# Willingness to participate and take risks in HIV cure research: survey results from 400 people living with HIV in the US

Karine Dubé<sup>1</sup>\*, David Evans<sup>2,3</sup>, Laurie Sylla<sup>4</sup>, Jeff Taylor<sup>5</sup>, Bryan J Weiner<sup>1,6</sup>, Asheley Skinner<sup>1,7</sup>, Harsha Thirumurthy<sup>1</sup>, Joseph D Tucker<sup>8,9</sup>, Stuart Rennie<sup>10</sup> and Sandra B Greene<sup>1</sup>

<sup>1</sup> University of North Carolina Gillings School of Global Public Health, Chapel Hill, NC, USA
<sup>2</sup> Delaney AIDS Research Enterprise (DARE) Community Advisory Board (CAB), Los Angeles, CA, USA
<sup>3</sup> Project Inform, Los Angeles, CA, USA
<sup>4</sup> defeatHIV CAB, Seattle, USA
<sup>5</sup> Collaboratory of AIDS Researchers for Eradication (CARE) CAB, Palm Springs, USA
<sup>6</sup> Department of Global Health, University of Washington, Seattle, WA, USA
<sup>7</sup> Duke Clinical Research Institute (DCRI), Durham, NC, USA
<sup>8</sup> UNC Project China, Guangzhou, China
<sup>9</sup> UNC Institute of Global Health and Infectious Diseases (IGHID), Chapel Hill, NC, USA
<sup>10</sup> Department of Social Medicine, UNC Bioethics Center, Chapel Hill, NC, USA

### Abstract

**Introduction:** Participation in early-phase HIV cure studies includes clinical risks with little to no likelihood of clinical benefit. Examining the willingness of people living with HIV to participate is important to guide study design and informed consent. Our study examined the overall willingness of people living with HIV to participate in HIV cure research in the US, focusing on perceived risks and benefits of participation.

**Methods:** We undertook an online survey of adults living with HIV in the US. Survey questions were developed based on previous research and a scoping review of the literature. We quantitatively assessed individuals' perceived risks and benefits of HIV cure-related research and respondents' willingness to participate in different modalities of HIV cure studies. **Results:** We recruited 409 study participants of whom 400 were eligible for the study and were included in the analysis (nine were not eligible due to self-declared HIV-negative status). We found >50% willingness to participate in 14 different types of HIV cure studies. Perceived clinical benefits and social benefits were important motivators, while personal clinical risks appeared to deter potential participation. Roughly two-thirds of survey respondents (68%) indicated that they were somewhat willing to stop treatment as part of HIV cure research. In the bivariate models, females, African Americans/blacks, Hispanics, individuals in the lowest income bracket, people living with HIV for longer periods of their lives, and people who were self-perceived 'very healthy' were less willing to participate in certain types of HIV cure studies than others. Multivariate results showed the perceived benefits (adjusted odds ratios >1) and perceived risks (adjusted odds ratios <1) acted as potential motivators and deterrents to participation, respectively.

**Conclusion:** Our study is the first attempt to quantify potential motivators and deterrents of participation in HIV cure research in the US using perceived risks and benefits. The results offer guidance to HIV cure researchers and developers of interventions about the beneficial and detrimental characteristics of HIV cure strategies that are most meaningful to people living with HIV. The study also highlights new potential lines of inquiry for further social science and ethics research.

Keywords: HIV cure research, willingness to participate, perceived risks, perceived benefits

### Introduction

The case of one individual, Timothy Ray Brown, thought to be cured of HIV, has inspired renewed scientific interest and investment in discovering an HIV cure, either one that eradicates the HIV reservoir, or one that induces mechanisms that result in durable viral suppression [1]. While researchers, bioethicists and regulators are attempting to minimise the risk to study participants, they must also balance the need to demonstrate that the intervention has the intended effect. As such, HIV cure research efforts carry great risks [2–4], including the need to withdraw antiretroviral therapy (ART) in order to prove whether a cure intervention has had its intended effect.

To date, little data are available on willingness of people living with HIV to participate in HIV cure studies. Although a few studies have explored perceptions of HIV cure research [5–7], none have focused systematically on perceived risks and benefits of study participation. Such studies could allow for a more informed *a priori* process for intervention candidate selection, study design, and

methods by which prospective participants are recruited, screened and informed about clinical research. This study reports results from a survey that explored individuals' perceived risks and benefits of participation in HIV cure research in the US.

### Methods

We administered an online, cross-sectional survey in autumn 2015 using Qualtrics software (Provo, Utah). We recruited study participants via a convenience sample of people living with HIV using established treatment and cure research listservs, including those for immune-based therapy (IBT), the Martin Delaney Collaboratories Community Advisory Board (MDC CAB), the AIDS Clinical Trials Group (ACTG), the AIDS Treatment Activists Coalition (ATAC) and others.

Inclusion criteria for survey participation were:

- Persons self-reported to be living with HIV
- Willingness to answer survey questions
- ≥18 years of age
- Living in the US or its territories
- Ability to read/write in English
- Willingness to provide informed consent.

<sup>\*</sup>Corresponding author: Karine Dubé, Public Health Leadership Program, UNC Gillings School of Global Public Health, McGavran Greenberg Hall, Campus Box 7469, Chapel Hill, NC, 27599-7469, USA Email: karine\_dube@med.unc.edu

The recruitment method included a reference to contributing to a study on willingness to participate in HIV cure research. People could participate regardless of whether they were on ART. We focused on the US because of the growing momentum for HIV cure research in the country and increased investment in an already sophisticated research infrastructure with the capacity to undertake HIV cure clinical research.

The survey questions were developed by previous work in the field and our scoping review of the literature focused on risks and benefits of study participation [8]. We pilot tested the survey and vetted key terms and definitions with the members of HIV cure research community advisory boards. The Institutional Review Board (IRB) of the University of North Carolina at Chapel Hill approved the study and participants provided consent online.

### Measures

The survey covered demographic characteristics, health status and perceptions, history with, and general interest in HIV cure-related research. Respondents reported yes/no/don't know about willingness to participate in each of the 14 types of HIV curerelated studies (listed in Figure 1). These correspond to the types of HIV cure studies most likely to enrol study participants in the coming years per our review of the literature (8). HIV cure study types were constructed as dichotomous variables by excluding all 'don't know' or incomplete responses. Additionally, using 5-point Likert scales, we asked survey respondents to rate 21 potential benefits and 35 potential risks in terms of how likely each one might motivate/discourage them from participation in studies. Given the distributions, the extreme answer (e.g. 'very important') was given a value of 1 and all other, lower levels of importance given a value of 0. We provided definitions of complex words in lay terms and used the survey as an educational opportunity for respondents. Figure 1 displays how the various study types were defined.

### Statistical analysis

We ran bivariate correlation tests between each individual-level characteristic and willingness to participate in 14 HIV cure study types, reporting Fisher's exact tests and odds ratios.

Using multivariate analysis, we examined the relationships between perceptions of potential benefits and potential risks and willingness to participate in five specific HIV cure study types with high risk interventions: (1) latency-reversing agents; (2) allogeneic stem cell transplants; (3) autologous stem cell transplants; (4) therapeutic vaccines; and (5) antibodies or molecules. For each of the five HIV cure study types, we estimated separate logistic regression models for each perception of potential benefit as a motivator or potential risk as a deterrent as the key independent variable, controlling for demographics and health status characteristics. Because this is an exploratory analysis, and not testing any single specific hypothesis, we did not make any adjustments for multiple testing; rather, we present all results and associated *P*-values. All data analyses were conducted using Stata (version 11).

### Results

### Demographics

Of the 400 eligible participants (nine were not eligible due to self-declared HIV-negative status), representing 38 states and Puerto Rico, 343 respondents completed the survey by answering all questions and 57 partially completed the survey. Respondents were 78% men and ranged in ages between 19 and 74 years of age (median age 51). The sample was ethnically diverse: 65%

Caucasians/whites, 17% African Americans/black, 12% Hispanic/ Hispanic descent and 4% mixed race. Virtually all survey respondents had at least a high school degree or equivalent and nearly half had a 4-year degree or higher. More than one-third (37%) of survey respondents earned less than \$25,000 annually and another third (35%) earned more than \$50,000 (Table 1).

### Willingness to participate in HIV cure-related studies

Figure 1 shows the hierarchy of the 14 different kinds of HIV cure-related studies that potential participants indicated they would be willing to join. There was a near universal willingness to participate in surveys, interviews, focus groups and basic blood draw studies (between 85% and 97%). For the other types of studies, willingness to participate ranged between 52% and 78%. Figure 2 disaggregates the data by sex/gender.

### Perceptions of potential benefits

Perceived clinical benefits or social benefits appeared to be more important motivators than personal benefits (Figure 3). Feeling good about contributing to HIV cure research was the most popular perceived personal benefit, and social benefits of helping find a cure for HIV; helping other people with HIV in the future; and contributing to scientific knowledge were three of the four highest ranked perceived benefits overall. Potential participants valued gaining knowledge about their health (78%), hoped their health would improve (73%), desired to improve their immune system (92%) and to reduce their HIV reservoir (85%). Figure 4 disaggregates these data by sex/gender.

### Perceptions of potential risks and burdens

Personal clinical risks appeared to be more likely to deter potential participation than personal risks or burdens or potential social risks (Figure 5). Risks were defined as potential harms or complications, while burdens included drawbacks of participation such as intensive time commitments and discomforts. Activation of genes that could cause cancer (49%) and the possibility of developing resistance to HIV treatment (37%) were the most prevalent perceived deterrents. Spinal tap (26%) and bone marrow biopsies (22%) were the least acceptable study procedures. Hair loss was a stronger possible deterrent than more immediate symptoms/side effects, such as vomiting, pain, headache, or nausea. Finally, the risk of transmitting HIV to others (in the case of an unsuspected viral rebound) was a real possible social deterrent. Figure 6 disaggregates these data by sex/gender.

Roughly two-thirds of survey respondents (68%) indicated they were somewhat or very willing to stop treatment as part of HIV cure research, versus 21% who were not at all or not very willing, and 11% who were not sure.

### Other descriptive results

Of the survey respondents, 8% thought a cure for HIV infection was presently available and 3% thought a cure would never materialise; the majority of respondents was evenly split across a perceived time to cure. In open-ended responses, participants most commonly defined HIV cure as 'not transmitting HIV to others' (68%), 'completely eliminating HIV from the body' (68%), and 'no more HIV treatment needed' (65%), above 'no longer testing positive on the antibody HIV test' (31%).

# Bivariate results: association of willingness to participate in HIV cure studies and demographics and health status characteristics

Using bivariate analyses (Appendices 3–17), we explored the socio-demographic and health status characteristics correlated with willingness to participate (WTP) in 14 HIV cure study types;

	Number	Percentage (%)
Gender		
п	400	
Male	310	78
Female	86	22
Transgender (male to female)	3	0.8
Transgender (female to male)	0	0
Other (did not specify)	1	0.3
Age (years)		
n	400	
Mean	50	
Median	51	
Minimum	19	
Maximum	74	
Age groups		
19–25	14	4
26–30	11	3
31–35	24	6
36–40	27	7
41–45	46	12
46–50	73	18
51–55	83	21
56–60	64	16
61–65	39	10
66–70	11	3
71–74	8	2
Ethnicity		
n	400	
Caucasian/white	258	65
African American/black	66	17
Hispanic or Hispanic descent	47	12
Mixed	15	4
Asian or Asian descent	7	2
American Indian or Alaska Native	2	0.5
Native Hawaiian or Pacific Islander	1	0.3
Other	4	1.0
Highest education level achieved		
n	399	
Less than high school	5	1
High school or GED	101	25
Some college	24	6
Associate degree	78	20
Undergraduate degree	103	26
Master's degree or its equivalent	66	17
Doctorate or its equivalent (e.g. PhD, MD, JD)	22	6

	Number	Percentage (%)
Yearly household income		
п	399	
Less than \$25,000	148	37
\$25,000-\$50,000	111	28
\$50,001-\$75,000	47	12
\$75,001-\$100,000	38	10
\$100,001-\$125,000	29	7
\$125,001-\$150,000	9	2
More than \$150,000	17	4
Self-reported current health status		
n	400	
Very healthy	80	20
Healthy	176	44
Somewhat healthy	120	30
Not very healthy	18	5
Not at all healthy	5	1
Don't know/not sure	1	0.3
Control over own healthcare		
n	400	
Yes	326	82
No	54	14
Don't know/not sure	20	5
Currently taking HIV medication		
n	400	
Yes	391	98
No	9	2
Don't know/not sure	0	0
Years since HIV diagnosis (years)		
n	394	
Mean	17	
Median	18	
Minimum	<1	
Maximum	36	
Percentage of lifetime with HIV-posit	ive status (%	5)
n	394	
Up to 25 of lifetime	144	37
26–50% of lifetime	187	47
51–75% of lifetime	59	15
More than 75% of lifetime	4	1
Ever volunteered for an HIV treatmen	it study	
n	399	
Yes	175	44
No	218	55
Don't know/not sure	6	2
General interest in HIV cure research		
п	399	
Yes	385	96
No	5	1
Don't know/not sure	9	2

Table 1. Continued



Figure 1. Willingness to consider participating in HIV cure-related studies in the US, 2015. Leukaphereses and aphereses were defined as 'laboratory procedures where selected immune cells are separated out from the blood and the rest of the blood is returned to the veins'. Therapeutic vaccines were defined as 'vaccines that control disease in people already infected rather than vaccines that prevent infection'. Phase II or III studies were defined as safety and efficacy studies. Use of unique antibodies or molecules was defined as using, for example, a protein that has a dual function. Autologous transplants of stem cells were defined as 'studies involving transplantation of your (autologous) stem cells'. First-in-human studies were defined as 'studies that involve totally new treatments or approaches'. Intensification of treatment was defined as 'studies that involve totally new treatments or approaches'. Intensification of treatment was defined as 'studies that involve totally new treatments or approaches'. Intensification of some agents that could reactivate HIV that has become dormant inside the cells'. Allogeneic transplants of stem cells were defined as 'studies that involve a transplantation of someone else's (allogeneic) stem cells'

	FEMALES	MALES	
	⊗ Don't know/Not	sure ∎No ∎Yes	Chi-squared test <i>P</i> -value
Survey/questionnaire research	1% 0% 99%	1% 2%: <b>97%</b>	0.694
Basic blood draw studies	1% 3% 96%	4% 5% <b>92%</b>	0.319
Interviews	5% 4% 🗍 91%	2% 6% 92%	0.770
Focus group discussions	3% 4% 93%	6% 11%	0.025*
Leukaphereses or aphereses	21%13% /// 66%	9% 10% 🖉 🛛 81%	0.002**
Therapeutic vaccines	17%18% // 64%	12% 9% 78%	0.008**
Phase II or III studies	21% 13% /// 66%	15% 9% 🅢 76%	0.051
Use of unique antibodies or molecules	27%13% //// 60%	14% 9% 🅢 77%	0.002**
Autologous transplant of stem cells	32%17%//// 51%	19% 11% 70%	0.001***
Modification of genes in immune cells	31%21%/// 48%	20% 13%	0.001***
First-in-human studies	32% 14%//// 54%	24% 15%/// 61%	0.211
Intensification of treatment	24% 20% //// 57%	23%17%/// 60%	0.497
Enroll own child in pediatric HIV cure study	20%22% /// 59%	26% 18%//// 56%	0.841
Latency reversing agents	25%29%/// 46%	27% 19%/// 55%	0.147
Allogeneic transplant of stem cells	36%20%///// 43%	27% 18%//// 55%	0.058

Figure 2. Difference between female and male willingness to consider participating in HIV cure-related studies in the US, 2015. Transgender women are included in the Females category; *P*-values reflect the chi-squared test result for differences between females and males in answering 'Yes'. \*\*\* Statistically significant at 0.1% level; \*\* statistically significant at 1% level; \* statistically significant at 5% level

significant results are summarised in Appendices 1–2. Briefly, females were less willing to participate in studies involving latency-reversing agents, gene modification, autologous stem cell transplant, and therapeutic vaccines. African Americans/blacks were less willing than Caucasians/whites to participate in studies involving latency-reversing agents, gene modification, autologous

stem cell transplants, therapeutic vaccines, and antibodies or molecules. Hispanics were less willing to participate in studies involving autologous stem cell transplants, therapeutic vaccines, treatment intensification, and antibodies or molecules. Individuals in the lowest income bracket (<\$25,000 household income) were much less willing to participate in nearly all of the studies than





their peers in higher income brackets. Furthermore, individuals in poorer health were considerably more willing to participate in studies involving latency-reversing agents and allogeneic stem cell transplants than healthier people. Recently diagnosed individuals were nearly two to three times more willing to participate in studies than people who had lived with the virus for a larger proportion of their lives across seven of the ten interventional HIV cure study types.

