

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

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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.

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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 cure-related 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;

Table 1. Demographic characteristics of survey respondents (*n*=400), United States, 2015

| | Number | Percentage (%) |
|--|--------|----------------|
| Gender | | |
| <i>n</i> | 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) | | |
| <i>n</i> | 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 | | |
| <i>n</i> | 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 | | |
| <i>n</i> | 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 |

Table 1. Continued

| | Number | Percentage (%) |
|--|--------|----------------|
| Yearly household income | | |
| <i>n</i> | 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 | | |
| <i>n</i> | 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 | | |
| <i>n</i> | 400 | |
| Yes | 326 | 82 |
| No | 54 | 14 |
| Don't know/not sure | 20 | 5 |
| Currently taking HIV medication | | |
| <i>n</i> | 400 | |
| Yes | 391 | 98 |
| No | 9 | 2 |
| Don't know/not sure | 0 | 0 |
| Years since HIV diagnosis (years) | | |
| <i>n</i> | 394 | |
| Mean | 17 | |
| Median | 18 | |
| Minimum | <1 | |
| Maximum | 36 | |
| Percentage of lifetime with HIV-positive status (%) | | |
| <i>n</i> | 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 treatment study | | |
| <i>n</i> | 399 | |
| Yes | 175 | 44 |
| No | 218 | 55 |
| Don't know/not sure | 6 | 2 |
| General interest in HIV cure research | | |
| <i>n</i> | 399 | |
| Yes | 385 | 96 |
| No | 5 | 1 |
| Don't know/not sure | 9 | 2 |

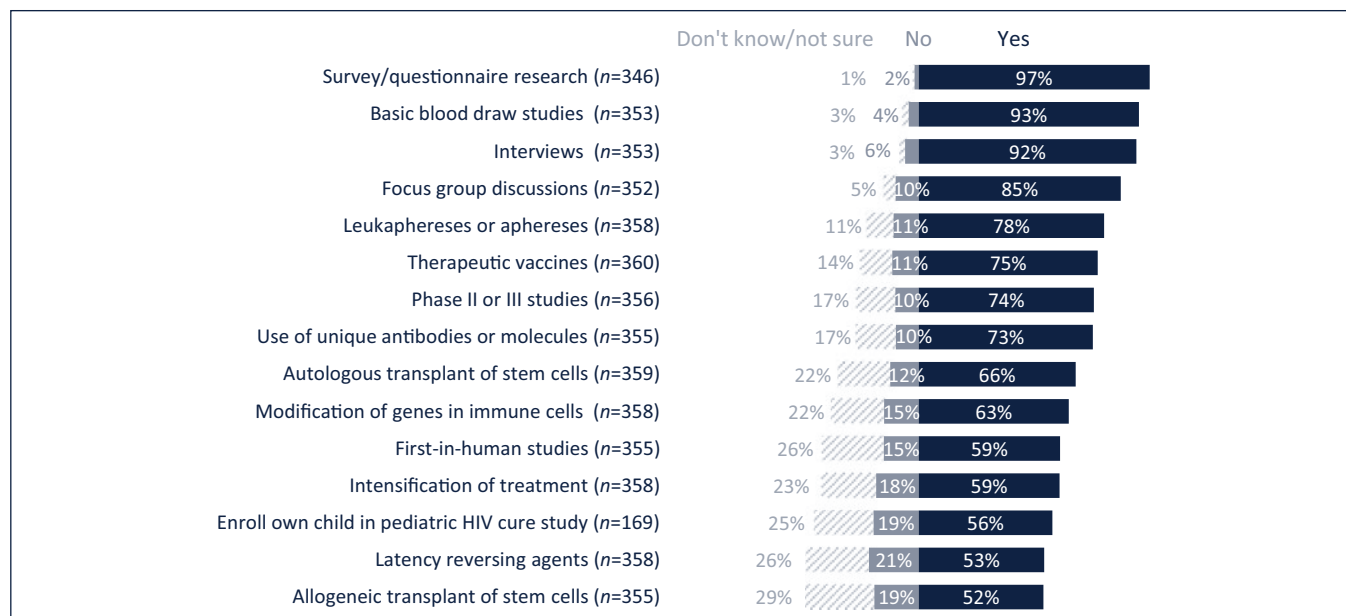


Figure 1. Willingness to consider participating in HIV cure-related studies in the US, 2015. **Leukaphereses** and **aphereses** were defined as ‘laboratory procedures where selected immune cells are separated out from the blood and the rest of the blood is returned to the veins’. **Therapeutic vaccines** 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 taking more than 3 different classes of drugs at the same time’. **Latency reversing agents** were defined as ‘studies that involve 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’

