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## HIV-related Mistrust and Willingness to Use PrEP Among Black Women in the United States

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### Abstract

Uptake of pre-exposure prophylaxis (PrEP) among Black women living in the US is suboptimal. We sought to determine the association between HIV conspiracy beliefs (HIV-related medical mistrust) and willingness to use PrEP among Black women. We analyzed data from the 2016 National Survey on HIV in the Black Community (NSHBC), a nationally representative cross-sectional survey. Among NSHBC participants, 522 were women and 347 (66.5%) reported expanded PrEP indications. Only 14.1% were aware that PrEP exists; 30.8% reported willingness to use PrEP. HIV-related medical mistrust was reported by 60.4% of women. In multivariable analysis, controlling for income, education, marital status and health care engagement, belief in conspiracy theories was significantly associated with higher willingness to use PrEP. The conspiracy scale item: “there is a cure for HIV, but the government is withholding it from the poor” was independently associated with PrEP willingness. This finding speaks to the need for an improved understanding of the role of HIV-related medical mistrust among Black women to improve uptake of biomedical HIV prevention.

### Keywords

HIV and women; women and pre-exposure prophylaxis; mistrust and PrEP; HIV conspiracy theories; HIV-related medical mistrust and PrEP; Black women and PrEP; African- American women and PrEP

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CONFLICT(S) OF INTEREST:

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## BACKGROUND

Though new diagnoses among women decreased from 2013 to 2017, Black women in the United States (US) remain at highest risk of HIV infection compared to White or Latinx women. [1,2] Pre-exposure prophylaxis (PrEP) using daily oral tenofovir disoproxil fumarate/emtricitabine (TDF/FTC) is an effective means of decreasing HIV transmission among women. [3,4] However, uptake is suboptimal, particularly among Black women. In an analysis of a prescription database containing all third party payers, including Medicaid, and prescriptions claims paid by medication assistance programs in 2016, among the 1,146 female PrEP users with available race and ethnicity data, 554 (48.3%) were White, 297 (25.9%) were Black, and 201 (17.5%) were Latinx. [5]

Barriers to PrEP use among Black women are multifactorial. Discordance between self-perceived and actual risk hinders PrEP uptake. [6–9] Underestimation of risk by health care providers is also a concern. Current PrEP guidelines emphasize sexual partner characteristics (e.g. injection drug use, HIV status) that may not be disclosed to female partners leading to underestimation of risk.[10,11] Health care providers may also have racial or other biases which lead to assumptions regarding risk compensation and lower willingness to prescribe PrEP. [12] Additionally, many women are not aware that PrEP exists and have questions regarding efficacy and potential side effects. [13,14] Although there are programs to reduce the expense associated with PrEP, concerns about cost remain. [13] Furthermore, lack of access to, and availability of, providers who prescribe PrEP also limits uptake. [15–17]

In addition to these factors, medical mistrust or mistrust of health care providers, health care institutions, and government in relation to health care may impact PrEP uptake. Medical mistrust has been identified as a primary driver of racial and ethnic inequities in health outcomes in the US. [18] As a construct, mistrust is the belief that an individual or entity is acting in opposition to one's best interest or well-being. [19,20] Viewed as such, mistrust is a normative response to an adverse environment or injurious experiences. Among Black individuals, medical mistrust stems from experiences with discrimination in healthcare and is the result of persistent social inequity and structural racism, both contemporary and historical.[21,22] Accordingly, Black individuals have been found to be less trusting of healthcare providers compared to White individuals. [23,24] In regards to PrEP use, several studies have identified medical mistrust as a barrier to uptake. [25,26]

The association of one specific form of mistrust, HIV-related medical mistrust or belief in “HIV conspiracy theories” with PrEP uptake among Black women has not been well-explored. In general, conspiracy theories are defined as beliefs that provide explanations for important events that involve “secret plots by powerful and malevolent groups”. [27] While this definition makes conspiracy theories sound apocryphal, these beliefs are not necessarily false. Identifying true or doubtful causal explanations for events, particularly those that are rooted in social inequity, promotes internal consistency and makes sense of occurrences that are inherently unfair. [28] Conspiracy beliefs regarding HIV are characterized by doubts or distrust surrounding the role of health care providers, the health care system, researchers, and/or government in the origin, prevention, treatment of HIV infection. [29] Examples

include genocidal beliefs, such as HIV is a man-made virus or AIDS was created by the government to control the Black population. [30] These beliefs are common within the Black community and have been associated with suboptimal condom use, decreased uptake of HIV testing and non-adherence to antiretroviral therapy. [31–33] Conversely, HIV-related mistrust has also been associated with increased rates of HIV testing. [34,35] This finding indicates that mistrust towards the health care system is not necessarily undesirable, and HIV-related mistrust may serve as a protective belief that could be harnessed to improve engagement in prevention. [36,37]