# Multivariate results: association of willingness to participate (WTP) in HIV cure studies and the self-assessed importance of potential benefits/risks as motivators/deterrents to participating

Multivariate results are shown in Tables 2 and 3. The summary results for the perceptions of the 21 potential benefits as very important motivators to participation are summarised in Table 2. The summary results for the perceptions of the 35 potential risks as very likely deterrents to participation can be found in Table 3. All models control for gender, age, ethnicity, education, income, region, health status, being in control of own healthcare, percentage of life lived with HIV, ever volunteered for HIV treatment study, ever volunteered for HIV cure study and general interest in HIV cure studies.

Perceptions of benefits (Table 2) were positively correlated with willingness to participate. Respondents who rated feeling good about contributing to HIV cure research as a very important

motivator had higher odds of being willing to participate in allogeneic stem cell transplant studies, autologous stem cell transplant studies, therapeutic vaccine studies and in antibody studies. The perception that helping find a cure for HIV as a very important motivator was associated with 12 times the odds of being willing to participate in allogeneic stem cell transplant studies.

Perceptions of risks (Table 3) were negatively correlated with willingness to participate. In particular, perceptions that the potential personal clinical risks, as well as potential risk of pain or discomfort from study procedures (spinal tap, bone marrow biopsies, rectal biopsies, isolation of white blood cells) were more significant in magnitude than other types of risks, symptoms (except for nausea), burdens, and potential social risks. Moreover, a small number of survey respondents found the risk factors very likely to discourage them from participating (Figure 5), generally overlapping with those who were not willing to participate in any of the study types, partly explaining the strong associations.

### Discussion

Our findings provide a unique perspective into willingness of individuals living with HIV in the US to participate in HIV curerelated studies, focusing on perceptions of risks and benefits. More than 50% of survey respondents indicated that they would be



Figure 4. Differences between females' and males' assessment of the importance of potential benefits to motivate participation in HIV cure-related studies in the US, 2015. Percentages reflect 'Very important'. The remainder (up to 100%) includes the sum of 'Somewhat important', 'Barely important', 'Not important' and 'Don't know/not sure'. Transgender women are included in the Females category. *P*-values reflect the chi-squared test result for differences between females and males in answering 'Very important'; \*\*\* Statistically significant at 0.1% level; \*\* statistically significant at 1% level; \* statistically significant at 5% level

willing to participate in all types of HIV cure-related studies. The high apparent willingness to participate in HIV cure research and the belief that a cure for HIV was already available by a minority of respondents underscores the need to better educate potential study candidates about the different types of HIV cure studies and their potential risks in order to prevent therapeutic or curative misconception [9]. Our study extends the literature in several ways, in that, although willingness to participate may not correlate with actual participation, the study shows there is a strong level of willingness to participate in HIV cure research in a diverse population of people living with HIV in the US. Furthermore, this was the first attempt to quantify motivation and deterrence of participation in HIV cure-related studies using perceived risks and benefits. The results offer guidance to HIV cure researchers and developers of interventions about the beneficial and detrimental characteristics of HIV cure strategies that are most meaningful to people living with HIV. The study also revealed differences in motivation across HIV cure study types and differences by gender, ethnicity and perceived health status that may be actionable as part of research recruitment efforts.

Descriptive results revealed potential misperceptions about clinical benefits. While people may be willing to participate in HIV cure research, they may be largely unaware of the potential risks and lack of direct clinical benefits in early HIV cure research and this has ethical implications for informed consent. For example, people living with HIV may expect to gain knowledge about their health but HIV cure research results are most often compiled and published in the aggregate and not returned to study participants. Hope that health will improve was also a strong motivator factor, yet there is a real possibility of individual harm while advancing scientific HIV cure knowledge. Reducing the HIV reservoir was perceived as a clinical benefit by potential participants, although a reservoir decrease may not confer direct clinical benefit. Thus, HIV cure research implementers need to be careful how knowledge of results, risk of harms, lack of direct clinical benefits and reservoir reductions are discussed in informed consent forms to avoid misperceptions around clinical benefits (or lack thereof). True informed consent and knowledge around clinical risks should be assured using tests of understanding in order to avoid underestimating risks and overestimating expectations for personal



Figure 5. Respondents' assessment of the likelihood of potential risks and burdens to discourage participation in HIV cure-related states, US, 2015. Percentages reflect 'Very likely to discourage'. The remainder (up to 100%) includes the sum of 'Somewhat likely to discourage', 'Barely likely to discourage', 'Not likely to discourage' and 'Don't know/Not sure'

benefits. Furthermore, the risk of transmitting HIV to others (in the case of an unsuspected viral rebound) was a real possible demotivator (28% very likely to be discouraged). This result was reminiscent of similar prior surveys that showed the importance placed on reducing HIV transmission risk [6,10].

Although early HIV cure studies confer little to no clinical benefit [3,11], it is possible that study participants still perceive the likelihood of benefits when deciding to join studies, either through therapeutic misconception or other tendencies to overstate the potential for benefits whilst simultaneously discounting potential risks to self. Our findings also demonstrated the importance of not underestimating the contribution of emotional and psychological benefits in HIV cure research participation in general. The highest rated social and personal benefits were most often psychological in nature, consistent with similar studies from the HIV prevention and treatment literature [12,13]. HIV cure scientists should appreciate the perceived intangible benefits to participation and seriously consider the altruistic appeal to scientific advancement when conducting recruitment efforts, while emphasising the lack of direct medical benefits.

We found that 68% of potential HIV cure research participants indicated they were very willing or somewhat willing to interrupt treatment as part of HIV cure research, consistent with a previously published US survey [7]. The finding is important because HIV treatment interruptions may become more prevalent as investigational HIV cure strategies start showing signals of potential efficacy.

### Limitations

Several limitations of the study should be acknowledged. First, questions regarding willingness to participate were hypothetical

	FEMALES	MA	LES	
■ Don't know/Not sure	Barely likely	Somewhat likely	Very likely	Chi squara
Potential personal clinical risks				test <i>P</i> -value
Activation of genes that could cause cancer	3	50%	48%	0.678
Possibility of developing resistance to drugs	2	46%	35%	0.089
Toxicities or adverse negative effects of drugs	1/	38%	28%	0.058
Known risks of stopping HIV medications	1	37%	27%	0.064
Unable to predict viral rebound	11	40%	23%	0.002**
Graft-versus-host disease		2%	23%	0.064
Invasive study procedures (e.g. biopsy)	2	3% ////	13%	0.017*
Potential personal risks and burdens			10/0	0.017
Commitment				
Long study visits (>4 hours each)	119	6 1////	8%	0.350
High frequency of study visits (>1 per month)	9%	1////	6%	0 383
Long study duration and follow-up (>5 years)	6%	1/////	6%	0.956
Study procedures				0.550
Spinal tap	111	34%	24%	0.042*
Bone marrow biopsies	11/	31%	19%	0.02*
Biopsies of lymph nodes	18	6 9////	11%	0.081
Rectal biopsies	2///// 2	8% //////	8%	< 0.001***
Organ donation after death	10%	=////////	7%	0.307
Isolating white blood cells (may take 2 hours)	///// 139	6 11/////	4%	0.001***
Collection of semen or vaginal fluids	6%	11//////	2%	0.070
Oral biopsies (e.g. saliva samples)	4%	1//////////////////////////////////////	3%	0.533
Blood draws	5%	1//////////////////////////////////////	2%	0.176
Symptoms or side effects				0.170
Hair loss	11	41%	29%	0.028*
Vomiting	2////	8% ///	21%	0.137
Pre-defined, controlled discomfort or pain	/// 21	%	12%	0.021*
Headache	18	6 1///	11%	0.083
Nausea	21	% 1///	10%	0.008**
Burdens				
Difficulty finding/paying for parking at the site	2	3%	17%	0.042*
Difficulty finding transportation to the site	////. 22	% */////	16%	0.244
Time away from work or school	129	6 9//////	8%	0.195
Time away from family	7%	11//////	4%	0.143
Challenges of finding child care	<i></i> 8%	3///////	4%	0.150
laving to explain study participation to others	5%	1//////////////////////////////////////	4%	0.536
Potential social risks				
Risk of transmitting HIV to a sexual partner	25	%	29%	0.603
Discrimination	169	6 1///////	10%	0.125
Stigma	149	6	6%	0.022*
Being recognised as a person living with HIV	10%	9///////	7%	0.471
Risk of losing "HIV-positive identity" if cured	6%	11/////////////////////////////////////	2%	0.030*

Figure 6. Difference between females' and males' assessment of the likelihood of potential risks and burdens to discourage participation in HIV cure-related states in the US, 2015. Percentages reflect 'Very likely to discourage'. The remainder (up to 100%) includes the sum of 'Somewhat likely to discourage', 'Barely likely to discourage', 'Not likely to discourage' and 'Don't know/Not sure'. Transgender women are included in the Females category. *P*-values reflect the chi-squared test result for differences between females and males in answering 'Very likely to discourage'. \*\*\* Statistically significant at 0.1% level. \*\* statistically significant at 1% level. \* statistically significant at 5% level

and it remains to be seen whether potential volunteers would participate if the opportunity arises. While results should not be used to predict enrolment rates, responses can inform study designs, including understanding of risks and benefits and considerations for informed consent and recruitment efforts. Study participants may have had limited knowledge of the inherent risks of each HIV cure study type, and if they knew more about them their responses might change. While the high level of willingness to participate is encouraging, previous research in HIV and other diseases suggests that stated willingness will not translate into *actual* research participation to the same degree and we suspect social desirability bias. Second, the sample may have been biased to those who had access to HIV cure/treatment listservs and the internet. As such, the sample was not representative of the overall population of people living with HIV in the US (median age 51). Individuals without internet access, non-English speakers and minors were excluded. Yet, the sample had proportionally more females and was ethnically more diverse than a previous US survey on willingness to participate in HIV cure studies [7]. Third, referencing HIV cure research as part of the survey recruitment may have biased the sample towards those with an interest in finding a cure. Fourth, the complexity of the survey wording may have limited full understanding of items, although we mitigated this risk by providing definitions of key concepts in lay terms throughout the survey instrument.

 Table 2. Odds ratios of willingness to participate in particular types of HIV cure-related studies based on perception that a potential benefit is a 'Very Important' motivating factor to participating in the US, 2015

Key independent (benefit) variable	Type of HIV cure-related study						
	Latency-reversing agents	Allogenic stem cell transplant	Autologous stem cell transplant	Therapeutic vaccine	Antibodies		
Potential personal benefit							
Feel good contributing to HIV cure research	1.78	5.69***	6.98***	8.34***	5.91**		
Gaining knowledge about own health/HIV	1.49	3.39**	2.81*	2.45	1.99		
Learning about new treatment options	0.67	3.63***	3.10*	3.04*	2.76		
Not wanting to give up	0.95	2.09*	1.98	2.38	1.80		
Hope that health will improve	0.48	1.97	0.78	1.72	0.76		
More/regular access to medical researchers	1.52	2.41*	2.20	1.61	1.68		
Additional laboratory work free of charge	2.03	2.90**	3.54**	2.40	5.42**		
Regular access to a study nurse	1.99	2.11*	1.98	1.84	1.78		
Transportation compensation to study site	1.07	1.40	1.26	1.15	1.61		
Being compensated or reimbursed	0.98	2.37*	1.69	1.20	1.50		
Being offered a meal at the study site	1.42	2.08	1.84	2.13	1.87		
Potential personal clinical benefit							
Preserve immune system ability to fight HIV	1.67	1.64	2.03	3.32*	3.93*		
Reducing HIV reservoir or HIV in entire body	3.09*	2.64*	3.56*	2.54	2.96		
Control viral load in absence of treatment	1.68	2.43*	2.83	2.81	2.82		
Prevent increase in virus for extended time	1.00	2.56*	1.97	1.42	1.88		
Less risk transmitting HIV to sex partner(s)	0.58	1.46	1.52	2.05	1.73		
Increased immune cell counts	0.96	1.89	1.81	2.30	1.45		
Potential social benefit							
Helping find a cure for HIV	3.75*	12.46***	10.10***	8.09***	5.48**		
Helping other people with HIV in the future	1.04	4.18*	5.44**	4.89*	2.85		
Contributing to scientific knowledge	3.50*	2.82	3.48*	2.64	1.62		
Receiving support from family and friends	0.62	0.72	0.78	0.89	0.72		

Each benefit variable was included in a separate model with the control variables: gender, age, ethnicity, education, income, region, health status, being in control of own healthcare, percentage of life lived with HIV, ever volunteered for HIV treatment study, ever volunteered for HIV cure study and general interest in HIV cure studies (except when omitted for perfect collinearity).

Odd ratios on the control variables are not displayed.

\*\*\* Statistically significant at the 0.1% level; \*\* statistically significant at the 1% level; \* statistically significant at the 5% level.

Robust standard errors estimated.

### Possible avenues for future research

Given the great risks involved in HIV cure research, we will need to better understand the role of altruism in high-risk/low-benefit studies. We will also need to better understand the factors that affect participation in specific types of HIV cure studies and assess potential participants' knowledge and understanding of the various cure research modalities. Table 4 summarises potential future study questions around HIV cure research participation. Social science research can help guide meaningful community and stakeholder engagement, enhance patient–participant and clinician–researcher communications and contribute to more successful clinical studies.

Moving forward, it is essential that we pursue HIV cure-related research in a way that places the needs and perspectives of people living with HIV at the centre of research. Human studies in HIV cure are part of a growing field that raises several complex implementation challenges as well as ethical issues related to participation. Understanding perceptions of risks and benefits of HIV cure research participation and factors that affect decisions to participate can, thus, help inform study design and the development of ethical informed consent procedures, enhance recruitment efforts and contribute to researcher–community collaboration towards finding a cure.