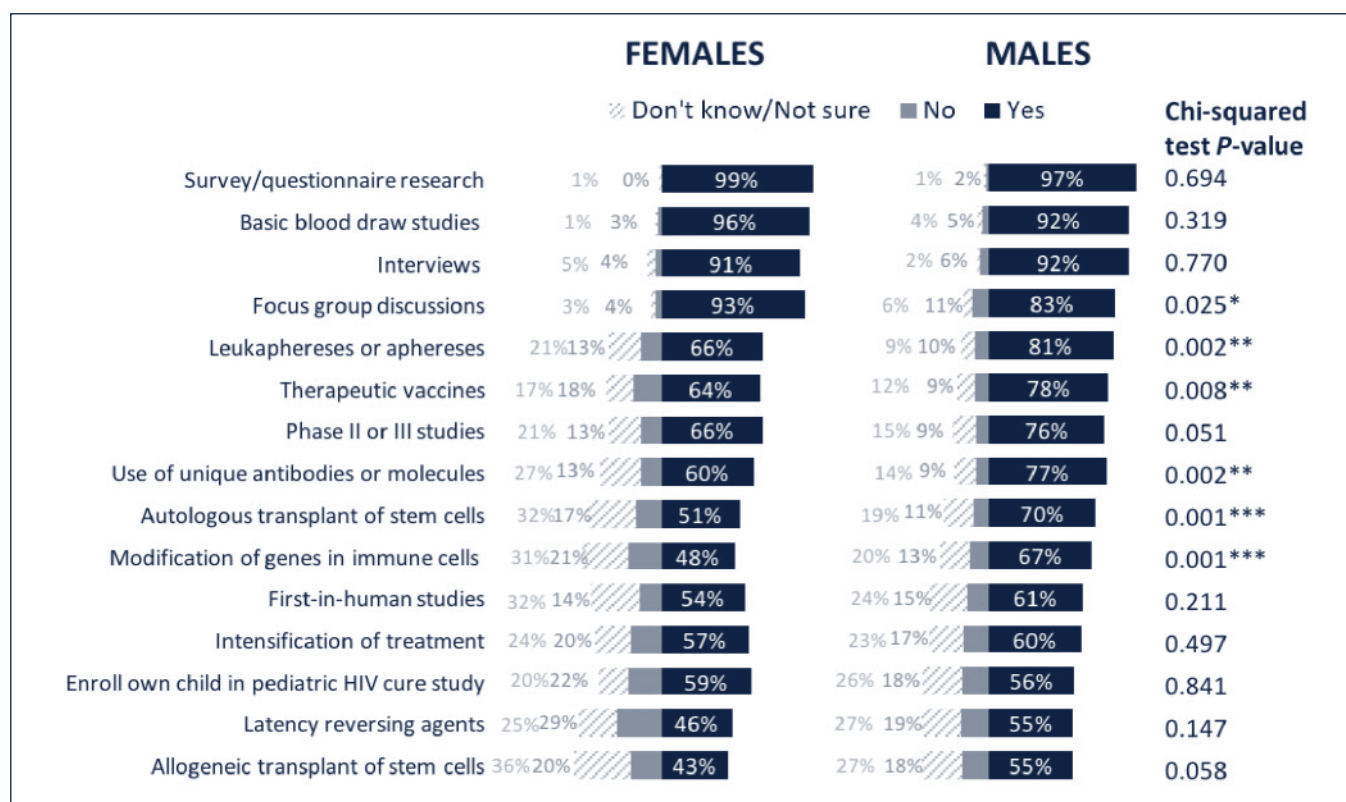


Figure 2. Difference between female and male willingness to consider participating in HIV cure-related studies in the US, 2015. Transgender women are included in the Females category; P-values reflect the chi-squared test result for differences between females and males in answering ‘Yes’. *** Statistically 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