Research devoted to understanding the relationship between HIV-related medical mistrust or belief in HIV conspiracy theories and uptake of PrEP may facilitate the development of interventions tailored to meet the unique needs of Black women. This study determines PrEP knowledge and willingness and explores the association between belief in HIV conspiracy theories and willingness to take PrEP among a nationally representative sample of Black women.

## Methods

The National Survey on HIV in the Black Community (NSHBC) was developed by an advisory committee comprised of academic, government, and community leadership, including people living with HIV, to capture factors associated with HIV risk and engagement in prevention. Between February and April 2016 the NSHBC was administered online to a nationally representative sample of Black individuals. [38] Participants were drawn from an online web panel recruited through address- based sampling to include households served by cell phones and without landline telephones. [39] After enrolling with the web panel, households were provided with internet access and a computer, if necessary. Boston Children’s Hospital Institutional Review Board approved all study protocols. Prior to participation written consent was obtained from participants. In total, 1,969 persons were sampled from the web panel; 49% (n = 970) completed the survey and among those, 89% (n = 868) were eligible and 522 women participated. Post-stratification weights were created so that estimates were representative of adults living in households in the US according to benchmarks from the latest March 2016 supplement of the Current Population Survey.

## Measures

**HIV-Related Medical Mistrust or Belief in “HIV Conspiracy Theories”**—Items were selected from a previously developed scale and explored via qualitative, one-on-one interviews with a convenience sample of 30 Black individuals living in the Greater Boston area (ages 18–50) to identify sources of response bias. [38] Four items were included that reflect two domains of HIV-related medical mistrust: *genocidal beliefs* and *medical mistrust*. Medical mistrust items were “There is a cure for HIV, but the government is withholding it from the poor” and “the government usually tells the truth about major health issues, like HIV/AIDS“. Genocidal beliefs were “The medicine that doctors prescribe to treat HIV is poison” and “HIV is a man-made virus.” Respondents reported their agreement on a 5-point scale [1 (strongly agree) to 5 (strongly disagree)]. Responses were re- coded so that a higher score (1–5) indicated a higher level of mistrust (Cronbach alpha 0.79). Trust in health care providers or clinic and quality of care received were also collected.

**HIV Risk**—Studies have suggested that HIV risk among women are often underestimated and that current PrEP guidelines in the US fail to accurately identify women who may be at risk of infection. [11] In order to capture all participants at risk for HIV infection, we used broad criteria to identify women at risk and hereafter identify women “at risk” as women with “expanded PrEP indications”. The expanded PrEP indications used in this study are one or more sexual partners (anal or vaginal) and no condom use in the prior 3 months, and/or sexually transmitted infection (gonorrhea, Chlamydia, herpes, syphilis, Trichomonas, genital warts, human papilloma virus or HPV) in the last three months or lifetime, and/or drug use (cocaine, heroin, or crystal meth) in the last 30 days, and/or any history of transactional sex assessed by asking, “Have you ever had sex with someone in exchange for any of the following items: money, food, clothes, drugs, alcohol, transportation, items for your children, or somewhere to sleep?” or “Have you ever given someone money, food, clothes, drugs, alcohol, transportation, items for their children, or somewhere to sleep in exchange for having sex with you?” or “Have you ever started a new sexual relationship in part because you hoped that your new partner would help you pay for things you couldn’t afford by yourself?”. History of hazardous drinking and alcohol use disorder measured by AUDIT-C which assess daily to monthly alcohol use was added given the association with HIV/STI risk. [40,41]

**PrEP Willingness**—Respondents were asked to respond yes/no or maybe to the following questions to, “If a pill that could prevent transmission of HIV from an infected (HIV positive) sex partner to an uninfected (HIV negative) partner were available I would take it.” “No” and “Maybe” responses were collapsed into one response versus “Yes”. If “No”, then respondents were asked “Why would you NOT want to take the pill?” Potential responses included the following: (1) I’m not at risk of HIV infection; (2) I would not want to pay for it; (3) I would be afraid that someone would find out that I was taking it; (4) I’m afraid of potential side effects (5) I don’t like taking pills daily (6) I don’t believe it would actually work.