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Table 3. Odds ratios of willingness to participate in particular types of HIV cure-related studies based on perception that a potential risk is 'Very likely to discourage' participation in studies in the US, 2015

Key independent (risk) variable Type of HIV cure-related study					
	Latency-reversing agents	Allogenic stem cell transplant	Autologous stem cell transplant	Therapeutic vaccine	Antibodies
Potential personal clinical risk					
Activation of genes that could cause cancer	0.22***	0.22***	0.31**	0.35*	0.38*
Possibility of developing resistance to drugs	0.1***	0.23***	0.13***	0.13***	0.12***
Toxicities or adverse negative effects of drugs	0.07***	0.09***	0.10***	0.16***	0.11***
Known risks of stopping HIV medications	0.09***	0.21***	0.22***	0.14***	0.16***
Unable to predict viral rebound	0.08***	0.25***	0.17***	0.14***	0.21***
Graft-versus-host disease	0.1***	0.12***	0.10***	0.11***	0.11***
Invasive study procedures (e.g. biopsy)	0.16***	0.24**	0.11***	0.07***	0.13***
Potential personal risk (commitment)					
Long study visits (>4 hours each)	0.16**	0.32*	0.12***	0.16**	0.13***
High frequency of study visits (>1 per month)	0.18**	0.21**	0.09***	0.09***	0.13**
Long study duration and follow-up (>5 years)	0.21*	0.18*	0.06***	0.06***	0.05***
Potential personal risk (study procedures)					
Spinal tap	0.15***	0.09***	0.05***	0.09***	0.11***
Bone marrow biopsies	0.22***	0.09***	0.06***	0.09***	0.07***
Biopsies of lymph nodes	0.27*	0.20**	0.10***	0.08***	0.12***
Rectal biopsies	0.32*	0.10***	0.01***	0.07***	0.07***
Organ donation after death	0.83	0.48	0.26	0.14**	0.16*
Isolating white blood cells (may take 2 hours)	0.24	0.08*	0.01***	0.08**	0.02***
Collection of semen or vaginal fluids	0.38	0.97	0.15*	0.25	0.53
Oral biopsies (e.g. saliva samples)	0.10**	0.27	0.10**	0.15*	0.34
Blood draws	0.87	0.17	0.16*	0.15	0.12*
Potential personal risk (symptoms or side effect	5)				
Hair loss	0.23***	0.44**	0.33**	0.30**	0.23**
Vomiting	0.48	0.13***	0.12***	0.13***	0.23**
Pre-defined, controlled discomfort or pain	0.19***	0.23**	0.09***	0.12***	0.16***
Nausea	0.32*	0.11***	0.05***	0.08***	0.08***
Headache	0.44	0.14***	0.09***	0.11***	0.13***
Potential personal risk (burdens)					
Difficulty finding/paying for parking at the site	0.61	0.54	0.36*	0.40*	0.46
Difficulty finding transportation to the site	0.68	0.44	0.43	0.44	0.55
Time away from work or school	0.29*	0.71	0.36*	0.67	0.94
Time away from family	0.84	0.64	0.37	0.92	0.46
Challenges of finding child care	0.94	0.34	0.27*	0.33	0.13*
Having to explain study participation to others	0.20*	0.13**	0.07***	0.17*	0.02***
Potential social risk					
Risk of transmitting HIV to a sexual partner	0.26***	0.40*	0.28**	0.37*	0.24**
Discrimination	0.29*	0.22**	0.10***	0.26*	0.19*
Stigma	0.26	0.17**	0.07***	0.22*	0.13*
Being recognized as a person living with HIV	0.19*	0.13***	0.16**	0.28	0.06***
Risk of losing 'HIV-positive identity' if cured	1.04	0.33	0.14*	0.48	1.67

Each risk variable was included in a separate model with the control variables: gender, age, ethnicity, education, income, region, health status, being in control of own healthcare, percentage of life lived with HIV, ever volunteered for HIV treatment study, ever volunteered for HIV cure study, and general interest in HIV cure studies (except when omitted for perfect collinearity).

Odd ratios on the control variables are not displayed.

\*\*\* Statistically significant at the 0.1% level; \*\* statistically significant at the 1% level; \* statistically significant at the 5% level.

Robust standard errors estimated.

### Table 4. Future potential social sciences questions to inform study participation in biomedical HIV cure-related research

#### Meanings of cure

- What are the various meanings of HIV cure research and how can we reconcile patient-participants, clinician-researchers and policy-makers/ regulators' perspectives?
- What are the various meanings of 'success' in HIV cure research (including intermediate outcomes)?
- What do potential participants understand about HIV cure research and how does that affect their willingness to participate?

#### Role of altruism

What role do altruism, expectations, optimism and hope play in HIV cure research participation?

#### Research with prospective study participants

- How do demographic characteristics (such as age, gender, socio-economic status, nationality) relate to HIV cure understanding, acceptability and willingness to participate?
- How do people undersand the purpose and risks of HIV cure studies?
- How does people's perceptions and experiences of their own health impact their willingness to assume risk in HIV cure studies?
- Discrete choice experiments borrowing from economic, cognitive psychology and decision-making literature what are common trends in HIV cure research decision making (e.g. anchoring, judmental heuristics and defaulting to patterns)?
- How can we increase recruitment of women and under-represented groups in HIV cure studies?
- Would asking for long-term follow-up of study participants negatively affect overall recruitment or would long-term follow-up make study participants feel better?
- How can we begin to study therapeutic (or curative) misconception in HIV cure research?
- What motivations to join HIV cure studies are ethically questionable?
- ♦ How does long-term survival with HIV affect willingness to participate and actual participation in HIV cure research?
- What factors affect willingness to participate in studies that include treatment interruption?

#### Research with actual study participants

- Would collaboration from biomedical HIV cure scientists, either retrospectively or prospectively as part of actual HIV cure studies (e.g. nested social sciences research), be required? What does HIV cure research mean for quality of life outcomes (such as Short-Form-36 Health Survey)?
- What factors predict retention (or serial participation) in HIV cure studies?

### Research with study decliners (more difficult)

♦ What are some of the reasons that cause people living with HIV to decline participation in HIV cure research?

#### Research with clinician-researchers and policy-makers

How do clinician-researchers and policymakers view risks in HIV cure research?

#### **Research ethics questions**

- What is an acceptable risk-benefit balance for potential HIV cure study participants?
- Are there groups who are more vulnerable than others in HIV cure research?
- How can HIV cure researchers best measure effective management of scientific uncertainty?

#### **Declaration of Interests**

None declared

### References

- Deeks SG, Autran B, Berkhout B et al. Towards an HIV cure: a global scientific strategy. Nature Rev Immunol 2012; 12: 607–614.
- Food and Drug Administration (FDA). HIV patient-focused drug development backgrounder document. 2014. Available at: www.fda.gov/ForConsumers/ ByAudience/ForPatientAdvocates/HIVandAIDSActivities/ucm353829.htm (accessed December 2016).
- Lo B, Grady C. Ethical considerations in HIV cure research: points to consider. Curr Opin HIV AIDS 2013; 8: 243–249.
- Sugarman J. HIV cure research. Expanding the ethical considerations. Ann Intern Med 2013; 159: 9–11.
- Simmons R, Porter K, Kall M et al. A UK survey of HIV-positive people's attitudes towards cure research (Abstract p 39). HIV Med 2015; 16 (suppl 2): 12–77.

- McMahon JH, Elliott J, Roney J *et al.* Experiences and expectations of participants completing an HIV cure focused clinical trial. *AIDS* 2015; 29: 248–250.
- Arnold M, Evans D, Vergel N. Recruitment and ethical considerations in HIV cure trials requiring treatment interruption. J Virus Erad 2015; 1: 43–48.
- Dubé K, Ramirez C, Handibode J et al. Participation in HIV cure-related research: a scoping review of the proxy literature and implications for future research. J Virus Erad 2015; 3: 14–20.
- Appelbaum P, Roth L, Lidz C. The therapeutic misconception: informed consent in psychiatric research. Int J Law Psychiat 1982; 5: 319–329.
- Grossman CI, Ross AL, Auerbach JD *et al.* Towards multidisciplinary HIV-cure research: integrating social science with biomedical research. *Trends Microbiol* 2016; 24: 5–11.
- 11. Peay H, Henderson GE. What motivates participation in HIV cure trials? A call for real-time assessment to improve informed consent. *J Virus Erad* 2015; 1: 51–53.
- Dhalla S, Poole G. Motivators to participation in medical trials: the application of social and personal categorization. *Psychol Health Med* 2013; 18: 664–675.
- FDA. The Voice of the Patient. 2014. Available at: www.fda.gov/downloads/ ForIndustry/UserFees/PrescriptionDrugUserFee/UCM389379.pdf (accessed December 2016).

# Appendix 1. Summary of bivariate results: sociodemographic and health status characteristics that are statistically significantly correlated (P<0.05) with willingness to participate (WTP) in different HIV cure-related studies (1–5), US, 2015

		Type of HIV cu	re-related study		
Characteristic	Leukapheresis or apheresis	Latency reversing agents	Gene modification	autologous stem cell transplant	Allogenic stem cell transplant
Gender		Females = $0.5 \times WTP$ of Males	Females = $0.4 \times WTP$ of Males	Females = $0.5 \times WTP$ of Males	
Ethnicity	African-Americans = $0.3$ × WTP of Caucasians	African-Americans = $0.4$ × WTP of Caucasians	$AA=0.3 \times WTP and$ Others = $0.2 \times WTP of$ Caucasians	AA= $0.3 \times WTP$ and Hispanics = $0.4 \times WTP$ of Caucasians	
Education		Doctorates 100% WTP (vs. 68% High School graduates)			
Household income	\$25k-\$50k group = 3.6 ×WTP of <\$25k group		$25k-50k = 3.8 \times WTP$ and $100k-125k = 9.1 \times WTP$ of <\$25k group	\$25k-\$50k group = 3.3 × WTP of <\$25k group	\$25k-\$50k group = 2.3 × WTP of <\$25k group
Health status		Not Very/not At All Healthy = 9.2 × WTP of Very Healthy			Not Very/not At All Healthy 100% WTP (vs 72% of others)
Percentage of life living with HIV diagnosis	Living with HIV <25% of Lifetime = $2.6 \times WTP$ of others	Living with HIV <25% of Lifetime = $2.9 \times WTP$ of others	Living with HIV <25% of Lifetime = $2.4 \times WTP$ of others		Living with HIV <25% of Lifetime = $1.9-3.0 \times WTP$ of others
Ever volunteered for an HIV treatment study					
Interested in HIV cure research	Non-interested 0% WTP (vs 90% of interested)	Non-interested = $0.09 \times WTP$ of interested	Non-interested 0% WTP (vs 84% of interested)	Non-interested 0% WTP (vs 87% of interested)	Non-interested 0% WTP (vs 76% of interested)

Age, region, being in control of own health care, currently taking HIV medications, and ever volunteered for an HIV cure study are not statistically significantly correlated with willingness to participate of any HIV cure-related study type. WTP=Willingness to Participate; AA=African Americans.

# Appendix 2. Summary of bivariate results: sociodemographic and health status characteristics that are statistically significantly correlated (P<0.05) with willingness to participate (WTP) in different HIV cure-related studies (6–10), US, 2015

		Type of HIV cu	re-related study		
Characteristic	Therapeutic vaccines	Treatment intensification	Antibodies or molecules	First-in-human studies	Phase II/III studies
Gender	$\label{eq:Females} \begin{array}{l} \mbox{Females} = 0.4 \times \mbox{WTP of} \\ \mbox{Males} \end{array}$				
Ethnicity	Caucasians = $2.9 \times WTP$ of AA, $3.6 \times WTP$ of Hispanics, $9 \times WTP$ of Others	Hispanics = $0.4 \times WTP$ of Caucasians	$AA=0.3 \times WTP$ and Hispanics = $0.3 \times WTP$ of Caucasians		
Education	College graduates 92% WTP (vs 81% of others)	Doctorates 100% WTP (vs 75% all others)			
Household income	25k-50k group = 2.4 × WTP of <\$25k group		25k-50k group = 4.0 × WTP of <\$25k group	25k-50k group = 2.5 × WTP of <\$25k group	\$25k-\$50k group = 3.0 × WTP of <\$25k group
Health status					
Percentage of life living with HIV diagnosis	Living with HIV <25% of Lifetime = $2.4 \times WTP$ of 25%-50% group		Living with HIV <25% of Lifetime = $2.9 \times WTP$ of others	Living with HIV <25% of Lifetime = 2.6 × WTP of >50% group	
Ever volunteered for an HIV treatment study			Previous volunteers = $2.3 \times WTP$ of non-volunteers		Previous volunteers = 2.2 × WTP of non-volunteers
Interested in HIV cure research	Non-interested 0% WTP (vs 89% of interested)	Non-interested = $0.07 \times WTP$ of interested	Non-interested 0% WTP (vs 91% of interested)	Non-interested 0% WTP (vs 83% of interested)	Non-interested 0% WTP (vs 91% of interested)

Age, region, being in control of own health care, currently taking HIV medications, and ever volunteered for an HIV cure study are not statistically significantly correlated with willingness to participate of any HIV cure-related study type. WTP=Willingness to Participate; AA=African Americans.

# Appendix 3. Bivariate association between sociodemographic and health status characteristics and general overall willingness to participate in HIV cure-related studies, US, 2015

Variable	п	Willingness HI	to participate in all 14 types of V cure-related studies	Odds ratio (95% CI)	P-value
		Yes (very willing to participate)	No (relatively less willing to participate; willing to participate in 13 or fewer types but not all 14)		
Gender					0.283
Male	284 (79%)	78 (27%)	206 (73%)	1.00	
Female	73 (20%)	15 (21%)	58 (79%)	0.68 (0.37–1.28)	0.232
Transgender male to female, Other	4 (1%)	2 (50%)	2 (50%)	2.64 (0.37–19.07)	0.336
Age					0.064
19–29	19 (5%)	6 (32%)	13 (68%)	1.00	
30–39	42 (12%)	17 (40%)	25 (60%)	1.47 (0.47–4.64)	0.508
40–49	91 (25%)	27 (30%)	64 (70%)	0.91 (0.31–2.66)	0.869
50–59	142 (39%)	34 (24%)	108 (76%)	0.68 (0.24–1.93)	0.471
60+	67 (19%)	11 (16%)	56 (84%)	0.43 (0.13–1.36)	0.150
As a continuous variable	361 (100%)			0.97 (0.95–0.99)	0.005**
Ethnicity					0.224
Caucasian/white	240 (66%)	71 (30%)	169 (70%)	1.00	
African-American/black	52 (14%)	12 (23%)	40 (77%)	0.71 (0.35–1.44)	0.347
Hispanic or Hispanic descent	43 (12%)	8 (19%)	35 (81%)	0.54 (0.24–1.23)	0.144
Other	12 (3%)	1 (8%)	11 (92%)	0.22 (0.03–1.71)	0.146
Mixed	14 (4%)	3 (21%)	11 (79%)	0.65 (0.18–2.40)	0.517
Education					0.356
High school or GED, or less	89 (25%)	27 (30%)	62 (70%)	1.00	
Some college/Associate degree	90 (25%)	26 (29%)	64 (71%)	0.93 (0.49–1.77)	0.832
Undergraduate degree	97 (27%)	26 (27%)	71 (73%)	0.84 (0.44–1.59)	0.594
Master's degree or its equivalent	62 (17%)	11 (18%)	51 (82%)	0.50 (0.22–1.09)	0.082
Doctorate or its equivalent	22 (6%)	4 (18%)	18 (82%)	0.51 (0.16–1.65)	0.261
Household income					0.471
Less than \$25,000	127 (35%)	32 (25%)	95 (75%)	1.00	
\$25,000-\$50,000	100 (28%)	31 (31%)	69 (69%)	1.33 (0.74–2.39)	0.333
\$50,001-\$75,000	45 (13%)	10 (22%)	35 (78%)	0.85 (0.38–1.90)	0.690
\$75,001-\$100,000	35 (10%)	7 (20%)	28 (80%)	0.74 (0.30–1.86)	0.525
\$100,001-\$125,000	28 (8%)	10 (36%)	18 (64%)	1.65 (0.69–3.94)	0.260
\$125,001-\$150,000	9 (3%)	3 (33%)	6 (67%)	1.48 (0.35–6.28)	0.592
More than \$150,000	16 (4%)	2 (13%)	14 (88%)	0.42 (0.09–1.97)	0.273
Region					0.699
Northeast	39 (11%)	9 (23%)	30 (77%)	1.00	
Midwest	62 (17%)	13 (21%)	49 (79%)	0.88 (0.34–2.32)	0.803
South	126 (35%)	35 (28%)	91 (72%)	1.28 (0.55–2.97)	0.562
West	130 (36%)	36 (28%)	94 (72%)	1.28 (0.55–2.95)	0.568
Health status					<0.001***
Very healthy	68 (19%)	16 (24%)	52 (76%)	1.00	
Healthy	162 (45%)	50 (31%)	112 (69%)	1.45 (0.76–2.78)	0.263
Somewhat healthy	110 (31%)	17 (15%)	93 (85%)	0.59 (0.28–1.27)	0.181
Not very healthy/not at all healthy	20 (6%)	12 (60%)	8 (40%)	4.88 (1.70–14.01)	0.003**
In control over own health care					0.666
No	48 (14%)	14 (29%)	34 (71%)	1.00	
Yes	298 (86%)	78 (26%)	220 (74%)	0.86 (0.44–1.69)	0.663
Percentage of life living with HIV diagno	sis				<0.001***
Up to 25%	129 (36%)	53 (41%)	76 (59%)	1.00	
26–50%	171 (48%)	29 (17%)	142 (83%)	0.29 (0.17–0.50)	<0.001***

### Appendix 3. Continued

Variable	п	Willingness Hl	to participate in all 14 types of V cure-related studies	Odds ratio (95% CI)	P-value
		Yes (very willing to participate)	No (relatively less willing to participate; willing to participate in 13 or fewer types but not all 14)		
More than 50%	56 (16%)	12 (21%)	44 (79%)	0.39 (0.19–0.81)	0.012*
As a continuous variable	356 (100%)			0.07 (0.02–0.28)	<0.001***
Ever volunteered for an HIV treatment study	1				0.075
No	199 (56%)	60 (30%)	139 (70%)	1.00	
Yes	156 (44%)	34 (22%)	122 (78%)	0.65 (0.40–1.05)	0.078
Ever volunteered for an HIV cure study					0.014*
No	329 (93%)	93 (28%)	236 (72%)	1.00	
Yes	25 (7%)	2 (8%)	23 (92%)	0.22 (0.05–0.95)	0.043*
Generally interested in HIV cure research					
No	5 (1%)	0 (0%)	5 (100%)	Perfect correlation	
Yes	346 (99%)	95 (27%)	251 (73%)		

\*\*\* Statistically significant at 0.1% level; \*\* statistically significant at 1% level; \* statistically significant at 5% level.