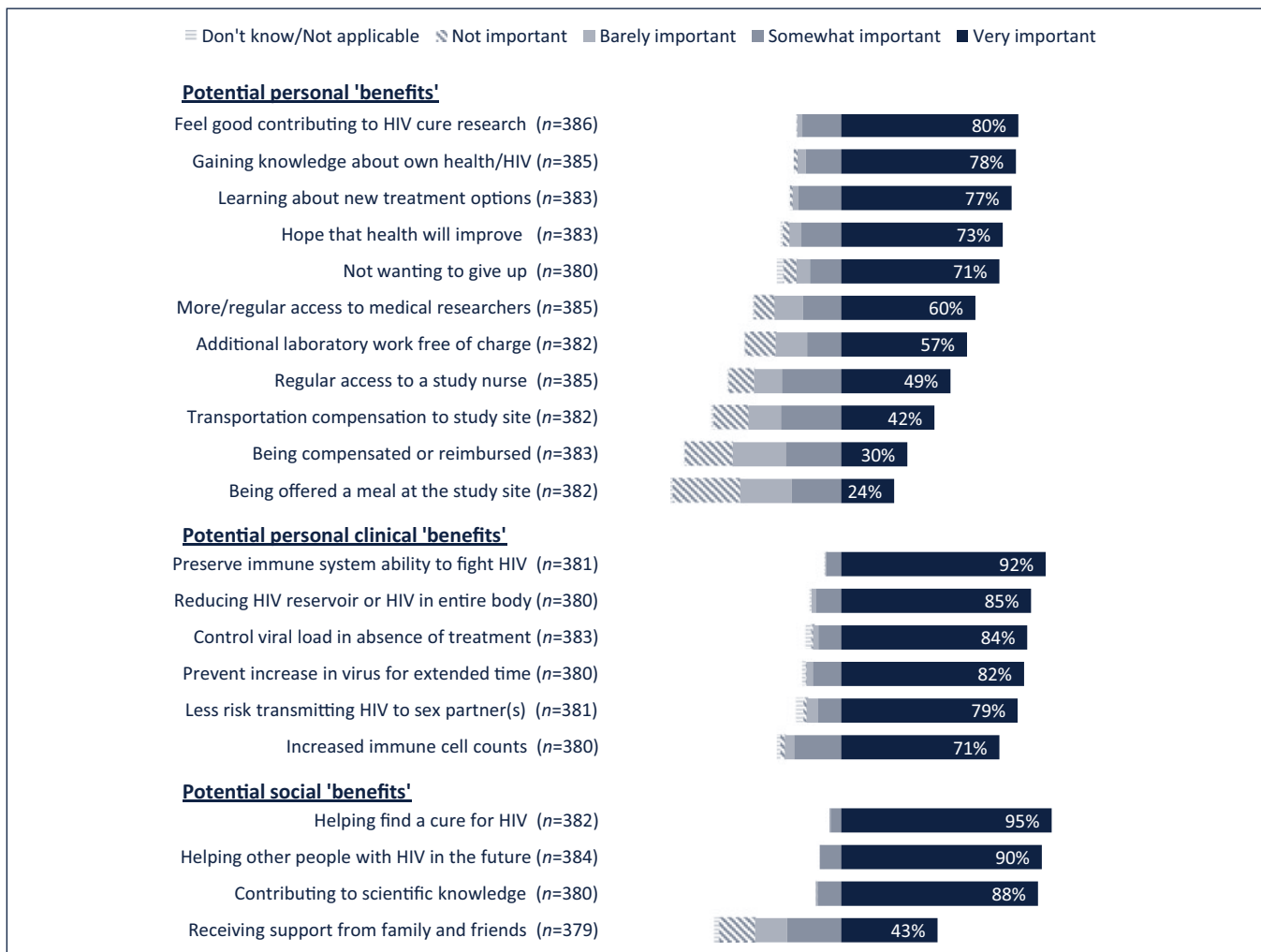


Figure 3. Respondents' assessment of the importance of potential benefits to motivate participation in HIV cure-related studies in the US, 2015. Percentages reflect 'Very important'; the remainder (up to 100%) includes the sum of 'Somewhat important', 'Barely important', 'Not important' and 'Don't know/not applicable'

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 cure-related studies, focusing on perceptions of risks and benefits. More than 50% of survey respondents indicated that they would be