Respondents could choose all responses that applied. Awareness of PrEP was also assessed by asking participants to respond true/false and don’t know to, “There is a medication that you can get from your doctor that can be taken daily to prevent transmission of HIV from an infected (HIV positive) sex partner to an uninfected (HIV negative) sex partner.”

**Sociodemographic Factors**—Age, income, education, employment, ethnicity, nativity (US versus non-US born), marital status, region of residence, and arrest history were collected given their association with HIV risk. [42,43]

**Data Analysis**—Descriptive statistics were generated, including sociodemographic variables of interest, HIV risk variables, and HIV-related mistrust variables. Post-stratification weighted bivariate analyses between willingness to take PrEP as the dependent variable and potential covariates of interest using simple logistic regression was conducted. Post-stratification weighted multiple logistic regression was used to examine the effect of each covariate on PrEP willingness, adjusting for all other covariates in the models. Two regression models were constructed using covariates that had a statistically significant bivariate association with PrEP willingness ( $p < 0.05$ ). The first model included the HIV-

Related Medical Mistrust Scale in its entirety, and the second included items found to be significantly associated with PrEP willingness. Odds ratios (ORs), adjusted ORs, 95% confidence intervals (CI), and p-values from all models were calculated.

## RESULTS

### Participant Characteristics

Of the 522 women who participated, 347 had expanded PrEP indications. More than half of the women with expanded PrEP indications had one or more sexual partners (anal or vaginal) and no condom use within the last 3 months (78.1%). A lifetime history of STI was reported by 48.9% of women with expanded PrEP indications. Transactional sex was reported by 15.7%. Drug use was reported by 4.7%, and 19.6% reported hazardous alcohol use. The mean age was 33.8 (SD 8.67), 53.4% resided in the South, 31.5% reported unemployment, and 11.4% were non-US born. (Table I)

### PrEP Knowledge and Willingness

No significant difference in PrEP knowledge was noted between women with expanded PrEP indications and women without expanded PrEP indications (14.1% vs 13.3%,  $p=0.8130$ ). Though few women with expanded PrEP indications had ever heard of PrEP, once made aware, 30.8% would be willing to use PrEP. The most commonly reported reason for unwillingness to use PrEP among women with expanded PrEP indications was no self-perceived risk of HIV infection (70.6%). No significant difference in self-perceived risk was noted between women with expanded PrEP indications and those without expanded PrEP indications ( $p=0.1950$ ). The second most reported reason for not taking PrEP was participants' belief that PrEP would not work to prevent HIV transmission (27.9%). Fear regarding potential side effects was reported by 18.8% of women. Women with expanded PrEP indications who were willing to take PrEP were lower income (41.8% vs 29.9%,  $p=0.003$ ) and more frequently reported a history of arrest (33.0% vs 20.5%,  $p=0.0025$ ). No other significant differences in sociodemographic or psychosocial characteristics between women with expanded PrEP indications who were willing to take PrEP and unwilling to take PrEP were noted.

### HIV-related Medical Mistrust or Belief in “HIV Conspiracy Theories”

Mistrust in their doctor or clinic was noted by 79.4% of women with expanded PrEP indications. However, a high HIV-related medical mistrust scale score was noted among 60.4% of women. “There is a cure for HIV but the government is withholding it from the poor” was endorsed by 47.5% of women with expanded PrEP indications. “The medicine that doctors prescribe to treat HIV is poison” was endorsed by 21.3%. Only 17.6% believed that the government usually tells the truth about major health issues, like HIV/AIDS; and 49.7% endorsed that “HIV is a man-made virus.” (Table II) Higher HIV-related medical mistrust scale scores were reported among younger women [beta estimate for age= $-0.0709$  ( $t=-3.49$ ,  $df=516$ ,  $p=0.0005$ )]. No differences were noted in HIV-related medical mistrust by region (South versus all other regions,  $p=0.7951$ ).