# Appendix 4. Survey/questionnaire research: bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related survey/questionnaire research, US, 2015

Variable	Total (n)	WTP in surveys/q	uestionnaires	OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
Gender					0.623
Male	272 (80%)	266 (98%)	6 (2%)	1.00	
Female	67 (20%)	67 (100%)	0 (0%)	Perfect correlation	
Transgender male to female, other	3 (1%)	3 (100%)	0 (0%)	Perfect correlation	
Age					0.299
19–29	17 (5%)	17 (100%)	0 (0%)	Perfect correlation	
30–39	40 (12%)	40 (100%)	0 (0%)	Perfect correlation	
40–49	87 (25%)	83 (95%)	4 (5%)	0.31 (0.05–1.71)	0.177
50–59	138 (40%)	136 (99%)	2 (1%)	1.00	
60+	60 (18%)	60 (100%)	0 (0%)	Perfect correlation	
Ethnicity					0.227
Caucasian/white	229 (67%)	226 (99%)	3 (1%)	1.00	
African-American/black	48 (14%)	47 (98%)	1 (2%)	0.62 (0.06–6.15)	0.686
Hispanic or Hispanic descent	40 (12%)	39 (98%)	1 (3%)	0.52 (0.05–5.12)	0.573
Other	11 (3%)	10 (91%)	1 (9%)	0.13 (0.01–1.4)	0.093
Mixed	14 (4%)	14 (100%)	0 (0%)	Perfect correlation	
Education					0.773
High school or GED, or less	82 (24%)	81 (99%)	1 (1%)	1.00	
Some college/Associate degree	86 (25%)	83 (97%)	3 (3%)	0.34 (0.03–3.36)	0.357
Undergraduate degree	92 (27%)	91 (99%)	1 (1%)	1.12 (0.07–18.33)	0.935
Master's degree or its equivalent	61 (18%)	60 (98%)	1 (2%)	0.74 (0.05–12.14)	0.833
Doctorate or its equivalent	20 (6%)	20 (100%)	0 (0%)	Perfect correlation	
Household income					0.316
Less than \$25,000	119 (35%)	116 (97%)	3 (3%)	1.00	
\$25,000-\$50,000	93 (27%)	93 (100%)	0 (0%)	Perfect correlation	
\$50,001-\$75,000	43 (13%)	42 (98%)	1 (2%)	1.09 (0.11–10.8)	0.944
\$75,001-\$100,000	34 (10%)	32 (94%)	2 (6%)	0.41 (0.07–2.6)	0.346
\$100,001-\$125,000	28 (8%)	28 (100%)	0 (0%)	Perfect correlation	
\$125,001-\$150,000	9 (3%)	9 (100%)	0 (0%)	Perfect correlation	
More than \$150,000	15 (4%)	15 (100%)	0 (0%)	Perfect correlation	

# Appendix 4. Continued

Variable	Total ( <i>n</i> )	WTP in surveys,	/questionnaires	OR (95% CI)	P-value <sup>1</sup>
		Yes	No		
Region					0.817
Northeast	63 (18%)	61 (97%)	2 (3%)	1.00	
Midwest	158 (46%)	156 (99%)	2 (1%)	0.47 (0.06–3.41)	0.453
South	100 (29%)	98 (98%)	2 (2%)	0.96 (0.13–6.94)	0.967
West	20 (6%)	20 (100%)	0 (0%)	Perfect correlation	
Health status					0.648
Very healthy	51 (20%)	35 (69%)	16 (31%)	1.00	
Healthy	111 (44%)	86 (77%)	25 (23%)	2.56 (0.35–18.62)	0.354
Somewhat healthy	72 (29%)	48 (67%)	24 (33%)	1.61 (0.22–11.74)	0.64
Not very healthy/not at all healthy	17 (7%)	17 (100%)	0 (0%)	Perfect correlation	
In control over own health care					0.597
No	46 (14%)	45 (98%)	1 (2%)	1.00	
Yes	284 (86%)	279 (98%)	5 (2%)	1.24 (0.14–10.9)	0.846
Currently taking HIV medication					1.000
No	7 (2%)	7 (100%)	0 (0%)	Perfect correlation	
Yes	335 (98%)	329 (98%)	6 (2%)	1.00	
Percentage of life living with HIV diagnosis					0.448
Up to 25%	126 (37%)	124 (98%)	2 (2%)	1.00	
26–50%	160 (47%)	158 (99%)	2 (1%)	1.27 (0.18–9.2)	0.81
More than 50%	51 (15%)	49 (96%)	2 (4%)	0.4 (0.05–2.89)	0.361
Ever volunteered for an HIV treatment study					0.237
No	189 (56%)	184 (97%)	5 (3%)	1.00	
Yes	147 (44%)	146 (99%)	1 (1%)	3.97 (0.46–34.44)	0.211
Ever volunteered for an HIV cure study					1.000
No	314 (93%)	309 (98%)	5 (2%)	1.00	
Yes	23 (7%)	23 (100%)	0 (0%)	Perfect correlation	
Generally interested in HIV cure research					1.000
No	5 (1%)	5 (100%)	0 (0%)	Perfect correlation	
Yes	329 (99%)	324 (98%)	5 (2%)	1.00	

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories.

# Appendix 5. Interviews: Bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related studies including interviews, US, 2015

Variable	Total ( <i>n</i> )	Total ( <i>n</i> ) WTP in interviews		OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
Gender					0.812
Male	272 (79%)	255 (94%)	17 (6%)	1.00	
Female	68 (20%)	65 (96%)	3 (4%)	1.44 (0.41–5.09)	0.567
Transgender male to female, other	3 (1%)	3 (100%)	0 (0%)	Perfect correlation	
Age					0.521
19–29	17 (5%)	16 (94%)	1 (6%)	1.00	
30–39	40 (12%)	39 (98%)	1 (3%)	2.44 (0.14–41.57)	0.538
40–49	88 (26%)	80 (91%)	8 (9%)	0.63 (0.07–5.37)	0.668
50–59	133 (39%)	125 (94%)	8 (6%)	0.98 (0.11–8.35)	0.983
60+	65 (19%)	63 (97%)	2 (3%)	1.97 (0.17–23.18)	0.59

# Appendix 5. Continued

Variable	Total (n)	WTP in interviews		OR (95% CI)	P-value	
		Yes	No			
Ethnicity					0.737	
Caucasian/white	229 (67%)	217 (95%)	12 (5%)	1.00		
African-American/black	49 (14%)	45 (92%)	4 (8%)	0.62 (0.19–2.02)	0.43	
Hispanic or Hispanic descent	40 (12%)	37 (93%)	3 (8%)	0.68 (0.18–2.54)	0.568	
Other	11 (3%)	11 (100%)	0 (0%)	Perfect correlation		
Mixed	14 (4%)	13 (93%)	1 (7%)	0.72 (0.09–5.98)	0.76	
Education					0.806	
High school or GED, or less	84 (25%)	77 (92%)	7 (8%)	1.00		
Some college/Associate degree	83 (24%)	79 (95%)	4 (5%)	1.8 (0.5–6.39)	0.366	
Undergraduate degree	94 (27%)	90 (96%)	4 (4%)	2.05 (0.58–7.26)	0.268	
Master's degree or its equivalent	60 (18%)	56 (93%)	4 (7%)	1.27 (0.35–4.57)	0.711	
Doctorate or its equivalent	21 (6%)	20 (95%)	1 (5%)	1.82 (0.21–15.69)	0.587	
Household income					0.444	
Less than \$25,000	116 (34%)	109 (94%)	7 (6%)	1.00		
\$25,000-\$50,000	95 (28%)	92 (97%)	3 (3%)	1.97 (0.49–7.85)	0.337	
\$50,001-\$75,000	44 (13%)	41 (93%)	3 (7%)	0.88 (0.22-3.56)	0.855	
\$75,001-\$100,000	35 (10%)	31 (89%)	4 (11%)	0.5 (0.14–1.81)	0.29	
\$100,001-\$125,000	27 (8%)	26 (96%)	1 (4%)	1.67 (0.2–14.22)	0.639	
\$125,001-\$150,000	9 (3%)	9 (100%)	0 (0%)	Perfect correlation		
More than \$150,000	16 (5%)	14 (88%)	2 (13%)	0.45 (0.08–2.39)	0.348	
Region					0.045*	
Northeast	37 (11%)	35 (95%)	2 (5%)	1.00		
Midwest	56 (16%)	48 (86%)	8 (14%)	0.34 (0.07–1.72)	0.193	
South	124 (36%)	118 (95%)	6 (5%)	1.12 (0.22–5.83)	0.889	
West	123 (36%)	119 (97%)	4 (3%)	1.7 (0.3–9.7)	0.55	
Health status					0.660	
Very healthy	66 (19%)	62 (94%)	4 (6%)	1.00		
Healthy	154 (45%)	146 (95%)	8 (5%)	1.18 (0.34–4.06)	0.796	
Somewhat healthy	103 (30%)	95 (92%)	8 (8%)	0.77 (0.22–2.66)	0.675	
Not very healthy/not at all healthy	19 (6%)	19 (100%)	0 (0%)	Perfect correlation		
In control over own healthcare					0.736	
No	46 (14%)	43 (93%)	3 (7%)	1.00		
Yes	284 (86%)	268 (94%)	16 (6%)	1.17 (0.33–4.19)	0.811	
Currently taking HIV medication					1.000	
No	7 (2%)	7 (100%)	0 (0%)	Perfect correlation		
Yes	336 (98%)	316 (94%)	20 (6%)	1.00		
Percentage of life living with HIV diagnosis					1.000	
Up to 25%	126 (37%)	119 (94%)	7 (6%)	1.00		
26–50%	163 (48%)	153 (94%)	10 (6%)	0.9 (0.33–2.44)	0.836	
More than 50%	49 (14%)	46 (94%)	3 (6%)	0.9 (0.22–3.65)	0.885	
Ever volunteered for an HIV treatment study					0.818	
No	189 (56%)	177 (94%)	12 (6%)	1.00		
Yes	150 (44%)	142 (95%)	8 (5%)	1.2 (0.48–3.03)	0.694	
Ever volunteered for an HIV cure study					0.161	
No	314 (93%)	297 (95%)	17 (5%)	1.00		
Yes	24 (7%)	21 (88%)	3 (13%)	0.4 (0.11–1.48)	0.17	
Generally interested in HIV cure research					0.243	
No	5 (1%)	4 (80%)	1 (20%)	1.00		
Yes	330 (99%)	313 (95%)	17 (5%)	4.6 (0.49–43.6)	0.183	

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories.
 \* Statistically significant at 5% level.

# Appendix 6. Focus group discussions: Bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related focus group discussions, US, 2015

Variable	Total (n)	WTP in focus groups		OR (95% CI)	P-value <sup>1</sup>
		Yes	No		
Gender					0.148
Male	261 (78%)	230 (88%)	31 (12%)	1.00	
Female	69 (21%)	66 (96%)	3 (4%)	2.97 (0.88–10.02)	0.08
Transgender male to female, other	3 (1%)	3 (100%)	0 (0%)	Perfect correlation	
Age					0.480
19–29	18 (5%)	15 (83%)	3 (17%)	1.00	
30–39	39 (12%)	37 (95%)	2 (5%)	3.7 (0.56–24.49)	0.175
40–49	87 (26%)	79 (91%)	8 (9%)	1.98 (0.47-8.33)	0.354
50–59	127 (38%)	115 (91%)	12 (9%)	1.92 (0.48–7.59)	0.354
60+	62 (19%)	53 (85%)	9 (15%)	1.18 (0.28–4.92)	0.822
Ethnicity					0.817
Caucasian/white	222 (67%)	200 (90%)	22 (10%)	1.00	
African-American/black	50 (15%)	46 (92%)	4 (8%)	1.27 (0.42–3.85)	0.679
Hispanic or Hispanic descent	37 (11%)	32 (86%)	5 (14%)	0.7 (0.25–2)	0.509
Other	10 (3%)	9 (90%)	1 (10%)	0.99 (0.12-8.21)	0.993
Mixed	14 (4%)	12 (86%)	2 (14%)	0.66 (0.14–3.15)	0.602
Education					0.727
High school or GED, or less	85 (26%)	73 (86%)	12 (14%)	1.00	
Some college/Associate degree	80 (24%)	73 (91%)	7 (9%)	1.71 (0.64–4.61)	0.285
Undergraduate degree	90 (27%)	81 (90%)	9 (10%)	1.48 (0.59–3.72)	0.405
Master's degree or its equivalent	57 (17%)	53 (93%)	4 (7%)	2.18 (0.66–7.14)	0.199
Doctorate or its equivalent	20 (6%)	18 (90%)	2 (10%)	1.48 (0.3–7.22)	0.628
Household income					0.020*
Less than \$25,000	115 (35%)	100 (87%)	15 (13%)	1.00	
\$25,000-\$50,000	94 (28%)	90 (96%)	4 (4%)	3.38 (1.08–10.56)	0.037*
\$50,001-\$75,000	40 (12%)	35 (88%)	5 (13%)	1.05 (0.35–3.11)	0.93
\$75,001-\$100,000	34 (10%)	29 (85%)	5 (15%)	0.87 (0.29–2.6)	0.803
\$100,001-\$125,000	26 (8%)	26 (100%)	0 (0%)	Perfect correlation	
\$125,001-\$150,000	8 (2%)	8 (100%)	0 (0%)	Perfect correlation	
More than \$150,000	15 (5%)	11 (73%)	4 (27%)	0.41 (0.12–1.47)	0.171
Region					0.362
Northeast	37 (11%)	36 (97%)	1 (3%)	1.00	
Midwest	58 (18%)	52 (90%)	6 (10%)	0.24 (0.03–2.09)	0.197
South	120 (36%)	108 (90%)	12 (10%)	0.25 (0.03–2)	0.191
West	115 (35%)	100 (87%)	15 (13%)	0.19 (0.02–1.46)	0.109
Health status					0.690
Very healthy	63 (19%)	54 (86%)	9 (14%)	1.00	
Healthy	149 (45%)	135 (91%)	14 (9%)	1.61 (0.66–3.94)	0.299
Somewhat healthy	102 (31%)	92 (90%)	10 (10%)	1.53 (0.59–4.02)	0.384
Not very healthy/not at all healthy	18 (5%)	17 (94%)	1 (6%)	2.83 (0.33–24.08)	0.34
In control over own healthcare					1.000
No	45 (14%)	41 (91%)	4 (9%)	1.00	
Yes	275 (86%)	247 (90%)	28 (10%)	0.86 (0.29–2.59)	0.789
Currently taking HIV medication					1.000
No	5 (2%)	5 (100%)	0 (0%)	Perfect correlation	
Yes	328 (98%)	294 (90%)	34 (10%)	1.00	

### Appendix 6. Continued

Variable	Total ( <i>n</i> ) WTP in focus groups		OR (95% CI)	P-value <sup>1</sup>	
		Yes	No		
Percentage of life living with HIV diagnosis					0.630
Up to 25%	123 (38%)	111 (90%)	12 (10%)	1.00	
26–50%	155 (47%)	138 (89%)	17 (11%)	0.88 (0.4–1.92)	0.743
More than 50%	50 (15%)	47 (94%)	3 (6%)	1.69 (0.46–6.29)	0.431
Ever volunteered for an HIV treatment study					0.201
No	184 (56%)	161 (88%)	23 (13%)	1.00	
Yes	144 (44%)	133 (92%)	11 (8%)	1.73 (0.81–3.68)	0.156
Ever volunteered for an HIV cure study					0.726
No	304 (93%)	273 (90%)	31 (10%)	1.00	
Yes	24 (7%)	21 (88%)	3 (13%)	0.79 (0.22–2.82)	0.723
Generally interested in HIV cure research					0.397
No	5 (2%)	4 (80%)	1 (20%)	1.00	
Yes	319 (98%)	289 (91%)	30 (9%)	2.41 (0.26–22.32)	0.439

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories.

