is the only dichotomous variable; poor and non-poor sub-groups stratified by income level and family size. R-squared values are underlined within latent variables (ellipses).  $p < .05$  for all parameters (parameters that were not significant were deleted)

### EXPLORATORY FACTOR ANALYSIS RESULTS: LATENT VARIABLES, INDICATORS, AND SAMPLE ITEMS UNDERLYING EACH INDICATOR

Latent Variables	Indicators (Factors)	Sample Items
RELIGIOSITY	Religious Activities	How often do you read religious materials?
	Religious Beliefs	How connected do you feel to God, your Creator, or some other Higher Power?
DISTRUST	Tuskegee	Compared to the Tuskegee Syphilis Study scientists, do you think HIV/AIDS scientists are more, about the same, or less respectful towards Blacks participating in their studies?
	AIDS Conspiracy Theories	It is possible that AIDS has been deliberately spread in the Black community.
	Perceptions of Scientists and Research Institutions	Scientists try to protect the people they study from unnecessary risk.
	Scientists Treatment of/Interactions With Blacks or the Poor	Compared to others, poor people are used more in research without their knowledge or permission.
ALTRUISM	--	Whether or not the study would be helpful to find a cure for AIDS.
FACILITATORS/BARRIERS	--	Whether or not participating would take time away from other responsibilities, like taking care of children or going to work.

### Unique Contributions of the Indicators Underlying the Latent Variables in Figure

Latent Variable	Indicators	R-squareds (in %)
Distrust	Perceptions of scientists and research institutions	56
	Treatment of Blacks/Poor by AIDS scientists	35
	Comparing Tuskegee scientists vs. AIDS scientists	30
	AIDS conspiracy theories	8
Facilitators/Barriers	Free transportation to study site	57
	Going to study site more than once	50
	Money as incentive for participation	28
	Free medical care as incentive for participation	27
	Access to study site	17
Willingness to Participate in AIDS Clinical Trials	Preventive HIV vaccine trials	56
	AIDS drug treatment/prophylaxis trials	42
	Therapeutic HIV vaccine trials	7

### EXPLORATORY FACTOR ANALYSIS LOADINGS FOR ITEMS UNDERLYING DISTRUST

Variables Measuring Institutional Distrust	# Items	EFA Loadings
Comparing the Tuskegee Syphilis Scientists with HIV/AIDS scientists of today	4	.968
		.955
		.922
		.699
AIDS Conspiracy Theories	4	.819
		.780
		.743
		.731
Scientists Treatment of/Interactions with Blacks or the Poor	5	.754
		.720
		.687
		.640
		.528
Perceptions of Scientists and Research Institutions	9	.697
		.687
		.672
		.665
		.650
		.637
		.604
		.521
		.451

Note: Loadings > .40 were considered good.

## CONCLUSION

The present study developed a multivariate model of the factors affecting African Americans' willingness to participate in different types of AIDS-related research. The multivariate model highlighted that any individual's overall decision to participate in AIDS research may require taking into account one or more of the factors examined. For this reason, factors surrounding willingness to participate in AIDS research are complex, interrelated, and require a greater understanding of the historically grounded experiences of African Americans in the United States.

The major finding was that, compared to the other factors examined, a multidimensional construct of institutional distrust was the strongest inverse predictor affecting willingness to participate in AIDS clinical trials in the multivariate model. Distrust was not, however, significantly associated with willingness to participate in AIDS surveys/educational interventions. Altruism was the only factor that was significantly associated with willingness to participate in AIDS surveys and educational interventions. Increasing enrollment and retention may require AIDS clinical trial researchers to be more proactive in engendering trust when developing collaborative relationships with African American communities.