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Assessing the Likelihood to Participate in HIV Prevention Research among African-American Men Who Have Sex with Men

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An abstract of
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Abstract

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This study surveyed 42 Black/African-American men from the Atlanta metropolitan area who self identified as having sex with other men. The objectives of this study were to assess black men who have sex with men (MSM) attitudes, concerns, and beliefs regarding HIV prevention research; to evaluate the relationship between black MSM's beliefs and their likelihood to participate in medical research studies; and to investigate upstream indirect reciprocity as a motivation for black MSM participation in medical research.

This study found that upstream indirect reciprocity, a component of the Theory of Human Cooperation, accounted for black MSM's likelihood to participate in medical research studies at Emory University. However, black MSM's concerns regarding benefits and cost to them were most indicative of their likelihood to participate in medical research regardless of the study institution.

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CHAPTER I: INTRODUCTION

HIV is a global human tragedy.[1] Since its identification in 1981, over 30 million people worldwide have died of HIV-related causes.[2] Today, the disease is estimated to affect 34 million men, women, and children worldwide.[3] In the United States, over 1.2 million people ages 15 and older are currently living with HIV.[4] Nearly 76% of all HIV positive Americans are men.[5] Among these men, African American/black men bear the greatest burden of disease. According to the Centers for Disease Control and Prevention (CDC), [5] in 2009, black men represented 70% of all new HIV cases in the US. Compared to other males, HIV incidence for black men was nearly seven times that of white men and more than two and a half times that of Latino men. Several factors have contributed to the HIV disparity among black men, including their socioeconomic status, participation in risky sexual behaviors, and choice of sexual partners.[5]

Being a black man who has sex with other men (hereafter, referred to as black MSM) carries the greatest risk of contracting HIV. According to the CDC, blacks tend to maintain sexual relationships with other blacks.[5] Given the high prevalence of HIV among all black men, black MSM who have sex with other black MSM significantly increase their risk of contracting HIV compared to heterosexual black men. In fact, for every one heterosexual black man becoming infected with HIV, there were nearly 5 black MSM who became infected with the disease in 2009.[6] Furthermore, black MSM who maintain interracial relationships do not decrease their risk of contracting HIV. One in every 5 MSM regardless of ethnicity is infected with HIV, according to a recent CDC report.[7] Consequently, black MSM are becoming infected with HIV more each year. New HIV infections in black MSM have increased by 48% between 2006 and 2009, while HIV infection rates in heterosexual black men have remained near

constant.[5,6] Due to these differences, black MSM have been recognized in the field of HIV prevention research as a unique subpopulation.

For decades, HIV prevention research has strived to understand the social, economic, and cultural components that contribute to the high incidence of HIV in black MSM and to employ intervention strategies/programs to combat risky behaviors in this subpopulation. In the past decade, HIV prevention studies have successfully reduced risky behaviors such as promiscuity, unprotected anal intercourse, and irregular usage of condoms in black MSM participants.[8-10] In most of these studies, participants also increased the frequency at which they received HIV screenings.[9] Yet, today nearly 1 in 2 Americans who become HIV positive are black MSM.[5] This phenomenon is possible because HIV prevention studies struggle to intervene and educate entire communities about HIV-related preventions.

In order to implement successful HIV prevention studies at the community level to combat HIV disparities in black MSM communities, several obstacles must be overcome. An HIV prevention study's protocol must be duplicated in multiple groups or populations. Training materials, program materials, budgets, etc. must all be comparable to the original study. This requirement in itself is a barrier.[11,12] Not all institutions receive equal funding or have equal staffing. Therefore, maintaining the fidelity of an HIV prevention study's core elements can prove difficult.[8] Furthermore, because HIV prevention studies use strict criteria and artificial conditions, these studies often do not always fit into daily life. This limits researchers' ability to duplication the study at a community level as a sustainable HIV prevention program. One potential pathway towards a solution is to assess which specific culturally tailored components in successful HIV prevention studies are the active ingredients underlying behavior changes in

black MSM.[13] This task is easier stated than done, because black MSM have proven difficult to recruit to HIV prevention research.

Two themes appeared in the literature pertaining to barriers to black MSM recruitment. First, not all black MSM identify as such. These men are often referred to as "being on the down-low" or as "homo thugs".[12] Past studies have found that some black MSM hide their sexual orientation and behaviors because they have experienced prejudice in the LGBT and/or black communities.[12,14] Other non-identifying black MSM experience internalized homophobia and refuse to participate publicly in activities associated with HIV. In many black communities, HIV remains negatively linked with being homosexual.[15-17] Secondly, as part of the black community, black MSM also experience distrust in research institutions and hold many conspiracy beliefs regarding HIV. For example, in 2007, a tri-city study[18] conducted by researchers in Detroit, Oakland, and Baltimore reported black MSM (n=244) were more likely than white and Latino MSM to believe that pharmaceutical companies are hiding an established cure for HIV/AIDS because of profits; that HIV drugs do more harm than good; that HIV does not cause AIDS; and that HIV is a man-made virus.

Significance of Problem

There is a growing need to increase black MSM participation in HIV prevention research.[12,13,19] One reason is to ensure the conclusions drawn about black MSM culture are generalizable to all black MSM, regardless of socio-demographic status. Another reason is to ensure that new HIV prevention technologies will be effective across all subpopulations and not exacerbate health disparities.[20] Since the 1990s, researchers and the US government have worked

to find a solution to the low number of ethnic minority participation in research. In 1993, the US government signed the National Institute of Health (NIH) legislation termed *The NIH Revitalization Act of 1993, PL 103-43,*[21] a policy that established guidelines for the inclusion of women and minorities in clinical trials. Concurrently, researchers investigated the effects of the Tuskegee syphilis trials, beliefs of conspiracy in the black community, and efforts to alleviate such distrust in the African American community.[20,22-25] Unfortunately, HIV prevention studies continue to face significant problems with rates of African American participation.[26]

Black MSM participation in HIV prevention research has been narrowly studied. While rare, HIV-related studies involving primarily black MSM have focused heavily on black MSM attitudes about HIV clinical trials. Such studies have been duplicated since 1994 and continue to yield little, if any, new information. For example, a 2006 tri-city study[14] found that black MSM were more likely than white and other ethnic MSM to distrust researchers and experience internalized homophobia. This information already existed and was cited in the field by Douglas, Judson et al[27] and Hays and Kegeles,[28] among many others. Review of the literature also revealed that researchers concentrate heavily on attitudes and beliefs about Tuskegee and/or conspiracy beliefs. This study aimed to address the gap in knowledge regarding black MSM likelihood to participate in HIV prevention research.

Research Objectives

The objectives of this study were to assess black men who have sex with men (MSM) attitudes, concerns, and beliefs regarding HIV prevention research; to evaluate the relationship between black MSM's beliefs and their likelihood to participate in medical research studies; and

to investigate upstream indirect reciprocity as a motivation for black MSM participation in medical research.

Hypotheses

This study will test the following hypotheses:

Ho_1: Black MSM's attitude, motivation to comply, and perceived benefits are associated with their likelihood to participate in a medical research study.

Ho_2: Black MSM's perceived norms and subjective norms are not associated with their likelihood to participate in a medical research study despite these measurements being informed by the TRA.

Ho_3: Persons who strongly agreed with the following measurements will rank their likelihood to participate between the values of 8 and 10:

- Attitude
- Perceived Benefits

And persons who strongly disagreed with the following measurement will rank their likelihood to participate between the values of 8 and 10:

- Motivation to Comply

Ho_4: Persons who strongly agreed with the following measurements will not exclusively rank their likelihood to participate between the values of 8 and 10:

- Perceived Norms
- Subjective Norms

CHAPTER II: THEORY

Effective quantitative research in the field of HIV prevention research is driven by theory-based investigations. This study aimed to investigate the relationship between black MSM attitudes, social norms, and likelihood of black MSM to participate in HIV prevention research. This study employed two theories to address its objective. The Theory of Reasoned Action informed this study's hypotheses. Upstream indirect reciprocity, a component of the Theory of Human Cooperation, was applied to the data to investigate whether black MSM participation in HIV prevention research is motivated by altruism.

Theory of Reasoned Action

Icek Ajzen once stated that people consider the implications of their actions before they decide whether or not to engage in a given behavior.[29] People contemplate their personal attitude and concerns and consider family and friends' attitudes about a behavior (known as subjective norms) before making a decision to participate. Ajzen and Martin Fishbein tested these assumptions throughout the 1970s and created the Theory of Reasoned Action (TRA) based on their findings.[29,30] According to the TRA, the strengths of a person's attitude and subjective norms towards a particular behavior influence a person's intentions to engage in that behavior. Whether a person actually takes action depends upon his intentions, because behavioral intentions precede the actual behavior.

As depicted in Figure 1, a person's attitude reflects his/her beliefs that a given behavior will lead to certain outcomes and a person's evaluation of that outcome.[29] If a person believes his engagement in a behavior will lead to mostly positive outcomes, he will have a more favorable

attitude about that behavior. And if a person believes his/her engagement in a behavior will lead to mostly negative outcomes, he will have a less favorable attitude about that behavior.