\* Statistically significant at 5% level.

# Appendix 7. Basic blood draw studies: Bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related basic blood draw studies, US, 2015

Variable	Total (n)	WTP in basic blood draw studies		OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
Gender					0.788
Male	267 (78%)	254 (95%)	13 (5%)	1.00	
Female	71 (21%)	69 (97%)	2 (3%)	1.77 (0.39–8.03)	0.462
Transgender male to female, other	4 (1%)	4 (100%)	0 (0%)	Perfect correlation	
Age					0.228
19–29	18 (5%)	18 (100%)	0 (0%)	Perfect correlation	
30–39	42 (12%)	41 (98%)	1 (2%)	0.67 (0.04–11.1)	0.781
40–49	88 (26%)	80 (91%)	8 (9%)	0.16 (0.02–1.35)	0.093
50–59	132 (39%)	127 (96%)	5 (4%)	0.42 (0.05–3.65)	0.429
60+	62 (18%)	61 (98%)	1 (2%)	1.00	
Ethnicity					0.355
Caucasian/white	231 (68%)	223 (97%)	8 (3%)	1.00	
African-American/black	49 (14%)	46 (94%)	3 (6%)	0.55 (0.14–2.16)	0.391
Hispanic or Hispanic descent	38 (11%)	35 (92%)	3 (8%)	0.42 (0.11–1.66)	0.215
Other	11 (3%)	10 (91%)	1 (9%)	0.36 (0.04–3.16)	0.356
Mixed	13 (4%)	13 (100%)	0 (0%)	Perfect correlation	
Education					0.894
High school or GED, or less	86 (25%)	82 (95%)	4 (5%)	1.00	
Some college/Associate degree	79 (23%)	74 (94%)	5 (6%)	0.72 (0.19–2.8)	0.637
Undergraduate degree	95 (28%)	91 (96%)	4 (4%)	1.11 (0.27–4.59)	0.886
Master's degree or its equivalent	60 (18%)	58 (97%)	2 (3%)	1.41 (0.25–8)	0.695
Doctorate or its equivalent	21 (6%)	21 (100%)	0 (0%)	Perfect correlation	
Household income					0.208
Less than \$25,000	116 (34%)	108 (93%)	8 (7%)	1.00	
\$25,000-\$50,000	96 (28%)	95 (99%)	1 (1%)	7.04 (0.86–57.48)	0.069
\$50,001-\$75,000	44 (13%)	42 (95%)	2 (5%)	1.56 (0.32–7.65)	0.587
\$75,001-\$100,000	34 (10%)	33 (97%)	1 (3%)	2.44 (0.29–20.33)	0.408
\$100,001-\$125,000	27 (8%)	26 (96%)	1 (4%)	1.93 (0.23–16.14)	0.546
\$125,001-\$150,000	8 (2%)	8 (100%)	0 (0%)	Perfect correlation	
More than \$150,000	16 (5%)	14 (88%)	2 (13%)	0.52 (0.1–2.7)	0.435

# Appendix 7. Continued

Variable	Total (n)	WTP in basic blood draw studies		OR (95% CI)	P-value <sup>1</sup>
		Yes	No		
Region					0.826
Northeast	37 (11%)	36 (97%)	1 (3%)	1.00	
Midwest	60 (18%)	56 (93%)	4 (7%)	0.39 (0.04–3.63)	0.407
South	122 (36%)	117 (96%)	5 (4%)	0.65 (0.07–5.76)	0.699
West	120 (35%)	115 (96%)	5 (4%)	0.64 (0.07–5.67)	0.687
Health status					0.738
Very healthy	62 (18%)	58 (94%)	4 (6%)	1.00	
Healthy	158 (46%)	152 (96%)	6 (4%)	1.75 (0.47–6.43)	0.401
Somewhat healthy	103 (30%)	98 (95%)	5 (5%)	1.35 (0.35–5.25)	0.663
Not very healthy/not at all healthy	18 (5%)	18 (100%)	0 (0%)	Perfect correlation	
In control over own healthcare					0.413
No	44 (13%)	41 (93%)	3 (7%)	1.00	
Yes	284 (87%)	273 (96%)	11 (4%)	1.82 (0.49–6.8)	0.376
Currently taking HIV medication					1.000
No	7 (2%)	7 (100%)	0 (0%)	Perfect correlation	
Yes	335 (98%)	320 (96%)	15 (4%)	1.00	
Percentage of life living with HIV diagnosis					0.339
Up to 25%	127 (38%)	124 (98%)	3 (2%)	1.00	
26–50%	160 (47%)	151 (94%)	9 (6%)	0.41 (0.11–1.53)	0.184
More than 50%	50 (15%)	47 (94%)	3 (6%)	0.38 (0.07–1.95)	0.246
Ever volunteered for an HIV treatment study					<0.001***
No	189 (56%)	174 (92%)	15 (8%)	1.00	
Yes	148 (44%)	148 (100%)	0 (0%)	Perfect correlation	
Ever volunteered for an HIV cure study					0.614
No	312 (93%)	297 (95%)	15 (5%)	1.00	
Yes	25 (7%)	25 (100%)	0 (0%)	Perfect correlation	
Generally interested in HIV cure research					0.013*
No	5 (2%)	3 (60%)	2 (40%)	1.00	
Yes	328 (98%)	317 (97%)	11 (3%)	19.21 (2.9–127.21)	0.002**

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories. \*\*\* Statistically significant at 0.1% level; \*\* statistically significant at 1% level; \* statistically significant at 5% level.

# Appendix 8. Leukapheresis and apheresis studies: bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related studies involving leukaphereses or aphereses, US, 2015

Variable	Total (n)	WTP in leukapheresis	OR (95% CI)	P-value <sup>1</sup>	
		Yes	No		
Gender					0.343
Male	257 (81%)	229 (89%)	28 (11%)	1.00	
Female	57 (18%)	47 (82%)	10 (18%)	0.57 (0.26–1.26)	0.169
Transgender male to female, other	3 (1%)	3 (100%)	0 (0%)	Perfect correlation	
Age					0.728
19–29	15 (5%)	12 (80%)	3 (20%)	1.00	
30–39	37 (12%)	34 (92%)	3 (8%)	2.83 (0.5–16.03)	0.239
40–49	83 (26%)	74 (89%)	9 (11%)	2.06 (0.48-8.71)	0.328
50–59	127 (40%)	112 (88%)	15 (12%)	1.87 (0.47–7.4)	0.374
60+	55 (17%)	47 (85%)	8 (15%)	1.47 (0.34–6.41)	0.609

# Appendix 8. Continued

Variable	Total (n)	WTP in leukapheresis	or apheresis studies	OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
Ethnicity					0.037*
Caucasian/white	219 (69%)	200 (91%)	19 (9%)	1.00	
African-American/black	43 (14%)	33 (77%)	10 (23%)	0.31 (0.13–0.73)	0.008**
Hispanic or Hispanic descent	31 (10%)	25 (81%)	6 (19%)	0.4 (0.14–1.09)	0.072
Other	12 (4%)	10 (83%)	2 (17%)	0.48 (0.1–2.33)	0.359
Mixed	12 (4%)	11 (92%)	1 (8%)	1.05 (0.13-8.57)	0.967
Education					0.345
High school or GED, or less	78 (25%)	66 (85%)	12 (15%)	1.00	
Some college/Associate degree	72 (23%)	60 (83%)	12 (17%)	0.91 (0.38–2.18)	0.831
Undergraduate degree	90 (28%)	81 (90%)	9 (10%)	1.64 (0.65–4.13)	0.297
Master's degree or its equivalent	55 (17%)	51 (93%)	4 (7%)	2.32 (0.7–7.63)	0.166
Doctorate or its equivalent	21 (7%)	20 (95%)	1 (5%)	3.64 (0.44–29.81)	0.229
Household income					0.039*
Less than \$25,000	108 (34%)	85 (79%)	23 (21%)	1.00	
\$25.000-\$50.000	86 (27%)	80 (93%)	6 (7%)	3.61 (1.39–9.33)	0.008**
\$50,001-\$75,000	41 (13%)	36 (88%)	5 (12%)	1 95 (0 69–5 54)	0.211
\$75,001-\$100,000	32 (10%)	30 (94%)	2 (6%)	4 06 (0 9–18 3)	0.068
\$100.001-\$125.000	25 (8%)	24 (96%)	1 (4%)	6 49 (0 83-50 75)	0.075
\$125,001-\$150,000	9 (3%)	9 (100%)	0 (0%)	Perfect correlation	0.075
More than \$150,000	15 (5%)	14 (03%)	1 (7%)	3 79 (0 47_30 44)	0.21
Pogion	15 (576)	14 (3576)	1 (770)	5.75 (0.47-50.44)	0.21
Northoast	21 (10%)	28 (00%)	2 (10%)	1.00	0.009
Midwort	51 (10%)	28 (90%) 45 (90%)	11 (20%)	0.44 (0.11, 1.71)	0 726
South	116 (27%)	45 (60%)	17 (20%)	0.44 (0.11-1.71)	0.250
West	110 (37%)	08 (90%)	12 (10%)	0.99 (0.24-3.33)	0.915
	110 (35%)	98 (89%)	12 (11%)	0.88 (0.23-3.33)	0.845
Health status	C1 (100()	F2 (070/)	0 (120/)	1.00	0.453
	61 (19%)	53 (87%)	8 (13%)	1.00	0.024
Healthy	141 (45%)	124 (88%)	17 (12%)	1.1 (0.45-2.71)	0.834
Somewhat healthy	95 (30%)	83 (87%)	12 (13%)	1.04 (0.4–2.73)	0.93
Not very healthy/not at all healthy	19 (6%)	19 (100%)	0 (0%)	Perfect correlation	
In control over own healthcare					0.322
No	45 (15%)	38 (84%)	7 (16%)	1.00	
Yes	260 (85%)	232 (89%)	28 (11%)	1.53 (0.62–3.75)	0.356
Currently taking HIV medication					1.000
No	7 (2%)	7 (100%)	0 (0%)	Perfect correlation	
Yes	310 (98%)	272 (88%)	38 (12%)	1.00	
Percentage of life living with HIV diagnosis					0.062
Up to 25%	121 (39%)	113 (93%)	8 (7%)	1.00	
26–50%	144 (46%)	123 (85%)	21 (15%)	0.41 (0.18–0.97)	0.044*
More than 50%	48 (15%)	40 (83%)	8 (17%)	0.35 (0.12–1.01)	0.052
Ever volunteered for an HIV treatment study					0.158
No	174 (56%)	149 (86%)	25 (14%)	1.00	
Yes	139 (44%)	127 (91%)	12 (9%)	1.78 (0.86–3.68)	0.123
Ever volunteered for an HIV cure study					1.000
No	287 (92%)	252 (88%)	35 (12%)	1.00	
Yes	24 (8%)	21 (88%)	3 (13%)	0.97 (0.28–3.44)	0.965
Generally interested in HIV cure research					<0.001***
No	4 (1%)	0 (0%)	4 (100%)	Perfect correlation	
Yes	304 (99%)	274 (90%)	30 (10%)	1.00	

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories. \*\*\* Statistically significant at 0.1% level; \*\* statistically significant at 1% level; \* statistically significant at 5% level.

# Appendix 9. Latency reversing agents: bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related studies involving latency reversing agents, US, 2015

Variable	Total (n)	WTP in studies involving latency reversing agents		OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
Gender					0.059
Male	206 (78%)	154 (75%)	52 (25%)	1.00	
Female	54 (20%)	33 (61%)	21 (39%)	0.53 (0.28–1)	0.049*
Transgender male to female, Other	4 (2%)	2 (50%)	2 (50%)	0.34 (0.05–2.47)	0.285
Age					0.184
19–29	17 (6%)	11 (65%)	6 (35%)	1.00	
30–39	34 (13%)	28 (82%)	6 (18%)	2.55 (0.67–9.64)	0.169
40–49	70 (27%)	49 (70%)	21 (30%)	1.27 (0.42–3.9)	0.673
50–59	95 (36%)	72 (76%)	23 (24%)	1.71 (0.57–5.14)	0.341
60+	48 (18%)	29 (60%)	19 (40%)	0.83 (0.26–2.64)	0.755
Ethnicity					0.012*
Caucasian/white	175 (66%)	137 (78%)	38 (22%)	1.00	
African-American/black	42 (16%)	24 (57%)	18 (43%)	0.37 (0.18–0.75)	0.006**
Hispanic or Hispanic descent	29 (11%)	18 (62%)	11 (38%)	0.45 (0.2–1.04)	0.063
Other	6 (2%)	3 (50%)	3 (50%)	0.28 (0.05–1.43)	0.126
Mixed	12 (5%)	7 (58%)	5 (42%)	0.39 (0.12–1.3)	0.124
Education					0.003 * *
High school or GED, or less	68 (26%)	46 (68%)	22 (32%)	1.00	
Some college/Associate degree	66 (25%)	38 (58%)	28 (42%)	0.65 (0.32–1.31)	0.23
Undergraduate degree	71 (27%)	55 (77%)	16 (23%)	1.64 (0.77–3.5)	0.197
Master's degree or its equivalent	43 (16%)	34 (79%)	9 (21%)	1.81 (0.74–4.42)	0.195
Doctorate or its equivalent	15 (6%)	15 (100%)	0 (0%)	Perfect correlation	
Household income					0.256
Less than \$25,000	90 (34%)	60 (67%)	30 (33%)	1.00	
\$25,000-\$50,000	76 (29%)	57 (75%)	19 (25%)	1.5 (0.76–2.96)	0.243
\$50,001-\$75,000	35 (13%)	21 (60%)	14 (40%)	0.75 (0.33–1.68)	0.485
\$75,001-\$100,000	24 (9%)	19 (79%)	5 (21%)	1.9 (0.65–5.6)	0.244
\$100,001-\$125,000	19 (7%)	17 (89%)	2 (11%)	4.25 (0.92–19.67)	0.064
\$125,001-\$150,000	6 (2%)	5 (83%)	1 (17%)	2.5 (0.28–22.46)	0.413
More than \$150,000	14 (5%)	10 (71%)	4 (29%)	1.25 (0.36–4.33)	0.725
Region					0.370
Northeast	27 (10%)	17 (63%)	10 (37%)	1.00	
Midwest	49 (19%)	32 (65%)	17 (35%)	1.11 (0.42–2.95)	0.838
South	93 (36%)	71 (76%)	22 (24%)	1.9 (0.76–4.75)	0.171
West	92 (35%)	67 (73%)	25 (27%)	1.58 (0.64–3.91)	0.326
Health status					0.082
Very healthy	52 (20%)	33 (63%)	19 (37%)	1.00	
Healthy	114 (43%)	84 (74%)	30 (26%)	1.61 (0.8–3.26)	0.183
Somewhat healthy	80 (30%)	56 (70%)	24 (30%)	1.34 (0.64–2.82)	0.435
Not very healthy/not at all healthy	17 (6%)	16 (94%)	1 (6%)	9.21 (1.13–75.35)	0.038*
In control over own healthcare					1.000
No	36 (14%)	26 (72%)	10 (28%)	1.00	
Yes	218 (86%)	157 (72%)	61 (28%)	0.99 (0.45–2.18)	0.98
Currently taking HIV medication					0.580
No	4 (2%)	4 (100%)	0 (0%)	Perfect correlation	
Yes	260 (98%)	185 (71%)	75 (29%)	1.00	