## Models: PrEP willingness

**Bivariate Analysis**—Bivariate analysis for all significant variables and the entire and individual HIV Conspiracy Belief Scale items are displayed in Table III. Women with high HIV conspiracy belief scores were more willing to use PrEP [OR 1.09 (95% CI 1.03, 1.16),  $p=0.0033$ ]. Among scale items, “there is a cure for HIV but the government is withholding it from the poor” and “HIV is a man-made virus” were associated with willingness to take PrEP [OR 2.80 (95% CI 1.72, 4.57),  $p<0.0001$ ] and [OR 1.69 (1.05, 2.72),  $p=0.0306$ ], respectively. Lower income [OR 1.89 (95% CI 1.10, 3.23),  $p=0.0204$ ], less well educated [OR 2.22 (95% CI 1.14, 4.29),  $p=0.0183$ ], and unmarried/non-cohabiting women [OR 2.76 (1.65, 4.62),  $p=0.0001$ ] were also more willing to take PrEP. Women who had not seen their doctor for more than one year were significantly less likely to be willing to take PrEP [OR 0.36 (95% CI 0.18, 0.73),  $p=0.0045$ ].

**Multivariable Models**—In Model 1, we included the entire HIV conspiracy belief scale and controlled for income, education, marital status and last seen doctor more than one year ago. Belief in HIV conspiracy theories remained significant [aOR 1.08 (1.01, 1.14),  $p=0.0207$ ], as did marital status and less frequent health care visits. In Model 2, we included the individual HIV conspiracy belief scale items that were significant in bivariate analysis and controlled for the same factors as in Model 1. The scale item: “there is a cure for HIV but the government is withholding it from the poor” remained significant [aOR 2.81 (1.61, 4.90),  $p=0.0003$ ]. Both models demonstrated goodness of fit by the Hosmer-Lemeshow test. Concordance statistics and receiver operator curves also demonstrated good predictive ability. (Table III)

## DISCUSSION

Consistent with the results of other studies, knowledge of and willingness to use PrEP were low among this nationally representative sample of Black women with expanded PrEP indications. [44,45] Belief in HIV conspiracy theories was common. The belief that “there is a cure for HIV but the government is withholding it from the poor” was found to be significantly associated with willingness to use PrEP. This finding speaks to the need for an improved understanding of the role of HIV conspiracy beliefs in uptake of biomedical HIV prevention among Black women.

The finding that belief in HIV conspiracy theories promotes willingness to use PrEP may seem counterintuitive. However, mistrust is not necessarily an inherently undesirable attitude. Mistrust, caution, or skepticism about health care providers, institutions or government may be an act of self- preservation within a society where racist and discriminatory behavior is common. Engaging in self- protection behaviors, such as taking PrEP, is a rational response if one believes that institutions or other individuals exist in opposition to one’s own self-interest. In this regard, use of PrEP or any other preventative medication is an act of empowerment. For example, a Black woman who distrusts the healthcare system may feel empowered to actively seek out a culturally competent provider and may feel more comfortable discussing their sexual health and PrEP with them. Thus, understanding how empowerment can shift perception regarding PrEP among vulnerable, at



risk individuals may be a key determinant in increasing uptake of biomedical HIV prevention. Interventions that focus on empowerment, through cultural or racial pride may work to increase PrEP uptake. Black women, particularly younger women who in this study reported higher HIV-related medical mistrust, could be engaged through initiatives, such as Black Lives Matter, a national movement to increase empowerment and decrease structural violence impacting Black individuals. In addition, community engagement and collaboration with Black women from biomedical intervention discovery to development and dissemination may work to empower women to protect themselves. The data may help to inform public health educational programs that focus on Black women by acknowledging their concerns and framing PrEP as a means of empowerment to protect themselves.

Willingness to use PrEP was low among women with expanded PrEP indications in this study. The most common reason for unwillingness to take PrEP was lack of self-perceived risk. Discordance between self-perceived and actual HIV risk among Black women has been noted in previous studies. [46,47] Further complicating assessment of risk for women and health care providers is the difficulty identifying individual-level behaviors that confer risk in a low-incidence setting such as the US. In the largest longitudinal study designed to understand HIV risk behaviors among U.S. women, no one specific individual-level sexual behavior among participants was predictive of increased HIV risk. [42] However, awareness of male partner's sexual behavior, drug use history and HIV serostatus would improve women's perception of their risk status. [48] Though it should not be assumed that all Black women have male partners who have multiple sexual partners, engage in condomless sex, and/or drug use, acknowledgement of the risk inherent to selecting sexual partners within higher incidence geographic areas would also help to improve women's self-perception of HIV risk.