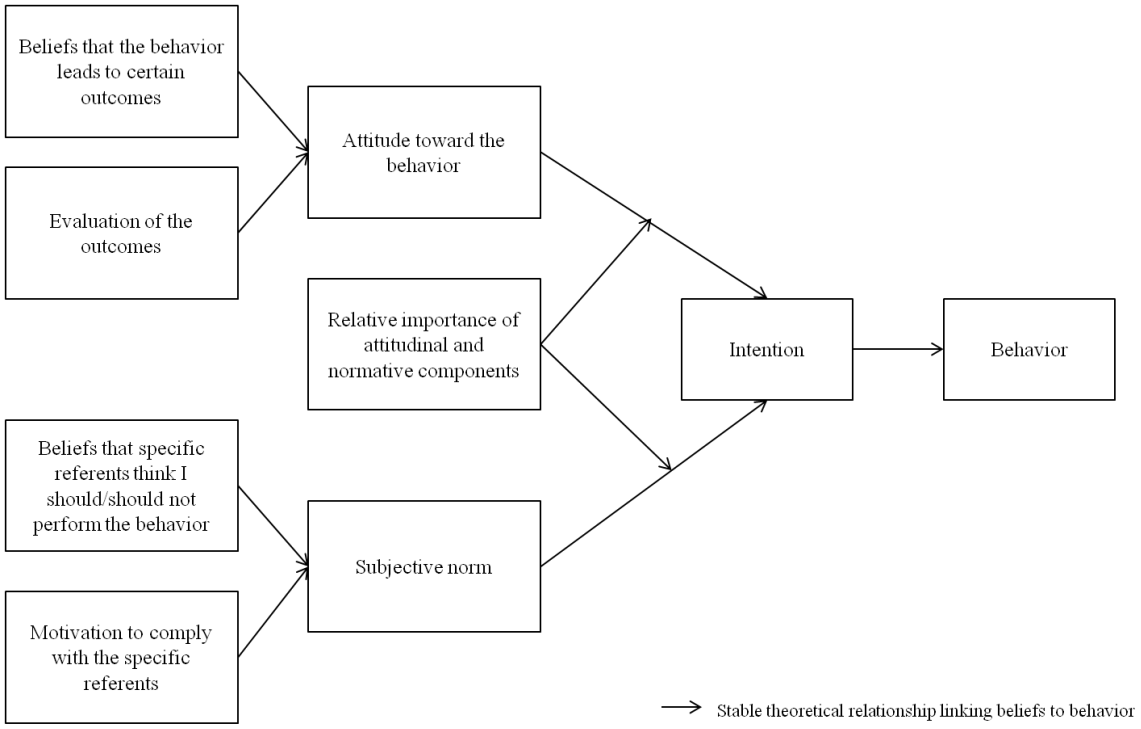


Figure 1. Illustration of how the components of the Theory of Reasoned Action lead to behavioral outcomes**.**[29]

Subjective norms reflect a person's perception of how his community will view him if he engages in a given behavior.[30] In laymen terms, subjective norms are peer pressures at the society level. A person's perception of social pressure depends on two factors. The first factor is a person's belief that a specific referent thinks he should or should not perform the behavior. In questionnaires, this referent is usually mentioned as "most people who are important to me". A person's motivation to comply reflects how easily a person's behavior can be influenced by the referent(s). Together, these factors influence the strength of subjective norms.

A person's attitude and subjective norms towards a behavior can complement or compete with one another. If a person's attitude and subjective norms are both unfavorable towards a behavior, a person's intentions to partake in that behavior will be unlikely. And if both of these variables are favorable towards a behavior, a person's intentions to engage in that behavior will be likely. However, if a person's attitude and subjective norms are in conflict, a person's intention to partake in a behavior depends on the strength of these two variables. For example, if a person has a favorable attitude about a behavior and subjective norms are unfavorable towards that behavior, a person's intentions will reflect what is more important in his decision making process: his own opinion or the referent's opinion.

Since its inception in 1980, the TRA was found to be a viable tool in measuring behavior intentions and predicting behavior.[31-33] Furthermore, TRA has been extensively used to evaluate changes in behavior and to inform behavioral intervention strategies in many fields, including marketing, social sciences, and HIV prevention research. This study integrates the TRA by using its principles to assess the relationship between participants' attitudes, beliefs and concerns about HIV prevention research and their likelihood to participate in HIV prevention studies. The concept of behavioral intentions was operationalized by asking respondent's about their likelihood to participate in HIV prevention research.

Upstream Indirect Reciprocity

According to evolutionary biologists, human societies represent a spectacular outlier with respect to all other animal species because they are based on large-scale cooperation among genetically unrelated individuals.[34,35] We humans undertake behaviors endorsed by social norms

that might not benefit ourselves or our blood relatives directly. (**Note**: Social norms in this context share the definition of subjective norms as defined in the TRA.[34,36]) A real life example is the act of paying federal taxes in the United States. Intuitively, not all acts of human cooperation are purely voluntary. In many cases there are social penalties and/or consequences for not conforming to social norms. But what explains why humans participate in behaviors that benefit others at a cost to themselves? One answer to this question is upstream indirect reciprocity.

A person who has had a recent positive experience may feel motivated to help another individual indirectly through his own behaviors.[37] This model is called upstream indirect reciprocity and is depicted below in Figure 2. An example of upstream reciprocity is a person donating to a charity that has helped him in his past. The premise of upstream indirect reciprocity is that a person will engage in a behavior that benefits a group of others at a cost to him because of a sense of altruism.[37,38]

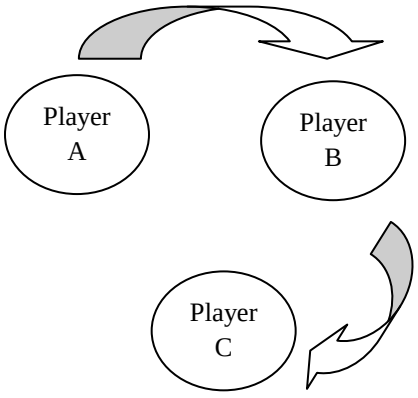


Figure 2. Upstream Indirect Reciprocity: Player A first helps player B who then helps player C. Player A was motivated to help player B due to recent positive experiences related to player B. Player B can represent an individual or an institution. Player C can represent an individual or group of individuals.

Indirect reciprocity and its role in the evolution of human cooperative behavior have been extensively investigated.[35,37-39] Investigations supporting indirect reciprocity, however, pertain mostly to economics, political science, and nonhuman models (i.e. chimpanzees, prairie dogs, etc.). At this time, extensive review of the literature has found that this study is the first to investigate upstream indirect reciprocity as a motivation for black MSM participation in HIV prevention research.

CHAPTER III: METHOD

Primary Study Design

"There's Hope in Our Soul" (HIOS) is a pilot study conducted by the Emory Hope Clinic. The purpose of the study was to test a 4-hour clinical trial education seminar that was culturally tailored to black/African-American. The purpose of this approach was to increase participation of blacks in HIV biomedical clinical trials at Emory University. HIOS collected data on participants' beliefs, attitudes, and perceptions about HIV prevention research using a 105-item questionnaire. Other variables measured by the questionnaire included the influence of social networks on black/African-American clinical trial participation and participants' experiences with stigma and discrimination. HIOS is a 1-year study that began in May of 2011. Participants completed a questionnaire at the time of enrollment and were retested after the intervention (if applicable), 3-months post-enrollment, and 6-months post-enrollment.

Recruitment

HIOS is a cluster randomized controlled trial that utilized a sampling frame of all faith-based organizations in the Atlanta metropolitan area (22 counties). Eligible churches were those with a congregation membership ≥60% black/African-American; had not previously hosted an HIOS colloquium; and were located within one of the metropolitan Atlanta counties. Convenience sampling of a minimum of 35 eligible participants at each eligible church was conducted. Individual eligibility criteria required participants to be aged 18 years or older; to live in one of the 22 counties comprising metropolitan Atlanta; to not plan to move outside the Atlanta area during the next 12 months; to not having previous participatory experience with

HIOS programs; to have no previous trial volunteer experience in a clinical trial; to attend or obtain services from one of the participating faith venues; and to be able to read and write English. Six churches were recruited to the study, and 208 persons were enrolled.

Thesis Study Design

This thesis study is a subset data analysis of the HIOS pilot study. It is a quantitative observational study that utilized cross-sectional design. This study collected questionnaires completed at the time of enrollment and 3-months post-enrollment by HIOS participants who met the thesis study participant inclusion criteria. This study examined the relationship among participants' attitudes, concerns, and beliefs regarding HIV prevention research as informed by the Theory of Reasoned Action. The outcome variable was defined by two model questions that indicated a participant's likelihood to participate in a medical study in the next 6 months.

Thesis Participant Inclusion Criteria

Participants must have been individuals 18 years or older who self-identified as being black/African-American men who were either homosexual, bi-sexual, or transgendered male to female. They must have been members of a faith-based organization participating in the HIOS study, residents in the metropolitan Atlanta area, and intend to remain a resident for the next twelve months.