## Appendix 9. Continued

Variable	Total ( <i>n</i> )	Total (n) WTP in studies involving latency reversing agents		OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
Percentage of life living with HIV diagnosis					0.002**
Up to 25%	110 (42%)	91 (83%)	19 (17%)	1.00	
26–50%	112 (43%)	73 (65%)	39 (35%)	0.39 (0.21–0.73)	0.003**
More than 50%	39 (15%)	23 (59%)	16 (41%)	0.3 (0.13–0.67)	0.004**
Ever volunteered for an HIV treatment study					0.097
No	152 (58%)	103 (68%)	49 (32%)	1.00	
Yes	110 (42%)	85 (77%)	25 (23%)	1.62 (0.92–2.84)	0.093
Ever volunteered for an HIV cure study					0.794
No	244 (93%)	175 (72%)	69 (28%)	1.00	
Yes	19 (7%)	13 (68%)	6 (32%)	0.85 (0.31–2.34)	0.76
Generally interested in HIV cure research					0.020*
No	5 (2%)	1 (20%)	4 (80%)	1.00	
Yes	253 (98%)	187 (74%)	66 (26%)	11.33 (1.24–103.67)	0.032*

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories.

\*\* Statistically significant at 1% level; \* statistically significant at 5% level.

# Appendix 10. Modification of genes in immune cells: bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related studies involving the modification of genes in their immune cells, US, 2015

Variable	Total (n)	WTP in studies invo of patient's gene	olving modification s in immune cells	OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
Gender					0.032*
Male	226 (81%)	190 (84%)	36 (16%)	1.00	
Female	49 (18%)	34 (69%)	15 (31%)	0.43 (0.21–0.87)	0.019*
Transgender male to female, other	3 (1%)	2 (67%)	1 (33%)	0.38 (0.03–4.31)	0.434
Age					0.428
19–29	16 (6%)	13 (81%)	3 (19%)	1.00	
30–39	35 (13%)	32 (91%)	3 (9%)	2.46 (0.44–13.86)	0.307
40–49	75 (27%)	60 (80%)	15 (20%)	0.92 (0.23–3.67)	0.909
50–59	104 (37%)	85 (82%)	19 (18%)	1.03 (0.27–3.99)	0.963
60+	48 (17%)	36 (75%)	12 (25%)	0.69 (0.17–2.86)	0.611
Ethnicity					0.007**
Caucasian/white	181 (65%)	157 (87%)	24 (13%)	1.00	
African-American/black	44 (16%)	29 (66%)	15 (34%)	0.3 (0.14–0.63)	0.002**
Hispanic or Hispanic descent	32 (12%)	25 (78%)	7 (22%)	0.55 (0.21–1.4)	0.209
Other	10 (4%)	6 (60%)	4 (40%)	0.23 (0.06–0.87)	0.031*
Mixed	11 (4%)	9 (82%)	2 (18%)	0.69 (0.14–3.39)	0.646
Education					0.357
High school or GED, or less	66 (24%)	50 (76%)	16 (24%)	1.00	
Some college/Associate degree	70 (25%)	55 (79%)	15 (21%)	1.17 (0.53–2.62)	0.697
Undergraduate degree	83 (30%)	71 (86%)	12 (14%)	1.89 (0.82–4.35)	0.133
Master's degree or its equivalent	41 (15%)	33 (80%)	8 (20%)	1.32 (0.51–3.44)	0.57
Doctorate or its equivalent	17 (6%)	16 (94%)	1 (6%)	5.12 (0.63–41.85)	0.128
Household income					0.013*
Less than \$25,000	96 (35%)	67 (70%)	29 (30%)	1.00	
\$25,000-\$50,000	79 (28%)	71 (90%)	8 (10%)	3.84 (1.64–9.01)	0.002**
\$50,001-\$75,000	35 (13%)	29 (83%)	6 (17%)	2.09 (0.78–5.59)	0.141
\$75,001-\$100,000	27 (10%)	23 (85%)	4 (15%)	2.49 (0.79–7.86)	0.12
\$100,001-\$125,000	22 (8%)	21 (95%)	1 (5%)	9.09 (1.16–71.07)	0.035*

# Appendix 10. Continued

Variable	Total ( <i>n</i> )	WTP in studies involving modification of patient's genes in immune cells		OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
\$125,001-\$150,000	7 (3%)	6 (86%)	1 (14%)	2.6 (0.3–22.64)	0.388
More than \$150,000	12 (4%)	9 (75%)	3 (25%)	1.3 (0.33–5.16)	0.711
Region					0.713
Northeast	25 (9%)	22 (88%)	3 (12%)	1.00	
Midwest	51 (19%)	39 (76%)	12 (24%)	0.44 (0.11–1.75)	0.245
South	101 (37%)	82 (81%)	19 (19%)	0.59 (0.16–2.18)	0.427
West	98 (36%)	80 (82%)	18 (18%)	0.61 (0.16–2.25)	0.455
Health status					0.187
Very healthy	55 (20%)	42 (76%)	13 (24%)	1.00	
Healthy	122 (44%)	104 (85%)	18 (15%)	1.79 (0.8–3.98)	0.154
Somewhat healthy	83 (30%)	64 (77%)	19 (23%)	1.04 (0.47–2.34)	0.919
Not very healthy/not at all healthy	17 (6%)	16 (94%)	1 (6%)	4.95 (0.6–41.16)	0.139
In control over own healthcare					0.129
No	41 (15%)	30 (73%)	11 (27%)	1.00	
Yes	227 (85%)	189 (83%)	38 (17%)	1.82 (0.84–3.96)	0.129
Currently taking HIV medication					0.565
No	4 (1%)	3 (75%)	1 (25%)	1.00	
Yes	274 (99%)	223 (81%)	51 (19%)	1.46 (0.15–14.36)	0.747
Percentage of life living with HIV diagnosis					0.028*
Up to 25%	111 (41%)	99 (89%)	12 (11%)	1.00	
26–50%	122 (45%)	93 (76%)	29 (24%)	0.39 (0.19–0.81)	0.011*
More than 50%	41 (15%)	32 (78%)	9 (22%)	0.43 (0.17–1.12)	0.084
Ever volunteered for an HIV treatment study					0.351
No	155 (57%)	123 (79%)	32 (21%)	1.00	
Yes	119 (43%)	100 (84%)	19 (16%)	1.37 (0.73–2.56)	0.326
Ever volunteered for an HIV cure study					0.212
No	256 (94%)	206 (80%)	50 (20%)	1.00	
Yes	17 (6%)	16 (94%)	1 (6%)	3.88 (0.5–30.09)	0.194
Generally interested in HIV cure research					<0.001***
No	5 (2%)	0 (0%)	5 (100%)	Perfect correlation	
Yes	268 (98%)	225 (84%)	43 (16%)	1.00	

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories. \*\*\* Statistically significant at 0.1% level; \*\* statistically significant at 1% level; \* statistically significant at 5% level.

# Appendix 11. Autologous stem cell transplants: bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related studies involving autologous stem cell transplants, US, 2015

Variable	Total (n)	WTP in autologous stem cell studies		OR (95% CI)	P-value <sup>1</sup>
		Yes	No		
Gender					0.067
Male	228 (81%)	198 (87%)	30 (13%)	1.00	
Female	49 (18%)	37 (76%)	12 (24%)	0.47 (0.22–1)	0.049*
Transgender male to female, other	3 (1%)	2 (67%)	1 (33%)	0.3 (0.03–3.46)	0.337
Age					0.522
19–29	16 (6%)	14 (88%)	2 (13%)	1.00	
30–39	35 (13%)	31 (89%)	4 (11%)	1.11 (0.18–6.79)	0.912
40–49	72 (26%)	58 (81%)	14 (19%)	0.59 (0.12–2.92)	0.519
50–59	108 (39%)	95 (88%)	13 (12%)	1.04 (0.21–5.14)	0.958
60+	49 (18%)	39 (80%)	10 (20%)	0.56 (0.11–2.87)	0.484

# Appendix 11. Continued

Variable	Total ( <i>n</i> )	WTP in autologous stem cell studies		OR (95% CI)	P-value <sup>1</sup>
		Yes	No		
Ethnicity					0.005**
Caucasian/white	189 (68%)	170 (90%)	19 (10%)	1.00	
African-American/black	40 (14%)	28 (70%)	12 (30%)	0.26 (0.11–0.6)	0.001***
Hispanic or Hispanic descent	30 (11%)	23 (77%)	7 (23%)	0.37 (0.14–0.97)	0.043*
Other	12 (4%)	9 (75%)	3 (25%)	0.34 (0.08–1.35)	0.124
Mixed	9 (3%)	7 (78%)	2 (22%)	0.39 (0.08–2.03)	0.263
Education					0.195
High school or GED, or less	67 (24%)	54 (81%)	13 (19%)	1.00	
Some college/Associate degree	71 (25%)	57 (80%)	14 (20%)	0.98 (0.42-2.28)	0.963
Undergraduate degree	82 (29%)	70 (85%)	12 (15%)	1.4 (0.59–3.33)	0.441
Master's degree or its equivalent	43 (15%)	39 (91%)	4 (9%)	2.35 (0.71–7.76)	0.162
Doctorate or its equivalent	16 (6%)	16 (100%)	0 (0%)	Perfect correlation	
Household income					0.053
Less than \$25,000	98 (35%)	74 (76%)	24 (24%)	1.00	
\$25,000-\$50,000	78 (28%)	71 (91%)	7 (9%)	3.29 (1.33–8.13)	0.01**
\$50,001-\$75,000	35 (13%)	28 (80%)	7 (20%)	1.3 (0.5–3.35)	0.591
\$75,001-\$100,000	28 (10%)	25 (89%)	3 (11%)	2.7 (0.75–9.77)	0.13
\$100,001-\$125,000	23 (8%)	22 (96%)	1 (4%)	7.14 (0.91–55.98)	0.062
\$125,001-\$150,000	6 (2%)	6 (100%)	0 (0%)	Perfect correlation	
More than \$150,000	11 (4%)	10 (91%)	1 (9%)	3.24 (0.39–26.76)	0.275
Region					0.259
Northeast	28 (10%)	24 (86%)	4 (14%)	1.00	
Midwest	47 (17%)	35 (74%)	12 (26%)	0.49 (0.14–1.69)	0.257
South	103 (37%)	89 (86%)	14 (14%)	1.06 (0.32–3.52)	0.925
West	99 (36%)	86 (87%)	13 (13%)	1.1 (0.33–3.7)	0.874
Health status					0.220
Very healthy	58 (21%)	48 (83%)	10 (17%)	1.00	
Healthy	126 (45%)	108 (86%)	18 (14%)	1.25 (0.54–2.91)	0.605
Somewhat healthy	78 (28%)	63 (81%)	15 (19%)	0.88 (0.36-2.12)	0.768
Not very healthy/not at all healthy	17 (6%)	17 (100%)	0 (0%)	Perfect correlation	
In control over own healthcare					0.151
No	39 (14%)	30 (77%)	9 (23%)	1.00	
Yes	230 (86%)	198 (86%)	32 (14%)	1.86 (0.81-4.28)	0.146
Currently taking HIV medication					0.595
No	6 (2%)	6 (100%)	0 (0%)	Perfect correlation	
Yes	274 (98%)	231 (84%)	43 (16%)	1.00	
Percentage of life living with HIV diagnosis					0.536
Up to 25%	111 (40%)	97 (87%)	14 (13%)	1.00	
26–50%	124 (45%)	102 (82%)	22 (18%)	0.67 (0.32–1.38)	0.279
More than 50%	40 (15%)	34 (85%)	6 (15%)	0.82 (0.29–2.3)	0.703
Ever volunteered for an HIV treatment study					0.319
No	160 (58%)	132 (83%)	28 (18%)	1.00	
Yes	116 (42%)	101 (87%)	15 (13%)	1.43 (0.72–2.82)	0.304
Ever volunteered for an HIV cure study					1.000
No	254 (92%)	214 (84%)	40 (16%)	1.00	
Yes	21 (8%)	18 (86%)	3 (14%)	1.12 (0.31–3.99)	0.86
Generally interested in HIV cure research					<0.001***
No	5 (2%)	0 (0%)	5 (100%)	Perfect correlation	
Yes	269 (98%)	234 (87%)	35 (13%)	1.00	

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories. \*\*\* Statistically significant at 0.1% level; \*\* statistically significant at 1% level; \* statistically significant at 5% level.