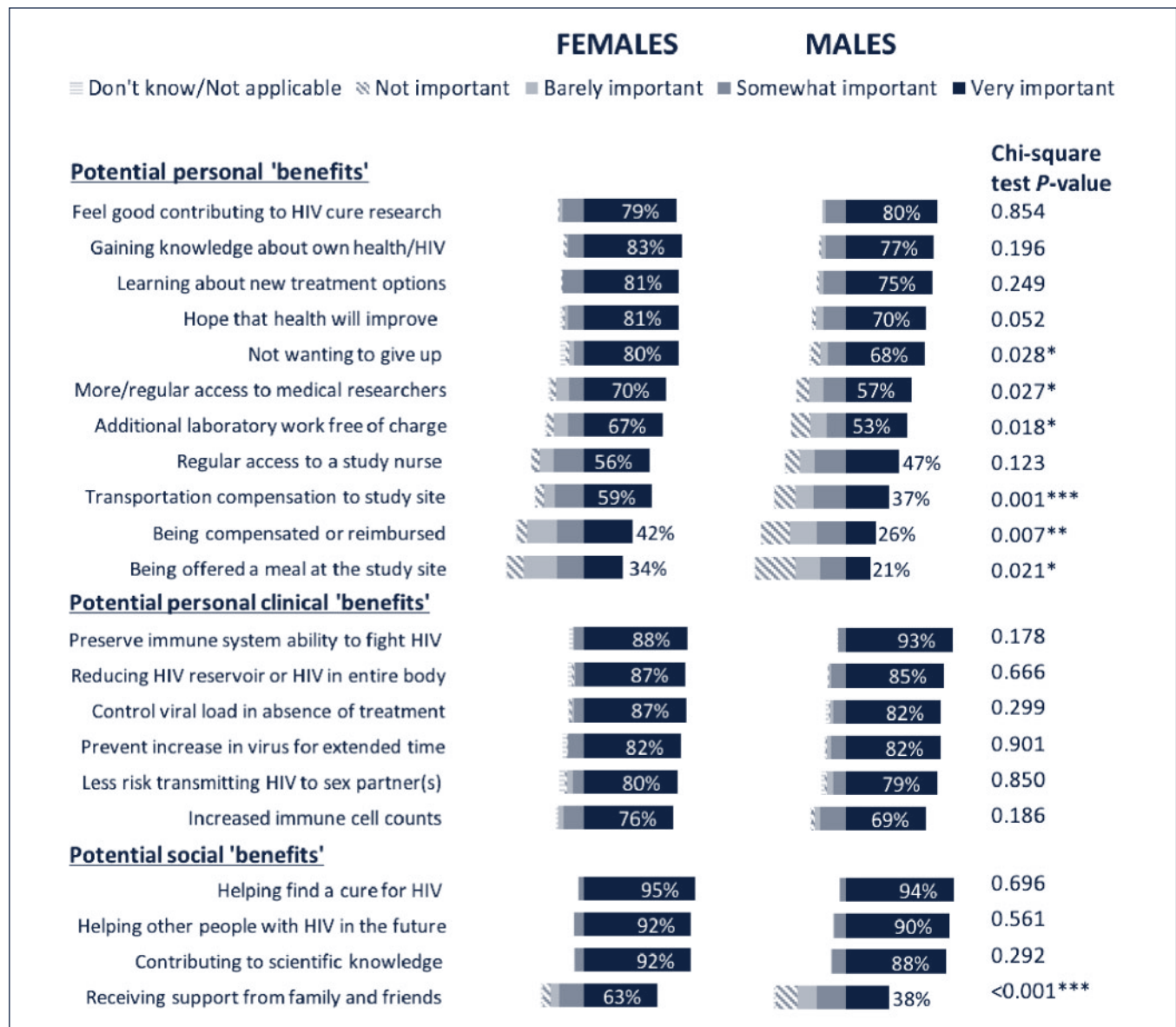


Figure 4. Differences between females' and males' assessment of the importance of potential benefits to motivate participation in HIV cure-related studies in the US, 2015. Percentages reflect 'Very important'. The remainder (up to 100%) includes the sum of 'Somewhat important', 'Barely important', 'Not 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