Several study limitations should be noted. Our survey did not include individuals who were homeless, transiently housed or institutionalized (e.g. incarcerated) because our sample was drawn from a web panel who were either provided with internet access or had internet access prior to joining the panel. Our survey was self-administered and may include social desirability and recall bias. Administration was anonymous and via web portal, therefore bias should be minimized. To minimize recall bias we asked respondents to recall behavior within short windows (e.g. 3 months for sexual behavior, 30 days for drug use). The survey was administered in 2016, perceptions regarding PrEP use among women may have changed. In addition, in order to identify high risk women we used criteria from previously published studies, not the US PrEP guidelines which may miss women who are at high risk of infection. [11].

As the development of biomedical HIV prevention expands, providers, public health practitioners, and researchers must fully understand the drivers of use among Black women who are at highest risk among women in the US. Understanding the complex role played by mistrust and HIV conspiracy beliefs in the decision to use (or not use) biomedical HIV prevention is critical to improving uptake. While understanding the role of mistrust as well as other cultural norms is important, our findings also suggest that health care providers and institutions caring for Black women should proactively work to enhance trust. Beyond the health care system, the root causes of mistrust (e.g. structural and social inequity, racism and

discrimination) must be acknowledged and addressed. Additional studies with a larger sample size and qualitative data collection to identify pervasive cultural norms are needed to further guide this process. Without an improved understanding of the role of HIV-related medical mistrust or “HIV conspiracy beliefs”, PrEP uptake among Black women will continue to be suboptimal and racial and ethnic disparities in HIV incidence among women will likely persist.

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**Table I.**

Characteristics of Women in the National Survey on HIV in the Black Community (NSHBC)

	<b>Total Women (N=522) n (%)<sup>a</sup></b>	<b>Women with Expanded PrEP Indications (n=347) n (%)</b>
<b>Race</b>		
Black/African-American	425 (94.7)	282 (95.0)
Two or more races	76 (5.3)	51 (5.0)
<b>Mean Age (SD)</b>	33.65 (8.7)	33.84 (8.7)
<b>Ethnicity</b>		
Latino	21 (3.4)	14 (4.1)
<b>Region of Origin<sup>1</sup></b>		
Northeast	92 (18.0)	58 (17.2)
Midwest	107 (18.0)	76 (19.5)
South	272 (53.4)	179 (52.3)
West	51 (10.6)	34 (11.0)
<b>Marital Status</b>		
Single	341 (65.3)	196 (57.5)
Married and Cohabiting w/partner	181 (34.7)	151 (42.5)
<b>Education</b>		
Less than high school	39 (10.5)	24 (9.2)
High school diploma or GED	121 (36.8)	76 (36.5)
Some college, college degree or more	362 (52.6)	247 (54.4)
<b>Unemployed</b>	171 (31.5)	104 (28.8)
<b>Household Income</b>		
<\$25,000	205 (26.9)	116 (22.8)
\$25,000 - <\$50,000	134 (29.2)	95 (30.7)
\$50,000	183 (43.9)	136 (46.6)
<b>Non-US born vs. US BORN</b>	58 (11.4)	28 (8.8)
Resided in US ≤ 10 yrs	12 (18.0)	7 (22.5)
Resided in US > 10 yrs	46 (82.0)	21 (77.5)
Immigration status (US citizen)	41 (72.4)	21 (72.7)
<b>Language</b>		
Other than English	96 (17.7)	64 (17.6)
The other language is Spanish	26 (25.5)	19 (29.8)
<b>Ever arrested</b>	104 (19.6)	84 (23.6)
<b>Last seen doctor more than 1 year ago or never</b>	93 (19.14)	58 (20.06)
<b>HIV Testing (Lifetime)</b>	397 (77.9)	300 (86.6)
<b>HIV Testing (Last 12 months)</b>	166 (39.7)	132 (42.5)