Procedure

Questionnaires were collected for black men enrolled in HIOS matching the thesis inclusion criterion. This study operated under the guidelines and approval of the Emory University Internal Review Board.

Questionnaire

The HIOS questionnaire consisted of 105 items. These items collected information regarding participants' socio-demographic status, attitude and subjective norms regarding HIV prevention research, and participants' perceived norms, motivation to comply, and perceived benefits of HIV prevention research. Thirty-seven items were adopted from the Clinical Research Involvement Scales[40] to evaluate all of the above measures, excluding socio-demographic status. Participants self-reported their responses using pen-and-pencil.

Measurements informed by TRA

SOCIO-DEMOGRAPHICS. Participants were asked to report their date of birth, sexual orientation, highest achieved educational level, annual income, and zip code. Sexual orientation was assessed using the question, "Do you consider yourself: straight (heterosexual), bisexual, gay (homosexual)/queer, or don't know/questioning."

ATTITUDE. Questionnaire items worded to evaluate participant's attitude regarding HIV prevention research was assessed using a 5-point Likert scale, where 1 = strongly agree, 2 =

agree, 3 = neutral/no opinion, 4 = disagree, and 5 = strongly disagree. A sample item is "I have enough time to be in an HIV prevention study."

SUBJECTIVE NORMS. Questionnaire items worded to evaluate participants' perception of community attitude about their involvement in HIV prevention research were responded to using the above 5-point Likert scale. A sample item is "I think my doctor would approve of my involvement in HIV prevention research."

PERCEIVED NORMS. Questionnaire items worded to evaluate the perceived attitudes of most people important to the participant regarding HIV prevention research were responded to using the above 5-point Likert scale. A sample item is "Most people important to me think my involvement in HIV prevention research is good."

MOTIVATION TO COMPLY. Questionnaire items worded to evaluate participant's likelihood to conform to social/peer pressure were responded to using the above 5-point Likert scale. A sample item is "I generally do what my family expects of me."

BENEFITS. Questionnaire items worded to evaluate participants' perception of the benefits/outcomes related to HIV prevention research were responded to using the above 5-point Likert scale. A sample item is "I would benefit from the medical care associated with an HIV prevention study."

Measurements informed by Upstream Indirect Reciprocity

COST TO SELF. Questionnaire items worded in a way that the respondent was to participate in HIV prevention research at a given cost to him were responded to using the above

5-point Likert scale. A sample item is "Having to give blood for the research study would not stop me from joining as a volunteer."

BENEFITS TO OTHER PLAYERS. Questionnaire items worded in a way that the respondent's behavior benefited someone else, his community, or society were responded to using the above 5-point Likert scale. A sample item is "My involvement in this program will improve my community's trust in medical research."

Outcome Variable

LIKELIHOOD TO PARTICIPATE**.** Two items evaluated participants' likelihood to participate in HIV prevention research. Item 1, referred to as 'model 1', asked participants about their likelihood of contacting Emory University about joining a medical research study in the next 6 months. Item 2, referred to as 'model 2', asked participants about their likelihood of joining a medical research study in the next 6 months. Participants were asked to rank their likelihood for each item on a scale of 1 (definitely not) to 10 (definitely so).

Data Analysis

SPSS version 19 software was used to conduct all data analysis unless otherwise stated. Descriptive characteristics were first calculated for socio-demographic items and items adopted from the Clinical Research Involvement Scales. To address the study hypotheses, exploratory factor analysis was conducted to reduce the Clinical Research Involvement Scales into five factors/subscales that reflected the measurements informed by TRA. Because several response

items were significantly skewed, principal axis factoring was employed as the extraction method.[41] Varimax rotation method was used because it was expected that the subscales were not correlated. Items achieving a loading factor greater than 0.45 after rotation and exhibiting no cross loading were included in a given subscale.

The reliability of each subscale was measured by Cronbach's alpha. Subscales with great reliability (i.e. $\alpha > 0.700$) were retained for correlation analysis. Bivariate correlation analysis was used to evaluate the relationship between each subscale and the two models measuring likelihood to participate in HIV prevention research. Bivariate correlation analysis was also conducted using selected socio-demographic items.

Lastly, participants who responded least favorable to the motivation to comply subscale and most favorable to the remaining subscales were filtered out from the sample using Microsoft® Access software. The responses "strongly agree" and "strongly disagree" were considered to be most favorable and least favorable responses, respectively. The relationship between having a most/least favorable response to a given subscale and the outcome variable was assessed by determining the mean, mode, and range of response choices to the outcome variable for these groups.

Related to Upstream Indirect Reciprocity

To address the study aim of investigating upstream indirect reciprocity as a potential explanation for the likelihood of black MSM to participate in HIV prevention research, items were selected from the questionnaire according to the descriptions for the measurements "cost to self" and "benefits to other players". Exploratory factor analysis and reliability testing as

described above was conducted to reduce these items into a subscale for each measurement. Bivariate correlation analysis was then conducted to evaluate the relationship between cost to self, benefits to other players, and the two models measuring the likelihood of black MSM to participate in HIV prevention research. A schematic of the data analysis procedure related to upstream indirect reciprocity can be found in the Appendix.

CHAPTER IV: RESULTS

Sample Characteristics

Table 1 shows the socio-demographic and network characteristics of the sample. Forty-two male participants matched the thesis inclusion criterion. The mean age was 42.1 years. Thirty-six respondents (85.7%) self identified as being homosexual. The remaining men self identified as being bi-sexual. The majority of respondents held a higher education degree (65.9%) and was employed (63.4%). Over half of the respondents (53%) knew of someone who had participated in a clinical trial. And nearly all respondents (97.6%) knew of someone who was HIV positive.

Table 1. Sample Characteristics (n = 42)

Variable	Level	n (%)
Sexual orientation	bi-sexual	6 (14)
	homosexual	36 (86)
Education level*	≤ high school	14 (34)
	≥ vocational or associates	27 (66)
Employment status*	employed	26 (63)
	unemployed	15 (37)
Income level	< $20,000	15 (36)
	> $20,000	27 (64)
Knowledge of someone who has participated in a clinical trial**	yes	20 (53)
	no	17 (45)
Knowledge of someone who is HIV positive*	yes	40 (98)
	no	1 (2)

* n = 41; participant elected to not respond to question
** n = 38; participants elected to not respond to question

TRA informed Measurement Characteristics

Table 2 shows the subscales resulting from the exploratory factor analysis. The 37 items adopted from the Clinical Research Involvement Scales were reduced to five subscales that

measure motivation to comply, attitude, perceived norms, subjective norms, and perceived benefits related to HIV prevention research. Each subscale exhibited great reliability ($\alpha > 0.700$) and contained items that loaded greater than 0.450 after rotation. It was important for each subscale to have loading factors greater than 0.450 and no items that crossloaded into other subscales, because this ensured that each subscale had the cleanest structure and would exhibit validity despite the small sample size.[41]

Table 2. Descriptive statistics for subscales, subscale items, factor loading, and alpha reliability for HIV prevention study enrollment (n = 42)

Subscales	Mean*	SD	Min.	Max.	Factor Loading
Motivation to Comply (α = 0.878)					
1. I generally do what my family expects of me.	3.25	1.410	1	5	0.961
2. I would not want to do something my friend disapproved of.	3.38	1.353	1	5	0.784
Attitude (α = 0.888)					
1. I benefit from health science research.	1.41	0.631	1	3	0.641
2. I would join a HIV prevention research study because it would help to prevent AIDS.	1.39 1.41	0.666 0.631	1 1	3 3	0.788 0.938
3. I think being in an HIV prevention research study would be worth the time and trouble involved.	1.76	1.044	1	5	0.784
4. I have enough time to be in an HIV prevention study.					
Perceived norms (α = 0.846)					
1. Most people important to me think my involvement in HIV prevention research is good.	1.69 1.95	0.924 0.936	1 1	5 4	0.527 0.778
2. Most people who are important to me think I should participate in the HIV prevention effort.	1.55 1.48	0.670 0.634	1 1	3 3	0.645 0.637
3. Most people who are important to me would approve of my involvement in this cause.					
4. Most people who are important to me would support my interest in this cause.					
Subjective Norms (α = 0.796)					
1. I think my doctor would approve of my involvement in HIV prevention research.	1.67 1.87	0.869 0.833	1 1	4 3	0.793 0.682
2. I think my work colleagues would approve of my involvement in this cause.	1.77	0.810	1	3	0.665
3. My immediate family would be supportive of my involvement in HIV prevention research.					
Benefits (α = 0.745)					
1. I would benefit from the medical care associated with an HIV prevention study.	1.38 1.48	0.586 0.784	1 1	3 4	0.893 0.628
2. My involvement in this program will improve my community's trust in medical research.	1.93	1.328	1	5	0.651
3. Having to give blood for the research study would not stop me from joining as a volunteer.					