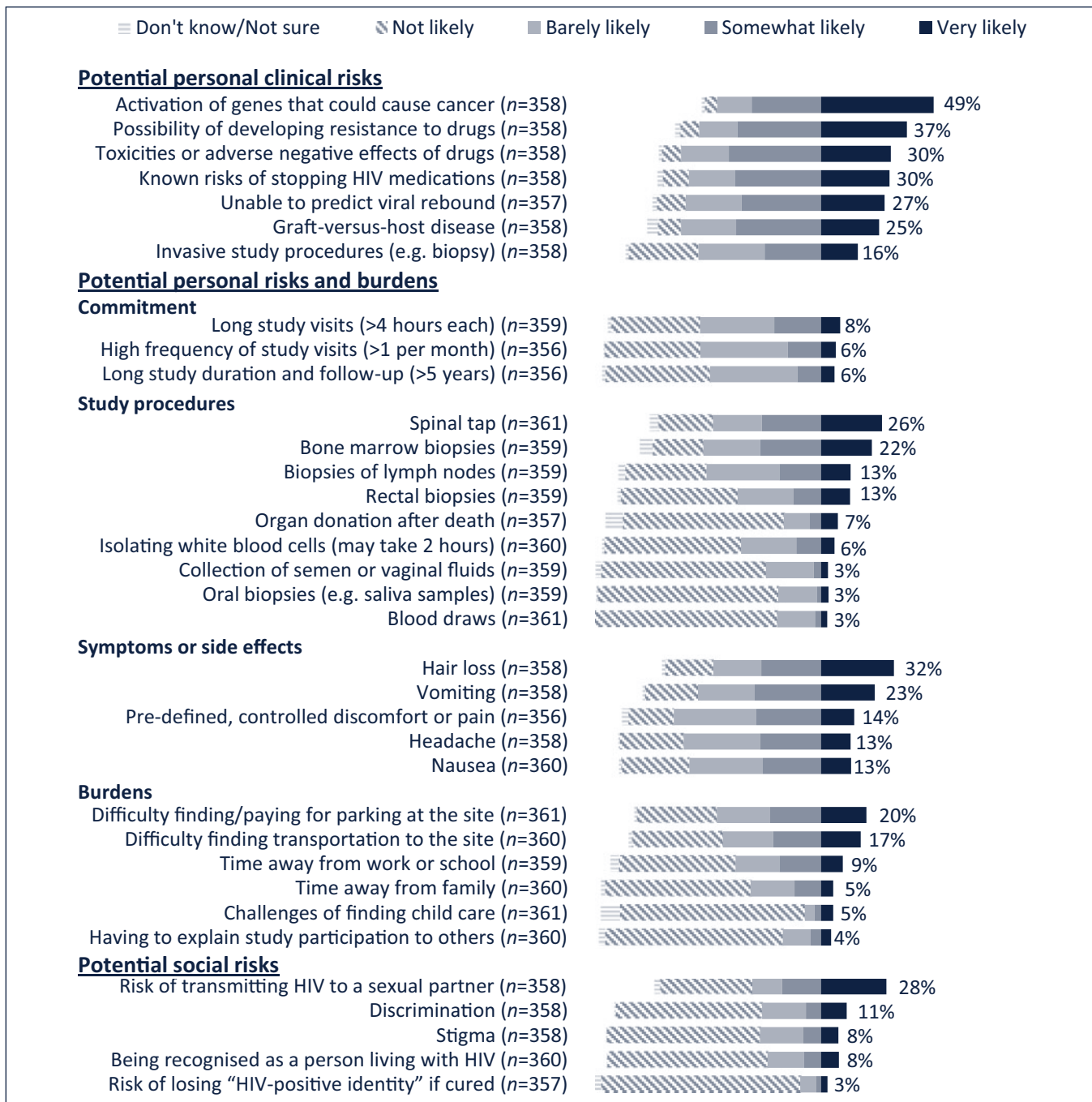


Figure 5. Respondents' assessment of the likelihood of potential risks and burdens to discourage participation in HIV cure-related states, US, 2015. Percentages reflect 'Very likely to discourage'. The remainder (up to 100%) includes the sum of 'Somewhat likely to discourage', 'Barely likely to discourage', '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