# Appendix 12. **Allogeneic stem Cell transplants:** bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related studies involving allogeneic stem cell transplants, US, 2015

Variable	Total (n)	WTP in allogenic stem cell studies		OR (95% CI)	P-value <sup>1</sup>	
		Yes	No			
Gender					0.354	
Male	205 (81%)	154 (75%)	51 (25%)	1.00		
Female	44 (17%)	29 (66%)	15 (34%)	0.64 (0.32–1.29)	0.212	
Transgender male to female, other	3 (1%)	3 (100%)	0 (0%)	Perfect correlation		
Age					0.245	
19–29	16 (6%)	12 (75%)	4 (25%)	1.00		
30–39	30 (12%)	25 (83%)	5 (17%)	1.67 (0.38–7.37)	0.501	
40–49	69 (27%)	53 (77%)	16 (23%)	1.1 (0.31–3.91)	0.878	
50–59	94 (37%)	70 (74%)	24 (26%)	0.97 (0.29–3.31)	0.964	
60+	43 (17%)	26 (60%)	17 (40%)	0.51 (0.14–1.85)	0.306	
Ethnicity					0.091	
Caucasian/white	170 (67%)	134 (79%)	36 (21%)	1.00		
African-American/black	40 (16%)	26 (65%)	14 (35%)	0.5 (0.24–1.05)	0.069	
Hispanic or Hispanic descent	26 (10%)	16 (62%)	10 (38%)	0.43 (0.18–1.03)	0.058	
Other	9 (4%)	6 (67%)	3 (33%)	0.54 (0.13–2.26)	0.397	
Mixed	7 (3%)	4 (57%)	3 (43%)	0.36 (0.08–1.68)	0.193	
Education					0.941	
High school or GED, or less	63 (25%)	47 (75%)	16 (25%)	1.00		
Some college/Associate degree	63 (25%)	44 (70%)	19 (30%)	0.79 (0.36–1.73)	0.552	
Undergraduate degree	76 (30%)	56 (74%)	20 (26%)	0.95 (0.44–2.05)	0.902	
Master's degree or its equivalent	38 (15%)	29 (76%)	9 (24%)	1.1 (0.43–2.81)	0.847	
Doctorate or its equivalent	11 (4%)	9 (82%)	2 (18%)	1.53 (0.3–7.87)	0.61	
Household income					0.197	
Less than \$25,000	86 (34%)	57 (66%)	29 (34%)	1.00		
\$25,000-\$50,000	71 (28%)	58 (82%)	13 (18%)	2.27 (1.07-4.81)	0.032*	
\$50,001-\$75,000	32 (13%)	24 (75%)	8 (25%)	1.53 (0.61–3.82)	0.367	
\$75,001-\$100,000	26 (10%)	20 (77%)	6 (23%)	1.7 (0.61–4.69)	0.309	
\$100,001-\$125,000	19 (8%)	16 (84%)	3 (16%)	2.71 (0.73–10.1)	0.137	
\$125.001-\$150.000	6 (2%)	3 (50%)	3 (50%)	0.51 (0.1–2.69)	0.426	
More than \$150.000	11 (4%)	7 (64%)	4 (36%)	0.89 (0.24–3.3)	0.862	
Region					0.454	
Northeast	26 (10%)	17 (65%)	9 (35%)	1.00		
Midwest	46 (18%)	32 (70%)	14 (30%)	1.21 (0.43–3.37)	0.715	
South	93 (37%)	73 (78%)	20 (22%)	1.93 (0.75–4.99)	0.174	
West	84 (34%)	61 (73%)	23 (27%)	1.4 (0.55–3.6)	0.48	
Health status					0.012*	
Very healthy	51 (20%)	35 (69%)	16 (31%)	1.00		
Healthy	111 (44%)	86 (77%)	25 (23%)	1.57 (0.75-3.3)	0.232	
Somewhat healthy	72 (29%)	48 (67%)	24 (33%)	0.91 (0.42–1.97)	0.82	
Not very healthy/not at all healthy	17 (7%)	17 (100%)	0 (0%)	Perfect correlation		
In control over own healthcare			0 (070)		0.686	
No	37 (15%)	26 (70%)	11 (30%)	1.00	01000	
Yes	205 (85%)	152 (74%)	53 (26%)	1.21 (0 56–2 63)	0 674	
Currently taking HIV medication	203 (05/0)		22 (20/0)		1 000	
No	4 (7%)	3 (75%)	1 (25%)	1 00	1.000	
Yes	248 (98%)	183 (74%)	65 (26%)	0.94 (0.1–9.22)	0 957	
	2 10 (3070)	105 (1470)	00 (20/0)	0.01 (0.1 0.22)	0.001	

## Appendix 12. Continued

Variable	Total ( <i>n</i> ) WTP in allogenic stem cell studies		OR (95% CI)	P-value <sup>1</sup>	
		Yes	No		
Percentage of life living with HIV diagnosis					0.022*
Up to 25%	105 (42%)	86 (82%)	19 (18%)	1.00	
26–50%	108 (44%)	76 (70%)	32 (30%)	0.52 (0.27–1)	0.051
More than 50%	35 (14%)	21 (60%)	14 (40%)	0.33 (0.14–0.77)	0.01**
Ever volunteered for an HIV treatment study					0.380
No	149 (60%)	113 (76%)	36 (24%)	1.00	
Yes	99 (40%)	70 (71%)	29 (29%)	0.77 (0.43–1.37)	0.37
Ever volunteered for an HIV cure study					1.000
No	232 (94%)	171 (74%)	61 (26%)	1.00	
Yes	15 (6%)	11 (73%)	4 (27%)	0.98 (0.3–3.2)	0.975
Generally interested in HIV cure research					0.001***
No	5 (2%)	0 (0%)	5 (100%)	Perfect correlation	
Yes	242 (98%)	184 (76%)	58 (24%)		

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories. \*\*\* Statistically significant at 0.1% level; \*\* statistically significant at 1% level; \* statistically significant at 5% level.

## Appendix 13. Therapeutic vaccines: bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related studies involving therapeutic vaccines, US, 2015

Variable	Total (n)	WTP in studies with therapeutic vaccines		OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
Gender					0.029*
Male	248 (80%)	222 (90%)	26 (10%)	1.00	
Female	60 (19%)	47 (78%)	13 (22%)	0.42 (0.2–0.89)	0.022*
Transgender male to female, other	3 (1%)	2 (67%)	1 (33%)	0.23 (0.02–2.68)	0.243
Age					0.343
19–29	17 (5%)	17 (100%)	0 (0%)	Perfect correlation	
30–39	39 (13%)	35 (90%)	4 (10%)	1.4 (0.39–5.02)	0.606
40–49	78 (25%)	64 (82%)	14 (18%)	0.73 (0.28–1.88)	0.517
50–59	119 (38%)	105 (88%)	14 (12%)	1.2 (0.47–3.05)	0.702
60+	58 (19%)	50 (86%)	8 (14%)	1.00	
Ethnicity					0.001***
Caucasian/white	209 (67%)	192 (92%)	17 (8%)	1.00	
African-American/black	48 (15%)	38 (79%)	10 (21%)	0.34 (0.14–0.79)	0.013*
Hispanic or Hispanic descent	33 (11%)	25 (76%)	8 (24%)	0.28 (0.11–0.71)	0.007**
Other	9 (3%)	5 (56%)	4 (44%)	0.11 (0.03–0.45)	0.002**
Mixed	12 (4%)	11 (92%)	1 (8%)	0.97 (0.12-8.03)	0.98
Education					0.045*
High school or GED, or less	74 (24%)	61 (82%)	13 (18%)	1.00	
Some college/Associate degree	77 (25%)	62 (81%)	15 (19%)	0.88 (0.39–2.01)	0.763
Undergraduate degree	86 (28%)	79 (92%)	7 (8%)	2.41 (0.9–6.4)	0.079
Master's degree or its equivalent	53 (17%)	48 (91%)	5 (9%)	2.05 (0.68–6.15)	0.202
Doctorate or its equivalent	20 (6%)	20 (100%)	0 (0%)	Perfect correlation	
Household income					0.032*
Less than \$25,000	105 (34%)	82 (78%)	23 (22%)	1.00	
\$25,000-\$50,000	87 (28%)	78 (90%)	9 (10%)	2.43 (1.06–5.59)	0.036*
\$50,001-\$75,000	37 (12%)	34 (92%)	3 (8%)	3.18 (0.89–11.32)	0.074
\$75,001-\$100,000	34 (11%)	31 (91%)	3 (9%)	2.9 (0.81–10.37)	0.102
\$100,001-\$125,000	26 (8%)	26 (100%)	0 (0%)	Perfect correlation	
\$125,001-\$150,000	7 (2%)	7 (100%)	0 (0%)	Perfect correlation	
More than \$150,000	15 (5%)	13 (87%)	2 (13%)	1.82 (0.38–8.69)	0.451

# Appendix 13. Continued

Variable	Total (n)	WTP in studies with therapeutic vaccines		OR (95% CI)	P-value <sup>1</sup>
		Yes	No		
Region					0.239
Northeast	31 (10%)	26 (84%)	5 (16%)	1.00	
Midwest	55 (18%)	44 (80%)	11 (20%)	0.77 (0.24–2.47)	0.659
South	112 (36%)	98 (88%)	14 (13%)	1.35 (0.44–4.09)	0.6
West	109 (36%)	99 (91%)	10 (9%)	1.9 (0.6–6.07)	0.276
Health status					0.065
Very healthy	62 (20%)	53 (85%)	9 (15%)	1.00	
Healthy	139 (45%)	126 (91%)	13 (9%)	1.65 (0.66–4.09)	0.283
Somewhat healthy	91 (29%)	74 (81%)	17 (19%)	0.74 (0.31–1.79)	0.502
Not very healthy/not at all healthy	18 (6%)	18 (100%)	0 (0%)	Perfect correlation	
In control over own healthcare					0.474
No	45 (15%)	38 (84%)	7 (16%)	1.00	
Yes	256 (85%)	225 (88%)	31 (12%)	1.34 (0.55–3.26)	0.523
Currently taking HIV medication					1.000
No	6 (2%)	6 (100%)	0 (0%)	Perfect correlation	
Yes	305 (98%)	265 (87%)	40 (13%)	1.00	
Percentage of life living with HIV diagnosis					0.081
Up to 25%	120 (39%)	111 (93%)	9 (8%)	1.00	
26–50%	142 (46%)	119 (84%)	23 (16%)	0.42 (0.19–0.95)	0.037*
More than 50%	46 (15%)	39 (85%)	7 (15%)	0.45 (0.16–1.3)	0.14
Ever volunteered for an HIV treatment study					0.084
No	171 (56%)	144 (84%)	27 (16%)	1.00	
Yes	136 (44%)	124 (91%)	12 (9%)	1.94 (0.94–3.99)	0.073
Ever volunteered for an HIV cure study					0.054
No	281 (92%)	242 (86%)	39 (14%)	Perfect correlation	
Yes	24 (8%)	24 (100%)	0 (0%)	1.00	
Generally interested in HIV cure research					<0.001***
No	5 (2%)	0 (0%)	5 (100%)	Perfect correlation	
Yes	299 (98%)	267 (89%)	32 (11%)	1.00	

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories. \*\*\* Statistically significant at 0.1% level; \*\* statistically significant at 1% level; \* statistically significant at 5% level.

# Appendix 14. Treatment intensification: bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related studies involving treatment intensification, US, 2015

Variable	Total ( <i>n</i> )	WTP in studies involving intensification of treatment		OR (95% CI)	P-value <sup>1</sup>
		Yes	No		
Gender					0.291
Male	217 (79%)	169 (78%)	48 (22%)	1.00	
Female	55 (20%)	41 (75%)	14 (25%)	0.83 (0.42–1.65)	0.599
Transgender male to female, other	4 (1%)	2 (50%)	2 (50%)	0.28 (0.04–2.08)	0.215
Age					0.663
19–29	15 (5%)	12 (80%)	3 (20%)	1.00	
30–39	37 (13%)	27 (73%)	10 (27%)	0.68 (0.16–2.91)	0.598
40–49	74 (27%)	57 (77%)	17 (23%)	0.84 (0.21–3.33)	0.802
50–59	103 (37%)	83 (81%)	20 (19%)	1.04 (0.27–4.04)	0.958
60+	47 (17%)	33 (70%)	14 (30%)	0.59 (0.14–2.42)	0.463
Ethnicity					0.069
Caucasian/white	185 (67%)	148 (80%)	37 (20%)	1.00	
African-American/black	43 (16%)	33 (77%)	10 (23%)	0.83 (0.37–1.83)	0.635

# Appendix 14. Continued

Variable	Total (n)	WTP in studies involving intensification of treatment		OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
Hispanic or Hispanic descent	29 (11%)	17 (59%)	12 (41%)	0.35 (0.16–0.81)	0.014*
Other	10 (4%)	6 (60%)	4 (40%)	0.38 (0.1–1.4)	0.145
Mixed	9 (3%)	8 (89%)	1 (11%)	2 (0.24–16.56)	0.52
Education					0.050*
High school or GED, or less	67 (24%)	55 (82%)	12 (18%)	1.00	
Some college/Associate degree	67 (24%)	46 (69%)	21 (31%)	0.48 (0.21–1.08)	0.075
Undergraduate degree	76 (28%)	59 (78%)	17 (22%)	0.76 (0.33–1.73)	0.51
Master's degree or its equivalent	50 (18%)	36 (72%)	14 (28%)	0.56 (0.23–1.35)	0.198
Doctorate or its equivalent	15 (5%)	15 (100%)	0 (0%)	Perfect correlation	
Household income					0.531
Less than \$25,000	104 (38%)	75 (72%)	29 (28%)	1.00	
\$25,000-\$50,000	73 (26%)	60 (82%)	13 (18%)	1.78 (0.85–3.73)	0.124
\$50,001-\$75,000	33 (12%)	25 (76%)	8 (24%)	1.21 (0.49–2.99)	0.682
\$75,001-\$100,000	27 (10%)	22 (81%)	5 (19%)	1.7 (0.59–4.93)	0.327
\$100,001-\$125,000	21 (8%)	18 (86%)	3 (14%)	2.32 (0.63-8.49)	0.204
\$125,001-\$150,000	7 (3%)	5 (71%)	2 (29%)	0.97 (0.18–5.28)	0.969
More than \$150,000	11 (4%)	7 (64%)	4 (36%)	0.68 (0.18-2.49)	0.557
Region					0.580
Northeast	26 (10%)	20 (77%)	6 (23%)	1.00	
Midwest	46 (17%)	32 (70%)	14 (30%)	0.69 (0.23–2.08)	0.505
South	100 (37%)	80 (80%)	20 (20%)	1.2 (0.43–3.39)	0.731
West	100 (37%)	76 (76%)	24 (24%)	0.95 (0.34–2.64)	0.922
Health status					0.122
Very healthy	47 (17%)	32 (68%)	15 (32%)	1.00	
Healthy	127 (46%)	102 (80%)	25 (20%)	1.91 (0.9–4.07)	0.092
Somewhat healthy	85 (31%)	63 (74%)	22 (26%)	1.34 (0.61–2.94)	0.461
Not very healthy/not at all healthy	16 (6%)	15 (94%)	1 (6%)	7.03 (0.84–58.52)	0.071
In control over own healthcare					1.000
No	39 (15%)	30 (77%)	9 (23%)	1.00	
Yes	229 (85%)	176 (77%)	53 (23%)	1 (0.44–2.23)	0.993
Currently taking HIV medication					1.000
No	5 (2%)	4 (80%)	1 (20%)	1.00	
Yes	271 (98%)	208 (77%)	63 (23%)	0.83 (0.09–7.55)	0.865
Percentage of life living with HIV diagnosis					0.261
Up to 25%	104 (38%)	85 (82%)	19 (18%)	1.00	
26–50%	125 (46%)	94 (75%)	31 (25%)	0.68 (0.36–1.29)	0.236
More than 50%	44 (16%)	31 (70%)	13 (30%)	0.53 (0.24–1.21)	0.132
Ever volunteered for an HIV treatment study					0.885
No	158 (58%)	122 (77%)	36 (23%)	1.00	
Yes	114 (42%)	87 (76%)	27 (24%)	0.95 (0.54–1.68)	0.863
Ever volunteered for an HIV cure study					0.771
No	258 (94%)	197 (76%)	61 (24%)	1.00	
Yes	16 (6%)	13 (81%)	3 (19%)	1.34 (0.37–4.88)	0.655
Generally interested in HIV cure research					0.010**
No	5 (2%)	1 (20%)	4 (80%)	1.00	
Yes	262 (98%)	206 (79%)	56 (21%)	14.71 (1.61–134.84)	0.017*

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories. \*\* Statistically significant at 1% level; \* statistically significant at 5% level.