*Scale 1=strongly agree, 2 = agree, 3 = neutral/no opinion, 4 = disagree, 5 = strongly disagree

The majority of respondents disagreed with items measuring motivation to comply, suggesting that these respondents are less likely to act according to peer pressure. Forty-five percent of respondents disagreed that they generally do what their family expects of them, and 48% of respondents disagreed that they would not want to do something their friends disapproved of. As shown in Table 3, over 75% of respondents hold positive attitudes regarding

HIV prevention research. In general, over 65% of respondents strongly agreed/agreed that most people important to them held positive attitudes about their participation in HIV prevention research and would offer the respondent support (see Perceived norms and Subjective norms in Table 3). Furthermore, the majority of respondents believed that positive outcomes would result from their participation in HIV prevention research. Ninety-five percent of respondents strongly agreed/agreed that they would benefit from the medical care associated with HIV prevention studies. Eighty-eight percent believed their involvement in HIV prevention studies would improve their community's trust in medical research.

Table 3. Descriptive statistics for items measured by subscales (n=42)

Subscale	Strongly Agree/Agree n (%)	No Opinion n (%)	Strongly Disagree/Disagree n (%)
Motivation to Comply			
1. I generally do what my family expects of me.	14 (35)	8 (20)	18 (45)
2. I would not want to do something my friend disapproved of.	10 (24)	12 (28)	20 (48)
Attitude			
1. I benefit from health science research.	39 (93)	3 (7)	0 (0)
2. I would join a HIV prevention research study because it would help to prevent AIDS.	37 (90)	4 (10)	0 (0)
	38 (93)	3 (7)	0 (0)
3. I think being in an HIV prevention research study would be worth the time and trouble involved.	32 (78)	6 (15)	3 (7)
4. I have enough time to be in an HIV prevention study.			
Perceived norms			
1. Most people important to me think my involvement in HIV prevention research is good.	34 (81)	7 (17)	1 (2)
	27 (65)	14 (33)	1 (2)
2. Most people who are important to me think I should participate in the HIV prevention effort.	38 (90)	4 (10)	0 (0)
	39 (93)	3 (7)	0 (0)
3. Most people who are important to me would approve of my involvement in this cause.			
4. Most people who are important to me would support my interest in this cause.			
Subjective Norms			
1. I think my doctor would approve of my involvement in HIV prevention research.	34 (81)	7 (17)	1 (2)
	29 (73)	11 (27)	0 (0)
2. I think my work colleagues would approve of my involvement in this cause.	22 (71)	9 (29)	0 (0)
3. My immediate family would be supportive of my involvement in HIV prevention research.			
Benefits			
1. I would benefit from the medical care associated with an HIV prevention study.	39 (95)	2 (5)	0 (0)
	37 (88)	4 (10)	1 (2)
2. My involvement in this program will improve my community's trust in medical research.	31 (78)	3 (7)	6 (15)
3. Having to give blood for the research study would not stop			

Outcome Variable Characteristics

Likelihood to participate was measured by two model questions. The first model assessed participants' likelihood to contact Emory to participate in a medical study in the next 6 months. The second model assessed participants' likelihood to join a medical study in the next 6 months. Responses to both models were normally distributed, with means (SD) of 6.57 (2.54) and 6.98

(2.41), respectively. Ranking of 1 meant respondents' were definitely not likely to participate and ranking of 10 meant respondents' were definitely likely to participate.

For model one, 19% of respondents ranked their likelihood of contacting Emory to participate in a medical study in the next 6 months between 1 and 4, 38% of respondents ranked their likelihood between 5 and 7, and 43% of respondents ranked likelihood between 8 and 10. For model two, 12% of respondents ranked their likelihood of joining a medical study in the next 6 months between 1 and 4; 36% of respondents ranked their likelihood between 5 and 7, and 52% of respondents ranked their likelihood between 8 and 10.

Predictors of Likelihood to Participate

Bivariate correlations were used to measure the relationship between select socio-demographic characteristics, measurement characteristics provided by the subscales, and models 1 and 2.

Model 1 – Likelihood to Contact Emory

Bivariate correlation analysis revealed no relation between age, highest level of education achieve, or annual income and either model. For model one, age, education and annual income held significance levels greater than 0.15 and Pearson r of -0.074, -0.101, and -0.220, respectively. Attitude (Pearson $r = -0.456$, $p < .0.01$) and benefits (Pearson $r = -0.356$, $p < 0.05$) were moderately correlated to the outcome variable. As shown in Table 4, no significant relationship was found between model one and the remaining measurements.

Table 4. Bivariate Correlation Analysis Results for Subscales and Models 1 and 2 (n=42)

	Model 1[†]		**Model 2**[‡]	
Subscale	Pearson r	Significance (2-tailed)	Pearson r	Significance (2-tailed)
Motivation to Comply I generally do what my family expects of me. I would not want to do something my friend disapproved of.	-0.108	0.506	-0.014	0.930
Attitude I benefit from health science research. I would join a HIV prevention research study because it would help to prevent AIDS. I think being in an HIV prevention research study would be worth the time and trouble involved. I have enough time to be in an HIV prevention study.	-0.456**	0.003	-0.375*	0.016
Perceived norms Most people important to me think my involvement in HIV prevention research is good. Most people who are important to me think I should participate in the HIV prevention effort. Most people who are important to me would approve of my involvement in this cause. Most people who are important to me would support my interest in this cause.	-0.301	0.053	-0.267	0.087
Subjective Norms I think my doctor would approve of my involvement in HIV prevention research. I think my work colleagues would approve of my involvement in this cause. My immediate family would be supportive of my involvement in HIV prevention research.	-0.288	0.075	-0.225	0.169
Benefits I would benefit from the medical care associated with an HIV prevention study. My involvement in this program will improve my community's trust in medical research. Having to give blood for the research study would not stop me from joining as a volunteer.	-0.356*	0.024	-0.309	0.053

†Rank your likelihood of contacting Emory about being in a medical research study in the next 6 months on a scale of 1 (definitely not) to 10 (definitely so).
‡Rank your likelihood of joining a medical research study within the next 6 months on a scale of 1 (definitely not) to 10 (definitely so).
*P < 0.05
**P < 0.01

Model 2 – Likelihood to Join a Medical Study

For model two, age, education and annual income held significance levels greater than 0.500 and Person r of 0.047, -0.077, and -0.103, respectively. As shown in Table 4, attitudes (Pearson r = -0.375, $p < 0.05$) were correlated to the outcome variable. The remaining subscale measurements were not significantly correlated to model 2.

Predictability of Measurements

Responses to model 1 and model 2 were categorized into three brackets. Response values ≤4 were considered indicative of respondents being less likely to participate. Response values between 5 and 7 were considered indicative of respondents being neither likely nor unlikely to participate. And response values ≥8 were considered indicative of respondents being more likely to participate. These brackets were chosen based on the normalcy of the sample responses as a whole.

Table 5 shows the responses to model 1 and model 2 for participants who strongly agreed with subscales for attitude, perceived norms, subjective norms and benefits of HIV prevention research and who strongly disagreed with the motivation to comply subscale. Despite sharing the same beliefs, concerns, and attitudes about HIV prevention research, respondents differed in their likelihood to participate in an HIV prevention medical study. In general, respondents ranked their likelihood to participate between scores of 6 and 8. However, most respondents were most likely to participate in model 1 and model 2 behaviors (mode = 10) if they strongly agreed with the subscales for attitude, perceived norms, subjective norms, and benefits of HIV

prevention research. Most respondents were only more likely to participate in model 2 behavior (mode =10) if they strongly disagreed with the subscale for motivation to comply.

Table 5. Responses to model 1 and model 2 for participants who strongly agreed with subscales for attitude, perceived norms, subjective norms, and benefits and who strongly disagreed with the motivation to comply subscale.

	Model 1†				Model 2‡			
Subscales	**Mean**	**Mode**	**Min.**	**Max.**	**Mean**	**Mode**	**Min.**	**Max.**
Motivation to Comply (n =9)	6.778	5	3	10	7.556	10	3	10
Attitudes (n = 19)	7.526	10	1	10	7.789	10	1	10
Perceived Norms (n = 15)	7.533	10	1	10	7.867	10	1	10
Subjective Norms (n = 12)	7.667	8	5	10	8.000	8	5	10
Benefits (n = 18)	7.722	10	2	10	8.000	10	5	10

†Rank your likelihood of contacting Emory about being in a medical research study in the next 6 months on a scale of 1 (definitely not) to 10 (definitely so).
‡Rank your likelihood of joining a medical research study within the next 6 months on a scale of 1 (definitely not) to 10 (definitely so).

Relationship between Upstream Indirect Reciprocity and Outcome Variable

Measurement Characteristics

Table 6 shows the subscales resulting from the exploratory factor analysis. The 37 items adopted from the Clinical Research Involvement Scales were reduced to two subscales that measure the cost to an individual and the benefits to others regarding HIV prevention research participation. Each subscale exhibited great reliability ($\alpha > 0.700$) and contained items that loaded greater than 0.450 after rotation.