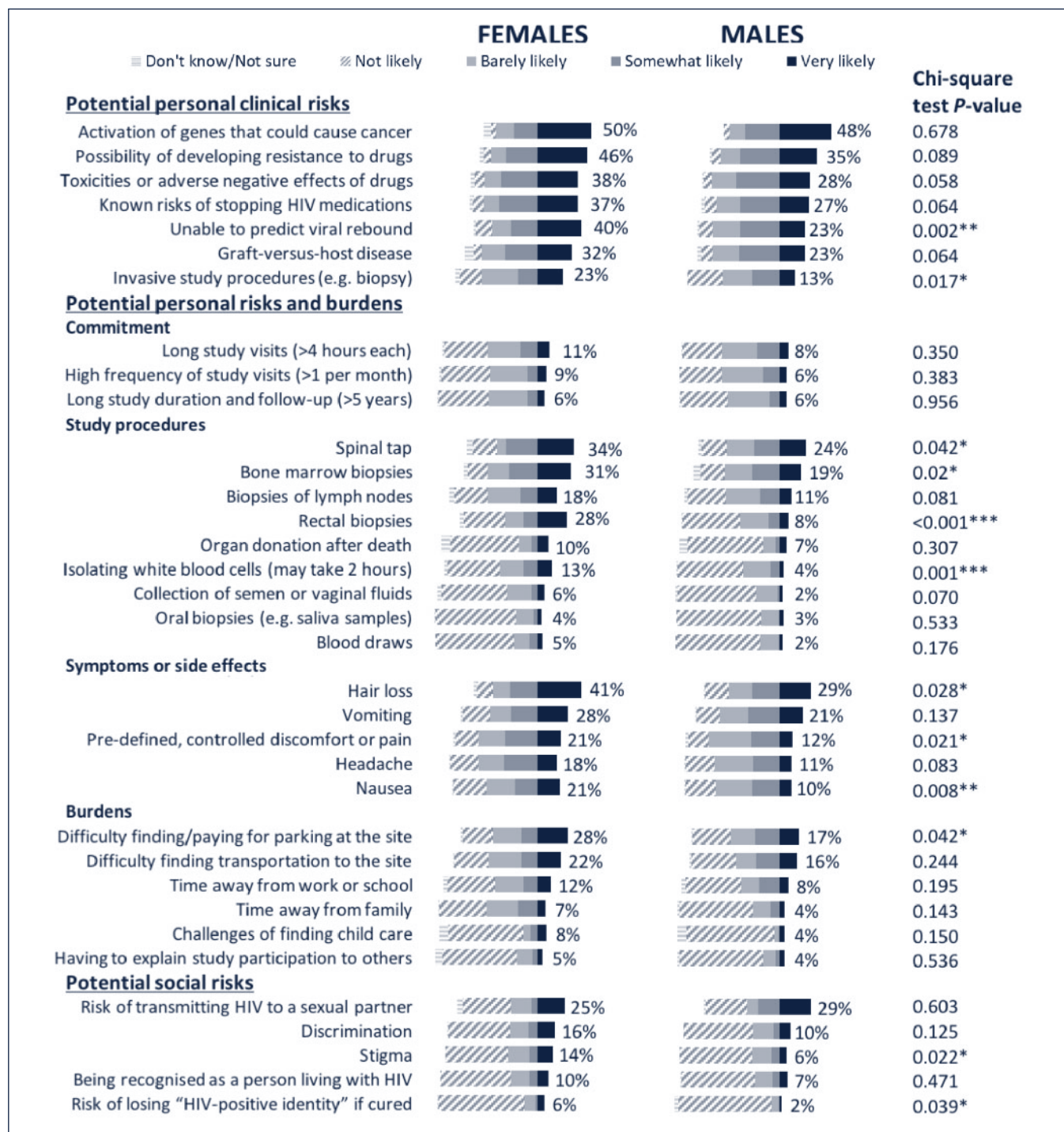


Figure 6. Difference between females' and males' assessment of the likelihood of potential risks and burdens to discourage participation in HIV cure-related states in the US, 2015. Percentages reflect 'Very likely to discourage'. The remainder (up to 100%) includes the sum of 'Somewhat likely to discourage', '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).

Odds 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.