**HIV Risk Behavior or Expanded PrEP Indications**

	<b>Total Women</b> (N=522) n (%) <sup>a</sup>	<b>Women with Expanded PrEP</b> <b>Indications</b> (n=347)  n (%)
<b>One or more sexual partner (anal or vaginal) and no condom use (last 3 months)</b>	257 (59.6)	-
<b>One sexual partner (anal or vaginal) and no condom use (last 3 months)</b>	232 (55.3)	-
<b>More than one sexual partner (anal or vaginal) and no condom use (last 3 months)</b>	25 (4.3)	-
<b>History of STD (lifetime)</b>	165 (37.4)	-
<b>History of STD (last three months)</b>	13 (3.0)	-
<b>Drug Use (last 30 days)</b>	18 (3.3)	-
<b>Hazardous Alcohol Use (monthly or greater)</b>	44 (14.5)	-
<b>Any Transactional Sex</b>	50 (10.9)	-
<b>Total</b>	347 (69.0)	-

<sup>a</sup>Counts are unweighted. Percentages are weighted.

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**Table II.**

General and HIV-related Medical Mistrust (Belief in HIV Conspiracy Theories) among Women, NSHBC

	<b>Total Women (N=522) n (%)<sup>a</sup></b>	<b>Women with Expanded PrEP Indications (n=347) n (%)</b>
Trust doctor or clinic (completely or mostly)	418 (82.3)	278 (79.4)
Quality of care received excellent, very good, or good (ref: poor or fair)	380 (88.3)	258 (88.2)
HIV Conspiracy Belief Scale (high score)	306 (57.9)	217 (60.4)
There is a cure for HIV but the government is withholding it from the poor, agree or strongly agree (agree/strongly agree vs. all others)	215 (42.4)	159 (47.5)
The government usually tells the truth about major health issues, like HIV/AIDS, agree or strongly agree (agree/strongly agree vs. all others)	97 (17.5)	66 (17.6)
HIV is a man-made virus. (agree/strongly agree vs. all others)	272 (49.9)	188 (49.7)
The medicine that doctors prescribe to treat HIV is poison. (agree/strongly agree vs. all others)	110 (19.5)	76 (21.3)

<sup>a</sup>Counts are unweighted. Percentages are weighted.

**Table III.** Models for Willingness to Use PrEP Among Women with Expanded PrEP Indications, NSHBC

	Bivariate Analysis			Multivariable Model 1		Multivariable Model 2	
	N	OR (95% CI)	p value	AOR (95% CI)	p value	AOR (95% CI)	p value
Income <25K (ref: 25K)	347	1.89 (1.10, 3.23)	0.0204	1.59 (0.89, 2.85)	0.1177	1.57 (0.86, 2.86)	0.1382
Did not finish college (ref: finished college)	347	2.22 (1.14, 4.29)	0.0183	1.89 (0.94, 3.83)	0.0764	1.90 (0.93, 3.91)	0.0793
Single, Widowed, divorced, separated (ref: married or cohabiting)	347	2.76 (1.65, 4.62)	0.0001	2.40 (1.41, 4.12)	0.0014	2.47 (1.43, 4.25)	0.0012
Last seen doctor more than 1 year ago (ref: 1 year ago or less)	347	0.36 (0.18, 0.73)	0.0045	0.32 (0.15, 0.66)	0.0021	0.28 (0.13, 0.58)	0.0007
<b>HIV-Related Medical Mistrust</b>							
Entire Scale	347	1.09 (1.03, 1.16)	0.0033	1.08 (1.01, 1.14)	0.0207		
<b>Items</b>							
There is a cure for HIV but the government is withholding it from the poor, agree or strongly agree (vs. all others)	346	2.80 (1.72, 4.57)	<0.0001			2.81 (1.61, 4.90)	0.0003
HIV is a man-made virus, agree or strongly agree (vs. all others)	347	1.69 (1.05, 2.72)	0.0306			1.07 (0.62, 1.85)	0.8110
The medicine that doctors prescribe to treat HIV is poison, (agree or strongly agree vs. all others)	346	0.95 (0.54, 1.67)	0.8601				
The government usually tells the truth about major health issues, like HIV/AIDS, agree or strongly agree (vs. all others)	346	1.13 (0.63, 2.01)	0.6857				