Table 6. Descriptive statistics for subscales, subscale items, factor loading, and alpha reliability for HIV prevention study enrollment (n = 42)

Subscales	Mean*	SD	Min.	Max.	Factor Loading
Cost to self (α = 0.802)					
1. I think being in an HIV prevention research study would be worth the time and trouble involved.	1.41	0.631	1	3	0.895
2. I have enough time to be in an HIV prevention study.	1.76	1.044	1	5	0.856
3. Being in an HIV prevention study does not seem risky.	1.95	1.071	1	5	0.508
Benefits to other players (α = 0.820)					
1. My involvement in this program will improve my community's trust in medical research.	1.45	0.772	1	4	0.860
2. I would join an HIV prevention research study because it would help to prevent AIDS.	1.39	0.666	1	3	0.788

*Scale 1=strongly agree, 2 = agree, 3 = neutral/no opinion, 4 = disagree, 5 = strongly disagree

Upstream Indirect Reciprocity and Outcome Variable

Bivariate correlations were used to measure the relationship between measurement characteristics provided by the subscales informed by upstream indirect reciprocity and models 1 and 2. Cost to self (Pearson r = -0.486, $p < 0.01$) and benefits to other players (Pearson r = -0.355, $p < 0.05$) were correlated to model 1. As shown in Table 7, only cost to self (Pearson r = -0.397, $p < 0.05$) was correlated to model 2.

Table 7. Bivariate Correlation Analysis Results for Subscales and Models 1 and 2 (n=42)

	Model 1†		Model 2‡	
Subscales	Pearson r	Sig. (2-tailed)	Pearson r	Sig. (2-tailed)
Cost to self I think being in an HIV prevention research study would be worth the time and trouble involved. I have enough time to be in an HIV prevention study. Being in an HIV prevention study does not seem risky.	-0.486**	0.001	-0.397*	0.011
Benefits to other players My involvement in this program will improve my community's trust in medical research. I would join an HIV prevention research study because it would help to prevent AIDS.	-0.355*	0.027	-0.301	0.062

†Rank your likelihood of contacting Emory about being in a medical research study in the next 6 months on a scale of 1 (definitely not) to 10 (definitely so).
‡Rank your likelihood of joining a medical research study within the next 6 months on a scale of 1 (definitely not) to 10 (definitely so).
*P < 0.05
**P < 0.01

CHAPTER V: DISCUSSION

The likelihood of black MSM to participate in HIV vaccine clinical trials has been evaluated since the early 1990s. Concurrently, researchers have strived to identify social barriers and facilitators to black MSM participation in HIV intervention studies. However, there is a gap in the field of HIV prevention research, which encompasses HIV vaccine clinical trials and intervention studies. Extensive review of published literature suggest this study to be among the first to generally evaluate the relationship between black MSM attitudes, beliefs, and concerns about HIV prevention research and their likelihood to participate in this research. This study found that black MSM's personal attitudes and concerns regarding HIV prevention research's benefits and cost to themselves are most indicative of black MSM's likelihood to participate in medical research.

This study found respondents' attitudes towards HIV prevention research to be moderately associated with black MSM likelihood to contact Emory University about joining a medical study in the next 6 months (model 1) and with black MSM likelihood to join a medical study in the next 6 months (model 2). Respondents' perceived benefits of HIV prevention research was moderately associated with model 1. Respondents' motivation to comply, perceived norms, and subjective norms were not associated with either model. These findings refuted hypothesis I – attitude, motivation to comply, and perceived benefits are associated with the outcome variable – and supported hypothesis II – perceived norms and subjective norms are not associated with the outcome variable.

It was suspected that perceived norms and subjective norms would not be correlated with the outcome variable despite being informed by the TRA due to certain findings in the literature.

According to Lula Beatty et al,[12] a degree of cultural diversity exists within the black community. There are several different normative beliefs regarding HIV prevention messages.[12] Consequently, there must be several different subjective norms. Furthermore, it is well documented that black MSM struggle with conflicting normative beliefs because of their racial and sexual identities.[12,15,17]

To further assess what factors influence black MSM participation in HIV prevention research, this study investigated whether strong responses to subscales informed by the TRA could predict respondents' likelihood to participate. Hypothesis III – a predictable relationship exists between attitude, motivation to comply, perceived benefits, and the outcome variable – was refuted by the findings, and hypothesis IV – no predictable relationship exists between perceived norms, subjective norms, and the outcome variable – was supported by the findings. Respondents' who shared the same beliefs (i.e. strongly agreed with items measuring attitude and benefits of HIV prevention research, perceived norms, and subjective norms and strongly disagreed with items measuring motivation to comply) did not all rank their likelihood to participate between values 8 and 10. Values of 8, 9, or 10 were considered representative of a respondent being most likely to participate.

It is important to note the majority of respondents who shared the same beliefs were most likely (mode=8 or 10) to engage in model 2's behavior. Excluding beliefs regarding motivation to comply, the majority of respondents who shared the remaining beliefs were most likely (mode=8 or 10) to engage in model 1's behavior. Nonetheless, participants who strongly agreed with items measuring attitude, perceived benefits, perceived norms, and subjective norms and who strongly disagreed with items measuring motivation to comply were only slightly more likely (mean values ranged from 6.778 to 8.000) to engage in either model's behavior. This

suggests that black MSM likelihood to participate in HIV prevention research cannot be increased by changing their attitudes, beliefs, and concerns about HIV prevention research. However, this study is a quantitative observational study; this causal relationship cannot be supported by the data.

This study also investigated upstream indirect reciprocity as a potential motivation for the likelihood of black MSM to participate in HIV prevention research. This research approach is novel. Indirect reciprocity involves two variables: the cost to the actor and the benefits to other players. The premise of upstream indirect reciprocity is that an actor (player A) will help another individual/institution (player B) at a cost to himself in order to allow this player to help someone else (player C) because player A is altruistic. This study found that both cost to self and benefits to other players were moderately to strongly associated (Pearson $r > -0.333$, $p < 0.05$) with model 1's behavior. Only cost to self was significantly associated with model 2's behavior. One implication of these findings is that upstream indirect reciprocity can explain why individuals cooperate with certain institutions' research efforts. More investigations with larger sample populations are needed to further explore the validity of this finding.

Strengths and Limitations

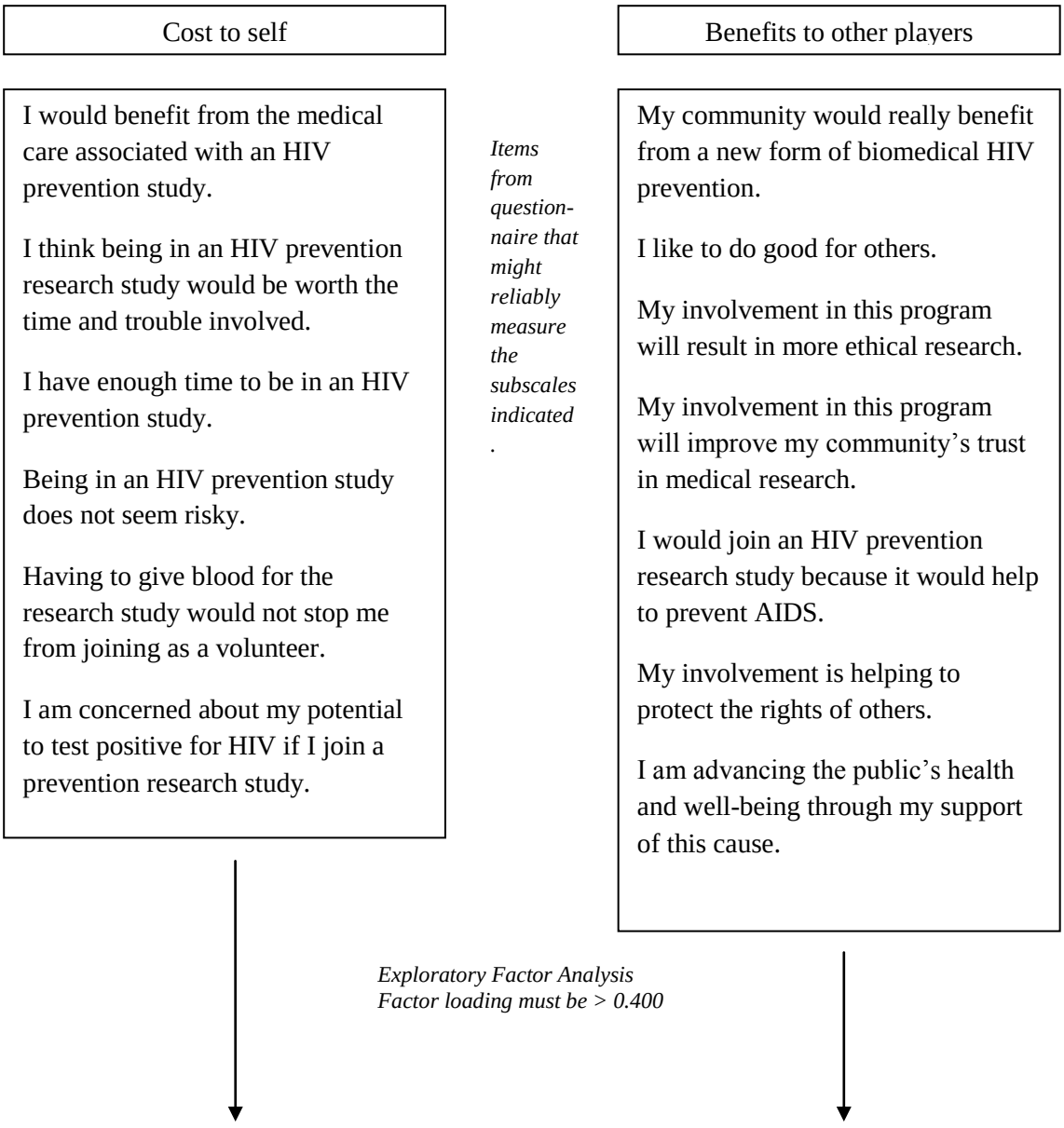
A strength of this study was the use of two models to evaluate the outcome variable. Superficially, these two models measure the same outcome. However, a key implication of using both models is that a respondent's likelihood to participate in HIV prevention research can be measured independently of their trust of the institution surveying them. The incorporation of the Theory of Reasoned Action into the methodology is also a strength of this study. By employing a