Appendix 15. Antibodies, proteins or molecules: bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related studies involving the use of unique antibodies, proteins or molecules, US, 2015

Variable	Total (n)	WTP in use of unique antibodies, proteins or molecules		OR (95% CI)	P-value <sup>1</sup>
		Yes	No		
Gender					0.162
Male	239 (81%)	215 (90%)	24 (10%)	1.00	
Female	52 (18%)	42 (81%)	10 (19%)	0.47 (0.21–1.05)	0.067
Transgender male to female, Other	3 (1%)	3 (100%)	0 (0%)	Perfect correlation	
Age					0.806
19–29	15 (5%)	14 (93%)	1 (7%)	1.00	
30–39	39 (13%)	35 (90%)	4 (10%)	0.63 (0.06–6.12)	0.686
40–49	74 (25%)	63 (85%)	11 (15%)	0.41 (0.05–3.45)	0.411
50–59	114 (39%)	103 (90%)	11 (10%)	0.67 (0.08–5.6)	0.711
60+	52 (18%)	45 (87%)	7 (13%)	0.46 (0.05–4.07)	0.485
Ethnicity					0.028*
Caucasian/white	195 (66%)	180 (92%)	15 (8%)	1.00	
African-American/black	42 (14%)	33 (79%)	9 (21%)	0.31 (0.12–0.76)	0.01**
Hispanic or Hispanic descent	35 (12%)	28 (80%)	7 (20%)	0.33 (0.12–0.89)	0.029*
Other	11 (4%)	9 (82%)	2 (18%)	0.38 (0.07–1.9)	0.236
Mixed	11 (4%)	10 (91%)	1 (9%)	0.83 (0.1–6.98)	0.866
Education					0.129
High school or GED, or less	65 (22%)	54 (83%)	11 (17%)	1.00	
Some college/Associate degree	74 (25%)	62 (84%)	12 (16%)	1.05 (0.43–2.58)	0.911
Undergraduate degree	83 (28%)	76 (92%)	7 (8%)	2.21 (0.8–6.08)	0.124
Master's degree or its equivalent	53 (18%)	49 (92%)	4 (8%)	2.5 (0.74–8.37)	0.139
Doctorate or its equivalent	18 (6%)	18 (100%)	0 (0%)	Perfect correlation	
Household income					0.033*
Less than \$25,000	99 (34%)	79 (80%)	20 (20%)	1.00	
\$25,000-\$50,000	83 (28%)	78 (94%)	5 (6%)	3.95 (1.41–11.07)	0.009**
\$50,001-\$75,000	38 (13%)	33 (87%)	5 (13%)	1.67 (0.58–4.84)	0.344
\$75,001-\$100,000	30 (10%)	27 (90%)	3 (10%)	2.28 (0.63–8.3)	0.212
\$100,001-\$125,000	24 (8%)	24 (100%)	0 (0%)	Perfect correlation	
\$125,001-\$150,000	7 (2%)	7 (100%)	0 (0%)	Perfect correlation	
More than \$150,000	13 (4%)	12 (92%)	1 (8%)	3.04 (0.37–24.86)	0.3
Region					0.235
Northeast	29 (10%)	26 (90%)	3 (10%)	1.00	
Midwest	52 (18%)	42 (81%)	10 (19%)	0.48 (0.12–1.93)	0.304
South	107 (37%)	94 (88%)	13 (12%)	0.83 (0.22–3.16)	0.79
West	102 (35%)	94 (92%)	8 (8%)	1.36 (0.33–5.49)	0.67
Health status					0.255
Very healthy	61 (21%)	52 (85%)	9 (15%)	1.00	
Healthy	134 (46%)	122 (91%)	12 (9%)	1.76 (0.7–4.44)	0.231
Somewhat healthy	83 (28%)	71 (86%)	12 (14%)	1.02 (0.4–2.61)	0.96
Not very healthy/not at all healthy	15 (5%)	15 (100%)	0 (0%)	Perfect correlation	
In control over own healthcare					0.306
No	43 (15%)	36 (84%)	7 (16%)	1.00	
Yes	240 (85%)	214 (89%)	26 (11%)	1.6 (0.65–3.97)	0.31
Currently taking HIV medication					1.000
No	5 (2%)	5 (100%)	0 (0%)	Perfect correlation	
Yes	289 (98%)	255 (88%)	34 (12%)	1.00	

## Appendix 15. Continued

Variable	Total ( <i>n</i> )	otal (n) WTP in use of unique antibodies, proteins or molecules		OR (95% CI)	P-value <sup>1</sup>
		Yes	No		
Percentage of life living with HIV diagnosis					0.039*
Up to 25%	119 (41%)	112 (94%)	7 (6%)	1.00	
26–50%	132 (45%)	112 (85%)	20 (15%)	0.35 (0.14–0.86)	0.022*
More than 50%	40 (14%)	34 (85%)	6 (15%)	0.35 (0.11–1.13)	0.079
Ever volunteered for an HIV treatment study					0.041*
No	161 (56%)	137 (85%)	24 (15%)	1.00	
Yes	129 (44%)	120 (93%)	9 (7%)	2.34 (1.04–5.23)	0.039*
Ever volunteered for an HIV cure study					0.145
No	270 (93%)	236 (87%)	34 (13%)	1.00	
Yes	20 (7%)	20 (100%)	0 (0%)	Perfect correlation	
Generally interested in HIV cure research					<0.001***
No	5 (2%)	0 (0%)	5 (100%)	Perfect correlation	
Yes	282 (98%)	256 (91%)	26 (9%)	1.00	

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories.

\*\*\* Statistically significant at 0.1% level; \*\* statistically significant at 1% level; \* statistically significant at 5% level.

# Appendix 16. First-in-human studies: bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related studies involving new treatments or approaches ('First-in-human' studies), US, 2015

Variable	Total (n)	WTP in first-in-human studies		OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
Gender					0.841
Male	211 (80%)	170 (81%)	41 (19%)	1.00	
Female	49 (19%)	38 (78%)	11 (22%)	0.83 (0.39–1.77)	0.635
Transgender male to female, other	3 (1%)	3 (100%)	0 (0%)	Perfect correlation	
Age					0.849
19–29	18 (7%)	16 (89%)	2 (11%)	1.00	
30–39	34 (13%)	27 (79%)	7 (21%)	0.48 (0.09–2.62)	0.398
40–49	68 (26%)	52 (76%)	16 (24%)	0.41 (0.08–1.96)	0.263
50–59	93 (35%)	75 (81%)	18 (19%)	0.52 (0.11–2.48)	0.413
60+	50 (19%)	41 (82%)	9 (18%)	0.57 (0.11–2.94)	0.501
Ethnicity					0.237
Caucasian/white	174 (66%)	144 (83%)	30 (17%)	1.00	
African-American/black	41 (16%)	32 (78%)	9 (22%)	0.74 (0.32–1.71)	0.483
Hispanic or Hispanic descent	27 (10%)	18 (67%)	9 (33%)	0.42 (0.17–1.02)	0.055
Other	10 (4%)	7 (70%)	3 (30%)	0.49 (0.12–1.99)	0.316
Mixed	11 (4%)	10 (91%)	1 (9%)	2.08 (0.26–16.96)	0.493
Education					0.097
High school or GED, or less	65 (25%)	55 (85%)	10 (15%)	1.00	
Some college/Associate degree	66 (25%)	51 (77%)	15 (23%)	0.62 (0.25–1.5)	0.288
Undergraduate degree	76 (29%)	61 (80%)	15 (20%)	0.74 (0.31–1.78)	0.502
Master's degree or its equivalent	40 (15%)	28 (70%)	12 (30%)	0.42 (0.16–1.1)	0.079
Doctorate or its equivalent	15 (6%)	15 (100%)	0 (0%)	Perfect correlation	
Household income					0.060
Less than \$25,000	101 (39%)	76 (75%)	25 (25%)	1.00	
\$25,000-\$50,000	68 (26%)	60 (88%)	8 (12%)	2.47 (1.04–5.87)	0.041*
\$50,001-\$75,000	34 (13%)	29 (85%)	5 (15%)	1.91 (0.67–5.47)	0.229
\$75,001-\$100,000	26 (10%)	22 (85%)	4 (15%)	1.81 (0.57–5.77)	0.316
\$100,001-\$125,000	19 (7%)	16 (84%)	3 (16%)	1.75 (0.47–6.54)	0.402

# Appendix 16. Continued

Variable	Total (n)	WTP in first-in-human studies		OR (95% CI)	P-value <sup>1</sup>
		Yes	No		
\$125,001-\$150,000	5 (2%)	4 (80%)	1 (20%)	1.32 (0.14–12.38)	0.81
More than \$150,000	9 (3%)	4 (44%)	5 (56%)	0.26 (0.07–1.06)	0.06
Region					0.946
Northeast	29 (11%)	22 (76%)	7 (24%)	1.00	
Midwest	47 (18%)	38 (81%)	9 (19%)	1.34 (0.44–4.12)	0.606
South	92 (35%)	74 (80%)	18 (20%)	1.31 (0.48–3.54)	0.597
West	92 (35%)	74 (80%)	18 (20%)	1.31 (0.48–3.54)	0.597
Health status					0.377
Very healthy	49 (19%)	38 (78%)	11 (22%)	1.00	
Healthy	123 (47%)	102 (83%)	21 (17%)	1.41 (0.62–3.19)	0.416
Somewhat healthy	75 (29%)	57 (76%)	18 (24%)	0.92 (0.39–2.16)	0.842
Not very healthy/not at all healthy	15 (6%)	14 (93%)	1 (7%)	4.05 (0.48–34.48)	0.2
In control over own healthcare					0.523
No	41 (16%)	31 (76%)	10 (24%)	1.00	
Yes	212 (84%)	171 (81%)	41 (19%)	1.35 (0.61–2.97)	0.463
Currently taking HIV medication					1.000
No	5 (2%)	4 (80%)	1 (20%)	1.00	
Yes	258 (98%)	207 (80%)	51 (20%)	1.01 (0.11–9.31)	0.99
Percentage of life living with HIV diagnosis					0.094
Up to 25%	106 (41%)	91 (86%)	15 (14%)	1.00	
26–50%	112 (43%)	90 (80%)	22 (20%)	0.67 (0.33–1.38)	0.283
More than 50%	40 (16%)	28 (70%)	12 (30%)	0.38 (0.16–0.92)	0.032*
Ever volunteered for an HIV treatment study					0.115
No	145 (56%)	111 (77%)	34 (23%)	1.00	
Yes	114 (44%)	97 (85%)	17 (15%)	1.75 (0.92–3.33)	0.089
Ever volunteered for an HIV cure study					1.000
No	241 (93%)	192 (80%)	49 (20%)	1.00	
Yes	17 (7%)	14 (82%)	3 (18%)	1.19 (0.33–4.32)	0.79
Generally interested in HIV cure research					<0.001***
No	5 (2%)	0 (0%)	5 (100%)	Perfect correlation	
Yes	254 (98%)	211 (83%)	43 (17%)	1.00	

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories.

\*\*\* Statistically significant at 0.1% level; \* statistically significant at 5% level.

# Appendix 17. Phase II or III studies: bivariate association between sociodemographic characteristics and willingness to participate (WTP) in HIV cure-related studies about safety and efficacy (Phase II or III studies), US, 2015

Variable	Total ( <i>n</i> )	WTP in Phase II or Phase III studies		OR (95% CI)	P-value <sup>1</sup>
		Yes	No		
Gender					0.155
Male	237 (80%)	212 (89%)	25 (11%)	1.00	
Female	57 (19%)	48 (84%)	9 (16%)	0.63 (0.28–1.44)	0.271
Transgender male to female, other	3 (1%)	2 (67%)	1 (33%)	0.24 (0.02–2.71)	0.246
Age					0.156
19–29	16 (5%)	15 (94%)	1 (6%)	1.00	
30–39	39 (13%)	37 (95%)	2 (5%)	1.23 (0.1–14.7)	0.868
40–49	75 (25%)	60 (80%)	15 (20%)	0.27 (0.03–2.19)	0.219
50–59	111 (37%)	100 (90%)	11 (10%)	0.61 (0.07–5.06)	0.644
60+	56 (19%)	50 (89%)	6 (11%)	0.56 (0.06–5)	0.6

# Appendix 17. Continued

Variable	Total ( <i>n</i> )	WTP in Phase II or Phase III studies		OR (95% CI)	<i>P</i> -value <sup>1</sup>
		Yes	No		
Ethnicity					0.321
Caucasian/white	197 (66%)	178 (90%)	19 (10%)	1.00	
African-American/black	44 (15%)	37 (84%)	7 (16%)	0.56 (0.22–1.44)	0.232
Hispanic or Hispanic descent	33 (11%)	27 (82%)	6 (18%)	0.48 (0.18–1.31)	0.153
Other	10 (3%)	8 (80%)	2 (20%)	0.43 (0.08–2.16)	0.304
Mixed	13 (4%)	12 (92%)	1 (8%)	1.28 (0.16–10.44)	0.817
Education					0.370
High school or GED, or less	71 (24%)	63 (89%)	8 (11%)	1.00	
Some college/Associate degree	72 (24%)	62 (86%)	10 (14%)	0.79 (0.29–2.13)	0.638
Undergraduate degree	85 (29%)	76 (89%)	9 (11%)	1.07 (0.39–2.95)	0.892
Master's degree or its equivalent	48 (16%)	40 (83%)	8 (17%)	0.63 (0.22–1.83)	0.4
Doctorate or its equivalent	20 (7%)	20 (100%)	0 (0%)	Perfect correlation	
Household income					0.019*
Less than \$25,000	102 (34%)	85 (83%)	17 (17%)	1.00	
\$25,000-\$50,000	80 (27%)	75 (94%)	5 (6%)	3 (1.05–8.54)	0.04*
\$50,001-\$75,000	38 (13%)	36 (95%)	2 (5%)	3.6 (0.79–16.44)	0.098
\$75,001-\$100,000	29 (10%)	24 (83%)	5 (17%)	0.96 (0.32–2.88)	0.942
\$100.001-\$125.000	25 (8%)	24 (96%)	1 (4%)	4.8 (0.61–38.06)	0.138
\$125.001-\$150.000	7 (2%)	7 (100%)	0 (0%)	Perfect correlation	
More than \$150,000	15 (5%)	10 (67%)	5 (33%)	0.4 (0.12–1.32)	0 133
Region			- ()		0.746
Northeast	34 (12%)	29 (85%)	5 (15%)	1.00	
Midwest	53 (18%)	45 (85%)	8 (15%)	0.97 (0.29–3.26)	0 961
South	102 (35%)	91 (89%)	11 (11%)	1 43 (0 46-4 45)	0.541
West	104 (35%)	93 (89%)	11 (11%)	1 46 (0 47-4 55)	0.516
Health status	101(3370)	55 (6576)		1.10 (0.17 1.55)	0.186
Very healthy	55 (19%)	45 (82%)	10 (18%)	1.00	
Healthy	142 (48%)	128 (90%)	14 (10%)	2 03 (0 84–4 9)	0 115
Somewhat healthy	83 (78%)	72 (87%)	11 (13%)	1 45 (0 57-3 71)	0.113
Not very healthy/not at all healthy	16 (5%)	16 (100%)	0 (0%)	Perfect correlation	0.452
In control over own bealthcare	10 (576)	10 (10070)	0 (070)	r enect conclution	0.613
No	/13 (15%)	37 (86%)	6 (14%)	1.00	0.015
 	243 (15%)	216 (90%)	29 (11%)	1.00	0.644
Currently taking HIV modication	244 (0570)	210 (0570)	20 (11/0)	1.25 (0.40-5.25)	1 000
	F (2%)	6 (100%)	0 (0%)	Derfect correlation	1.000
 	201 (09%)	256 (99%)	25 (12%)	1 00	
Tes	291 (90%)	250 (86%)	55 (12%)	1.00	0.104
	115 (200/)	106 (02%)	0 (99/)	1.00	0.194
26 50%	122 (46%)	112 (95%)	20 (15%)	0.49 (0.21, 1, 1)	0.002
20-30%	133 (40%)	30 (80%)	20 (13%)	0.48 (0.21-1.1)	0.005
	44 (15%)	29 (09%)	5(11%)	0.00 (0.21-2.1)	0.404
Ever volunteered for an HIV treatment study	162 (550/)	127 (050/)		1.00	0.047 **
No	162 (55%)	137 (85%)	25 (15%)	1.00	0.045*
res	131 (45%)	121 (92%)	10 (8%)	2.21 (1.02-4.79)	0.045^
Ever volunteered for an HIV cure study	270 (222)			1.00	0.088
	270 (92%)	235 (8/%)	35 (13%)		
Yes	22 (8%)	22 (100%)	0 (0%)	Perfect correlation	
Generally interested in HIV cure research					<0.001***
No	5 (2%)	0 (0%)	5 (100%)	Pertect correlation	
Yes	285 (98%)	259 (91%)	26 (9%)	1.00	

<sup>1</sup> Fisher's exact test statistic for the categorical variable (in italics) and *P*-values shown for the odds ratios next to individual categories. \*\*\* Statistically significant at 0.1% level; \* statistically significant at 5% level.