Acknowledgements

The authors thank the study participants, Collaboratory of AIDS Researchers for Eradication (CARE – U19 AI096113), Delaney AIDS Research Enterprise (DARE – U19AI096109), defeatHIV (U19AI096111) Community Advisory Boards, International AIDS Society (IAS) Towards an HIV Cure Psychosocial Working Group, Forum for Collaborative HIV Research – Cure Project (Group 3: Patient Education, Recruitment and Informed Consent) (including Veronica Miller) and the CUREiculum (<http://www.avac.org/cureiculum>) team. Special thanks must be given to Lynda Dee, Alasdair Burton and Loreen Willenberg who provided input to the study survey. We also thank Shadi Eskaf who provided technical assistance with biostatistics. The authors would also like to acknowledge the guidance received from the searchHIV working group (Joseph Tucker and Stuart Rennie: Principal Investigators), supported by R01A108366.

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 effects) | | | | | |
| 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 understand 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, judgmental 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

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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

| Characteristic | Type of HIV cure-related study | | | | |
|---|--|---|---|--|--|
| | Leukapheresis or apheresis | Latency reversing agents | Gene modification | autologous stem cell transplant | Allogenic stem cell transplant |
| Gender | | Females = 0.5 × WTP of Males | Females = 0.4 × WTP of Males | Females = 0.5 × WTP of Males | |
| Ethnicity | African-Americans = 0.3 × WTP of Caucasians | African-Americans = 0.4 × WTP of Caucasians | AA=0.3 × WTP and Others = 0.2 × WTP of Caucasians | AA=0.3 × WTP and Hispanics = 0.4 × 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 × WTP and \$100k–\$125k = 9.1 × 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 × WTP of others | Living with HIV <25% of Lifetime = 2.9 × WTP of others | Living with HIV <25% of Lifetime = 2.4 × WTP of others | | Living with HIV <25% of Lifetime = 1.9–3.0 × 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 × 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

| Characteristic | Type of HIV cure-related study | | | | |
|---|---|---|--|--|---|
| | Therapeutic vaccines | Treatment intensification | Antibodies or molecules | First-in-human studies | Phase II/III studies |
| Gender | Females = 0.4 × WTP of Males | | | | |
| Ethnicity | Caucasians = 2.9 × WTP of AA, 3.6 × WTP of Hispanics, 9 × WTP of Others | Hispanics = 0.4 × WTP of Caucasians | AA=0.3 × WTP and Hispanics = 0.3 × 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 × WTP of 25%–50% group | | Living with HIV <25% of Lifetime = 2.9 × 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 × 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 × 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 | n | Willingness to participate in all 14 types of HIV 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 diagnosis | | | | | <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 | n | Willingness to participate in all 14 types of HIV 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 | | | | | 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/questionnaires | | OR (95% CI) | P-value ¹ |
|-----------------------------------|-----------|-------------------------------|--------|---------------------|----------------------|
| | | 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 (n) | WTP in surveys/questionnaires | | OR (95% CI) | P-value ¹ |
|---|-----------|-------------------------------|----------|---------------------|----------------------|
| | | 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 | |

¹ 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 (n) | WTP in interviews | | OR (95% CI) | P-value ¹ |
|-----------------------------------|-----------|-------------------|---------|---------------------|----------------------|
| | | 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 ¹ |
|---|-----------|-------------------|---------|---------------------|----------------------|
| | | 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 |

¹ 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 ¹ |
|--|-----------|---------------------|----------|---------------------|----------------------|
| | | 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 (n) | WTP in focus groups | | OR (95% CI) | P-value ¹ |
|---|-----------|---------------------|----------|-------------------|----------------------|
| | | 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 |

¹ 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) | P-value ¹ |
|-----------------------------------|-----------|---------------------------------|---------|---------------------|----------------------|
| | | 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 ¹ |
|---|-----------|---------------------------------|---------|---------------------|----------------------|
| | | 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** |

¹ 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 apheresis studies | | OR (95% CI) | P-value ¹ |
|-----------------------------------|-----------|---|----------|---------------------|----------------------|
| | | 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) | P-value ¹ |
|---|-----------|---|----------|---------------------|----------------------|
| | | 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 | |
| More than \$150,000 | 15 (5%) | 14 (93%) | 1 (7%) | 3.79 (0.47–30.44) | 0.21 |
| Region | | | | | 0.339 |
| Northeast | 31 (10%) | 28 (90%) | 3 (10%) | 1.00 | |
| Midwest | 56 (18%) | 45 (80%) | 11 (20%) | 0.44 (0.11–1.71) | 0.236 |
| South | 116 (37%) | 104 (90%) | 12 (10%) | 0.93 (0.24–3.53) | 0.913 |
| West | 110 (35%) | 98 (89%) | 12 (11%) | 0.88 (0.23–3.33) | 0.845 |
| Health status | | | | | 0.453 |
| Very healthy | 61 (19%) | 53 (87%) | 8 (13%) | 1.00 | |
| 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 | |