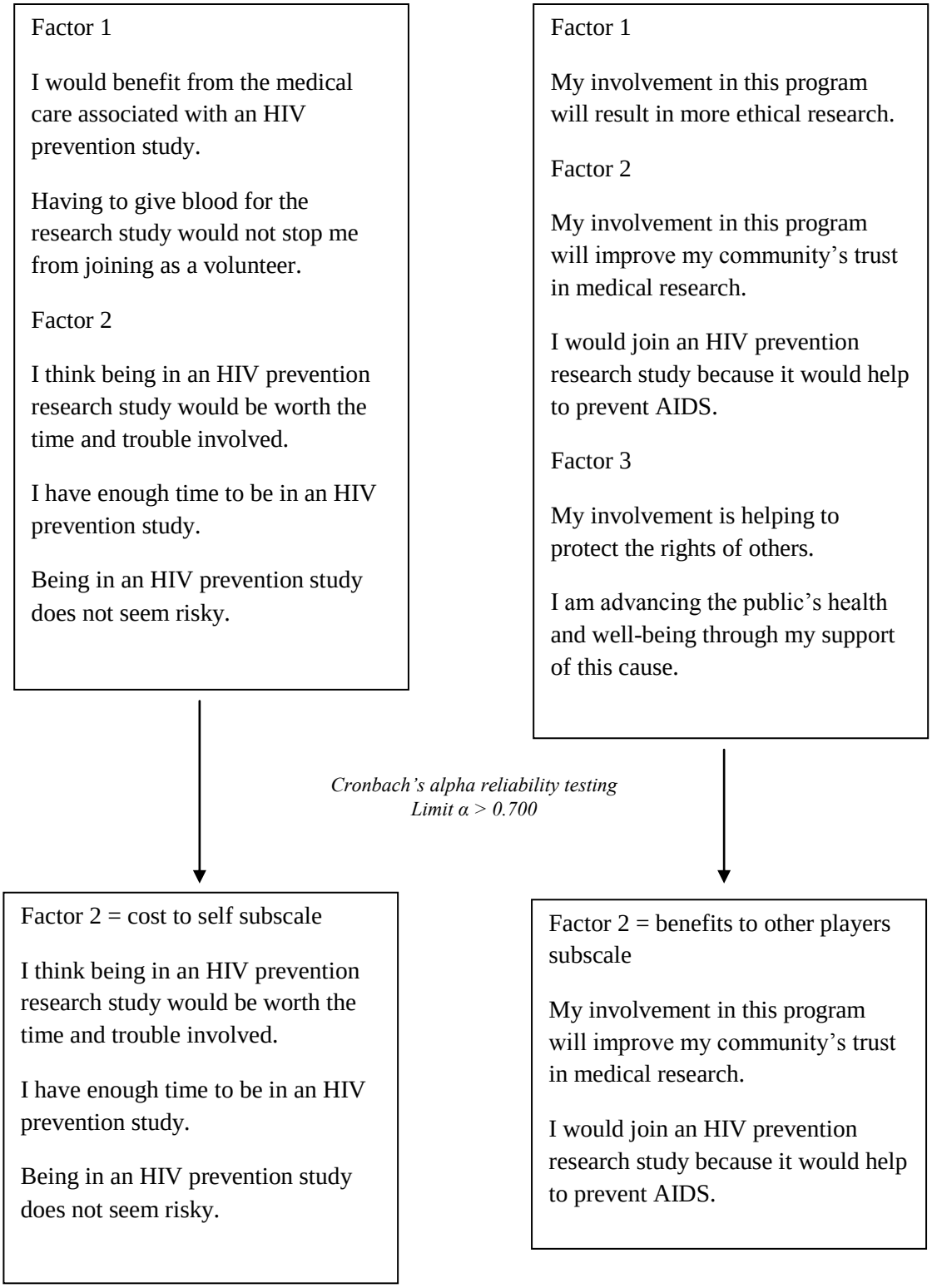
well-supported theory, this study was able to infer causal relationships between the independent and dependent variables in a reliable manner, and is better able to be duplicated.

There are several limitations to this study. One of the main limitations was sample size. Because the sample was composed of less than 100 participants, the causal relationships established by this study should be cautiously considered. The sample is not representative of the general black MSM population due to the recruitment method. Also, participants were recruited to this study via self-referral. This limitation makes the study susceptible to selection bias. Another limitation to this study was the questionnaire used to survey black MSM attitudes, concerns, and beliefs. The questionnaire was not exhaustive of all the attitudes, beliefs, and concerns a member of the black MSM community could have regarding HIV prevention research. Therefore, the content validity for the subscales informed by the TRA need to be evaluated in future studies.

APPENDIX I: SCHEMATIC OF EXPLORATORY FACTOR ANALYSIS

For upstream indirect reciprocity:




Factor 1
I would benefit from the medical care associated with an HIV prevention study.
Having to give blood for the research study would not stop me from joining as a volunteer.
Factor 2
I think being in an HIV prevention research study would be worth the time and trouble involved.
I have enough time to be in an HIV prevention study.
Being in an HIV prevention study does not seem risky.
Factor 1
My involvement in this program will result in more ethical research.
Factor 2
My involvement in this program will improve my community's trust in medical research.
I would join an HIV prevention research study because it would help to prevent AIDS.
Factor 3
My involvement is helping to protect the rights of others.
I am advancing the public's health and well-being through my support of this cause.
Cronbach's alpha reliability testing
Limit α > 0.700
Factor 2 = cost to self subscale
I think being in an HIV prevention research study would be worth the time and trouble involved.
I have enough time to be in an HIV prevention study.
Being in an HIV prevention study does not seem risky.
Factor 2 = benefits to other players subscale
My involvement in this program will improve my community's trust in medical research.
I would join an HIV prevention research study because it would help to prevent AIDS.

APPENDIX II: HIOS ENROLLMENT SURVEY

ID#_____A
Example: CL1971

An Assessment of Community Attitudes, Beliefs, and Perceptions toward Medical Research

Thank you for taking the time to complete this survey. It should take no more than 20 minutes to complete this 104-item questionnaire. Your participation is completely voluntary. You may choose not to participate or not to answer any specific question. You may skip any question you do not wish to answer.

The purpose of this study is to learn about your attitudes regarding participating in clinical trials. This information will help us to improve community education programs and health communication strategies created for different populations. All of the information that you share with us and the material that we use to capture the information will only be accessible to the members of our research team. There is no right or wrong answer. Please answer each question as honest as possible. All answers are kept strictly confidential.

This survey is being used to better understand community attitudes, beliefs, and perceptions toward medical research, biomedical HIV prevention, and other new medical technologies to develop communication approaches. The survey is being conducted by Dr. Paula Frew of the Hope Clinic of the Emory Vaccine Center, 603 Church St. Decatur, GA, 30030.

If you still have questions or concern about your rights as a participant in this survey, you may contact the Chair of the Institutional Review Board of Emory University, who oversees the protection of human research participants. An IRB officer may be reached at (404) 712-0720.

Thank you for taking the time to complete this survey.
We appreciate your participation!

Please fill in the blank space or check the box next to the response that best expresses your assessment of the items below.

A. Demographics and Community Affiliations:

A1. What is your gender?

[ ] Male
[ ] Female
[ ] Transgender
    [ ] Male → Female
    [ ] Female → Male

A2. What is your date of birth? ____/____/_____
mm/ dd/ yyyy

A3. How old are you? _____years old

A4. What is the highest level of school that you have completed?

[ ] K-8 grade
    [ ] 9-11 grade
[ ] High school graduate/ GED
    [ ] Technical/ Vocational or Associates
    [ ] Bachelor degree
    [ ] Master's degree
    [ ] Doctorate

A5. How would you describe your race?

[ ] African American/ Black
[ ] Caucasian/ White
[ ] Asian/ Asian American/ Pacific Islander
    [ ] Native American/ American Indian/ Alaskan Native
    [ ] Multiracial/ multicultural

A6. How would you describe your ethnic background?

[ ] Hispanic/ Latino/ Chicano
[ ] non-Hispanic

A7. Do you consider yourself:

[ ] Straight (Heterosexual)
    [ ] Bisexual
    [ ] Gay (Homosexual)/Queer
    [ ] Don't Know/Questioning

A8. What is your relationship status?

[ ] Single/Never Married
[ ] Married/ Domestic Partner
[ ] Divorced/ Separated
[ ] Widowed
[ ] Other (specify)_____

A9. Which of the following best describes your current employment status?

[ ] Employed—full time
[ ] Employed—Part-time
[ ] Unemployed
[ ] Other (specify) _____

A10. What is your annual household income (i.e., combined income of all members of your family)?

[ ] Less than $20,000
[ ] $20,001-$40,000
[ ] $40,001-$60,000
[ ] $60,001-$80,000
[ ] $80,001-$100,000
[ ] More than $100,001

A11. Where do you primarily receive healthcare? *(select only one)*

[ ] Healthcare provider office
[ ] Community clinic or health center
[ ] Hospital
[ ] Prison clinic
[ ] Other (specify) _____

A12. What is your home zip code? _____

B. Event Details/Site Perceptions:

B1. How far did you travel to this location?

[ ] Less than 5 miles
[ ] 6-9 miles
[ ] 10-20 miles
[ ] More than 20 miles

B2. In the past year, have you: *(select all that apply)*

[ ] Given blood
[ ] Signed an organ donation card or donated an organ
[ ] Given bone marrow
[ ] Given sperm or eggs
[ ] Donated your body to science
[ ] Given money to a healthcare cause
[ ] Been in a health research study

B3. In the past year, about how many times have you been treated for an illness or condition by a healthcare provider?

[ ] 0 times
[ ] 1-4 times
[ ] 5-9 times
[ ] 10 times or more

B4. Do you have access to transportation to get to a healthcare provider, clinic, or hospital?

[ ] Always
[ ] Most of the time
[ ] Sometimes
[ ] Not often
[ ] Never

B5. Do you know where to go to be seen by a doctor, nurse, or other healthcare provider if you are sick?

[ ] Always
[ ] Most of the time
[ ] Sometimes
[ ] Not often
[ ] Never

B6. Do you have a regular doctor?

[ ] Yes
[ ] No, *skip to question B13*

B7. Do you trust your doctor?

[ ] Yes
[ ] No
[ ] Don't know/Not sure

B8. Has your doctor ever recommended that you join in a clinical trial?

[ ] Yes
[ ] No
[ ] Don't know/Not sure

B9. Do you know anyone who has been in a clinical trial?

[ ] Yes
[ ] No
[ ] Don't know/Not sure

B10. Do you know anyone infected with HIV?

[ ] Yes
[ ] No, *skip to question B20*
[ ] Don't know/Not sure

B11. How many HIV+ persons do you know? _____

B12. What is your relationship to the HIV+ persons you know? *Check all that apply*

[ ] Relative
    [ ] Friend
    [ ] Co-worker
[ ] Spouse/partner
    [ ] Other, please specify _____

B13. Have you seen/heard any advertisements for medical research studies at the following places?

	Yes	No	Don't know/Not sure
Television	[ ]	[ ]	[ ]
Online	[ ]	[ ]	[ ]
Radio	[ ]	[ ]	[ ]

B14. Are you more likely to join a medical research study after seeing the any of these ads?

[ ] Yes, if so which one(s):
    [ ] Television
    [ ] Online
    [ ] Radio
[ ] No
[ ] Don't know/Not sure

B15. Would you be more likely to join a medical research study if a health care provider recommended it?

[ ] Yes
[ ] No
[ ] Don't know/Not sure

B16. Do you think many of your friends would join a medical research study?

[ ] Yes
[ ] No
[ ] Don't know/Not sure

B17. In the past 12 months, was there a time when you didn't meet basic expenses such as food, clothing, or shelter?

[ ] Yes
[ ] No
[ ] Don't know/Not sure

B18. In the past 12 months, was there a time when you didn't pay full gas, electricity or oil?

[ ] Yes
[ ] No
[ ] Don't know/Not sure

B19. In the past 12 months, was there a time when you had your home or cellular phone service suspended?

[ ] Yes
[ ] No
[ ] Don't know/Not sure

B20. In the past 12 months, was there a time when you couldn't afford to pay for daycare or babysitting?

[ ] Yes
[ ] No
[ ] Not applicable/No kids
[ ] Don't know/Not sure

B21. In the past 12 months, was there a time when you couldn't afford leisure activities such as seeing movies or going out to dinner?

[ ] Yes
[ ] No
[ ] Don't know/Not sure

B22. Do you get services, goods, or any support from any community organizations? If so, which ones?

_____

B23. Are you involved in any activities or programs with any community organizations? If so, which ones?

_____

B24. On a scale from 1 (definitely not) to 10 (definitely so), rank your likelihood of *contacting* Emory about being in a medical research study in the next 6 months:

1 2 3 4 5 6 7 8 9 10

B25. On a scale from 0 (definitely not) to 10 (definitely so), rank your likelihood of *joining* a medical research study within the next 6 months:

1 2 3 4 5 6 7 8 9 10

C. Attitudes about HIV Prevention Research

Please place an x in the appropriate box for each question, to indicate how much you agree with each statement (1 = 'Strongly Agree,' 5 = 'Strongly Disagree')

	1 Strongly Agree	**2** Agree	**3** Neutral/No Opinion	**4** Disagree	**5** Strongly Disagree
My community would really benefit from a new form of biomedical HIV prevention (e.g., vaccine, microbicide, PrEP).					
I like getting involved with HIV prevention research.					
My actions can inspire other to act.					
My participation in an HIV prevention study would be very good.					

	1 Strongly Agree	**2** Agree	**3** Neutral/No Opinion	**4** Disagree	**5** Strongly Disagree
I like to do good for others.					
My involvement in this program will result in more ethical research.					
My involvement in this program will improve my community's trust in medical research.					
I believe that HIV testing is a benefit of an HIV prevention studies.					
I benefit from health science research.					
I would benefit from the medical care associated with an HIV prevention study.					
HIV is a serious concern in my immediate community.					
I would join an HIV prevention research study because it would help to prevent AIDS.					
I think being in an HIV prevention research study would be worth the time and trouble involved.					
I have enough time to be in an HIV prevention study.					
Being in an HIV prevention study does not seem risky.					
Having to give blood for the research study would not stop me from joining as a volunteer.					
I am concerned about my potential to test positive for HIV if I join a prevention research study.					

D. Clinical Study Participation

How likely are the following factors to influence your decision to participate in a medical research study or clinical trial?

	Very Likely	**Somewhat Likely**	**Not Likely at All**
Caring provider/study staff			
A welcome feeling at study site			
Immediate answers to your questions			
Discussion about the background of the study, including information and results from prior studies			
Positive experiences from other studies			
A specific interest by the staff in the you			
A convenient location for the study site			
Appropriate money for time and travel to do study visits			
The wish to be a change agent in my community			
A track record of success with previous clinical studies at the study site			

E. Community Perceptions of HIV Vaccine Research Involvement

Please place an x in the appropriate box for each question, to indicate how much you agree with each statement (1 = 'Strongly Agree,' 5 = 'Strongly Disagree')

	1 Strongly Agree	**2** Agree	**3** Neutral/No Opinion	**4** Disagree	**5** Strongly Disagree
I think my doctor would approve of my involvement in HIV prevention research.					
I think my work colleagues would approve of my involvement in this cause.					
I tend to be concerned about what people think of me, even if I don't know them.					
I generally do what my family expects of me.					
I would not want to do something my friends disapproved of.					
My immediate family would be supportive of my involvement in HIV prevention research.					
If my superiors told me to do something I disagreed with, I would obey their wishes.					
Sometimes I do what my friends say to do, even though I know they are wrong.					
Most people important to me think my involvement in HIV prevention research is good.					
Most people important to me usually support my interests.					
If my pastor supported HIV prevention research, I would be inclined to get involved.					

Most people who are important to me think I should participate in the HIV prevention effort.					
Most people who are important to me would approve of my involvement in this cause.					
Most people who are important to me would support my interest in this cause.					

F. Stigma
Please rate the following situations on level of embarrassment

	Not Embarrassing	**Somewhat Embarrassing**	**Very Embarrassing**
Getting examined for Sexually Transmitted Diseases (STDs)			
Using condoms			
Asking a partner to use condoms			
Getting an HIV test			
Asking a partner to get an HIV test			
Refusing a sexual partner's request for unprotected sex			
Not being able to please your partner sexually			

G. Discrimination

In your lifetime, how often have you experienced racial discrimination in the following situations?

	Never	**Once**	**More than Once**	**Not Applicable**
At school				
Applying for a job				
At work				
In a store, restaurant, or other public place				
Getting medical care				
From the police or in the courts				
Volunteering for a medical research study				
Interacting with medical research study staff				
At a college or university				
At church or a faith organization				
At a community-based organization				

H. Discrimination & Coping

When you have experienced racial discrimination, how often did you respond in any of the following ways?

	Never	**Sometimes**	**Often**	**Very Often**
Talk to other people about it				
Keep it to yourself				

I. Volunteer Affiliations

Please place an x in the appropriate box for each question, to indicate how much you agree with each statement (1 = 'Strongly Agree,' 5 = 'Strongly Disagree')

	1 Strongly Agree	**2** Agree	**3** Neutral/No Opinion	**4** Disagree	**5** Strongly Disagree
I experience a sense of community in this cause.					
I feel a sense of belonging through my participation in this effort.					
My involvement is helping to protect the rights of others.					
I am advancing the public's health and well-being through my support of this cause.					
Getting involved in the HIV prevention effort is liberating.					
I feel a sense of purpose in this cause.					

Optional Question: If you are willing to provide your contact information for future participation in a survey study, please fill in the following:

Name: _____

Address: _____

City: _____

Zip Code: _____

Phone Number: _____

THANK YOU
for your valuable feedback!

REFERENCES

1. *The demographic impact of HIV/AIDS: Report on the technical meeting*: United Nations; 10 November 1998 1998.

2. Global HIV/AIDS Response. *Epidemic Update and Health Sector Progress Towards Universal Access Progress Report* 2011; www.who.int/hiv/pub/progress_report2011/hiv_full_report_2011.pdf. Accessed 21 February, 2012.

3. Global HIV/AIDS Response. *Epidemic update and health sector progress towards universal access* 2011; who.int/hiv/pub/progress_report2011/hiv_full_report_2011.pdf.

4. HIV and AIDS Estimates - United States of America. 2009; unaids.org/en/regionscountries/unitedstatesofamerican. Accessed 28 February 2012.

5. HIV among African Americans. 2012; www.cdc.gov/hiv/topics/aa/index.htm. Accessed 28 February, 2012.

6. HIV in the United States. 2012; http://www.cdc.gov/hiv/resources/factsheets/us.htm. Accessed 28 February, 2012.

7. HIV among Gay, Bisexual, and Other Men Who Have Sex With Men. 2010; http://www.cdc.gov/hiv/topics/msm/index.htm.

8. Jones KT, Gray P, Whiteside YO, et al. Evaluation of an HIV prevention intervention adapted for Black men who have sex with men. *Am J Public Health.* Jun 2008;98(6):1043-1050.

9. Johnson WD, Hedges LV, Ramirez G, et al. HIV prevention research for men who have sex with men: a systematic review and meta-analysis. *J Acquir Immune Defic Syndr.* Jul 1 2002;30 Suppl 1:S118-129.

10. Johnson WD, Holtgrave DR, McClellan WM, Flanders WD, Hill AN, Goodman M. HIV intervention research for men who have sex with men: a 7-year update. *AIDS Educ Prev.* Dec 2005;17(6):568-589.

11. Elford J, Hart G. If HIV prevention works, why are rates of high-risk sexual behavior increasing among MSM? *AIDS Educ Prev.* Aug 2003;15(4):294-308.

12. Beatty LA, Wheeler D, Gaiter J. HIV Prevention Research for African Americans: Current and Future Directions. *Journal of Black Psychology.* 2004;30(1):40-58.

13. Darbes L, Crepaz N, Lyles C, Kennedy G, Rutherford G. The efficacy of behavioral interventions in reducing HIV risk behaviors and incident sexually transmitted diseases in heterosexual African Americans. *AIDS.* Jun 19 2008;22(10):1177-1194.

14. Silvestre AJ, Hylton JB, Johnson LM, et al. Recruiting minority men who have sex with men for HIV research: results from a 4-city campaign. *Am J Public Health.* Jun 2006;96(6):1020-1027.

15. Fullilove M, Fullilove RE. Stigma as an obstacle to AIDS action: the case of the African American community. *American Behavioral Scientist.* 1999;42(7):1117-1129.

16. Jeffries WL, Dodge B, Sandfort TG. Religion and spirituality among bisexual Black men in the USA. *Cult Health Sex.* Jun 2008;10(5):463-477.

17. Derose K, Mendel P, Palar K, et al. Religious Congregations¸Äô Involvement in HIV: A Case Study Approach. *AIDS and Behavior.* 2011;15(6):1220-1232.

18. Hutchinson AB, Begley EB, Sullivan P, Clark HA, Boyett BC, Kellerman SE. Conspiracy beliefs and trust in information about HIV/AIDS among minority men who have sex with men. *J Acquir Immune Defic Syndr.* Aug 15 2007;45(5):603-605.

19. Millett GA, Flores SA, Peterson JL, Bakeman R. Explaining disparities in HIV infection among black and white men who have sex with men: a meta-analysis of HIV risk behaviors. *AIDS.* Oct 1 2007;21(15):2083-2091.

20. Yancey AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of minority research participants. *Annual review of public health.* 2006;27:1-28.

21. NIH Revitilzation Act of 1993. In: Health NIo, ed. Vol Public Law 103-43. United States: United States Department of Health and Human Services; 1993.

22. Bogart LM, Bird ST. Exploring the relationship of conspiracy beliefs about HIV/AIDS to sexual behaviors and attitudes among African-American adults. *J Natl Med Assoc.* Nov 2003;95(11):1057-1065.

23. Bogart LM, Thorburn S. Are HIV/AIDS conspiracy beliefs a barrier to HIV prevention among African Americans? *J Acquir Immune Defic Syndr.* Feb 1 2005;38(2):213-218.

24. Gamble VN. Under the shadow of Tuskegee: African Americans and health care. *Am J Public Health.* Nov 1997;87(11):1773-1778.

25. Thomas SB, Quinn SC. The burdens of race and history on Black Americans' attitudes toward needle exchange policy to prevent HIV disease. *Journal of public health policy.* Autumn 1993;14(3):320-347.

26. Adams-Campbell LL, Ahaghotu C, Gaskins M, et al. Enrollment of African Americans onto clinical treatment trials: study design barriers. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology.* Feb 15 2004;22(4):730-734.

27. Douglas JM, Jr., Judson FN, Parks JP, Buchbinder S, McKirnan D. Participation of homosexual/bisexual men in preventive HIV vaccine trials: baseline attitudes and concerns and predicted behaviors during trials. *AIDS Res Hum Retroviruses.* 1994;10 Suppl 2:S257-260.

28. Hays RB, Kegeles SM. Factors related to the willingness of young gay men to participate in preventive HIV vaccine trials. *J Acquir Immune Defic Syndr Hum Retrovirol.* Feb 1 1999;20(2):164-171.

29. Ajzen I, Fishbein M. *Understanding Attitudes and Predicting Social Behavior*. Englewood Cliffs: Prentice-Hall, Inc.; 1980.

30. Madden T, Scholder Ellen P, Ajzen I. A Comparison of the Theory of Planned Behavior and the Theory of Reasoned Action. *Personality and Social Psychology Bulletin.* 1992;18(3):3-9.

31. Sheppard BH, Hartwick J, Warshaw PR. The Theory of Reasoned Action: A Meta-Analysis of Past Research with Recommendations for Modifications and Future Research. *Journal of Consumer Research.* 1988;15(3):325-343.

32. Greene K, Hale JI, Rubin DI. A Test of the Theory of Reasoned Action in the Context of Condom Use and AIDS. *Communication Reports.* 1997;10(1):21-33.

33. Fishbein M. A reasoned action approach to health promotion. *Med Decis Making.* Nov-Dec 2008;28(6):834-844.

34. Fehr E, Fischbacher U. Social norms and human cooperation. *Trends Cogn Sci.* Apr 2004;8(4):185-190.

35. Henrich J, Bowles S, Richerson PJ, Weissing F. The cultural and genetic evolution of human cooperation. In: Hammerstein P, ed. *Genetic and Cultural Evolution of Cooperation*. Cambridge: MIT Press; 2002:445-468.

36. Horne C. Sociological perspectives on the emergence of norms. In: Hechter M, Opp KD, eds. *Social Norms*: Russell Sage Foundation; 2001:3-34.

37. Nowak MA, Highfield R. *SuperCooperators : altruism, evolution, and why we need each other to succeed*. 1st Free Press hardcover ed. New York: Free Press; 2011.

38. Nowak MA. Five rules for the evolution of cooperation. *Science.* Dec 8 2006;314(5805):1560-1563.

39. Nowak MA, Sigmund K. Evolution of indirect reciprocity. *Nature.* Oct 27 2005;437(7063):1291-1298.

40. Frew PM, Hou SI, Davis M, et al. The likelihood of participation in clinical trials can be measured: the Clinical Research Involvement Scales. *J Clin Epidemiol.* Oct 2010;63(10):1110-1117.

41. Costello AB, Osborne JW. Best Practices in Exploratory Factor Analysis: Four Recommendations for Getting the Most From Your Analysis. *Practical Assessment, Research & Evaluation.* 2005;10(7). http://pareonline.net/getvn.asp?v=10&n=7. Accessed 15 February 2012.