¹ 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) | P-value ¹ |
|--|-----------|---|----------|---------------------|----------------------|
| | | 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 (n) | WTP in studies involving latency reversing agents | | OR (95% CI) | P-value ¹ |
|---|-----------|---|----------|---------------------|----------------------|
| | | 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* |

¹ 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 involving modification of patient's genes in immune cells | | OR (95% CI) | P-value ¹ |
|-----------------------------------|-----------|--|----------|-------------------|----------------------|
| | | 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 (n) | WTP in studies involving modification of patient's genes in immune cells | | OR (95% CI) | P-value ¹ |
|---|-----------|--|----------|---------------------|----------------------|
| | | 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 | |

¹ 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 ¹ |
|-----------------------------------|-----------|-------------------------------------|----------|------------------|----------------------|
| | | 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 (n) | WTP in autologous stem cell studies | | OR (95% CI) | P-value ¹ |
|---|-----------|-------------------------------------|----------|---------------------|----------------------|
| | | 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 | |

¹ 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 allogeneic stem cell studies | | OR (95% CI) | P-value ¹ |
|--|-----------|-------------------------------------|----------|---------------------|----------------------|
| | | 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 | | | | | |
| | | | | | 0.686 |
| No | 37 (15%) | 26 (70%) | 11 (30%) | 1.00 | |
| Yes | 205 (85%) | 152 (74%) | 53 (26%) | 1.21 (0.56–2.63) | 0.624 |
| Currently taking HIV medication | | | | | |
| | | | | | 1.000 |
| No | 4 (2%) | 3 (75%) | 1 (25%) | 1.00 | |
| Yes | 248 (98%) | 183 (74%) | 65 (26%) | 0.94 (0.1–9.22) | 0.957 |

Appendix 12. Continued

| Variable | Total (n) | WTP in allogenic stem cell studies | | OR (95% CI) | P-value ¹ |
|---|-----------|------------------------------------|----------|---------------------|----------------------|
| | | 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%) | | |

¹ 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) | P-value ¹ |
|-----------------------------------|-----------|--|----------|---------------------|----------------------|
| | | 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 ¹ |
|---|-----------|--|----------|---------------------|----------------------|
| | | 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 | |

¹ 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 (n) | WTP in studies involving intensification of treatment | | OR (95% CI) | P-value ¹ |
|-----------------------------------|-----------|---|----------|------------------|----------------------|
| | | 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) | P-value ¹ |
|---|-----------|---|----------|---------------------|----------------------|
| | | 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* |

¹ 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 ¹ |
|--|-----------|--|----------|---------------------|----------------------|
| | | 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 (n) | WTP in use of unique antibodies, proteins or molecules | | OR (95% CI) | P-value ¹ |
|---|-----------|--|----------|---------------------|----------------------|
| | | 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 | |

¹ 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) | P-value ¹ |
|-----------------------------------|-----------|-------------------------------|----------|---------------------|----------------------|
| | | 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 ¹ |
|---|-----------|-------------------------------|----------|---------------------|----------------------|
| | | 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 | | | | | <i>0.946</i> |
| 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 | | | | | <i>0.377</i> |
| 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 | | | | | <i>0.523</i> |
| 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 | | | | | <i>1.000</i> |
| 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 | | | | | <i>0.094</i> |
| 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 | | | | | <i>0.115</i> |
| 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 | | | | | <i>1.000</i> |
| 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 | | | | | <i><0.001***</i> |
| No | 5 (2%) | 0 (0%) | 5 (100%) | Perfect correlation | |
| Yes | 254 (98%) | 211 (83%) | 43 (17%) | 1.00 | |

¹ 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 (n) | WTP in Phase II or Phase III studies | | OR (95% CI) | P-value ¹ |
|-----------------------------------|-----------|--------------------------------------|----------|------------------|----------------------|
| | | Yes | No | | |
| Gender | | | | | <i>0.155</i> |
| 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 | | | | | <i>0.156</i> |
| 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 (n) | WTP in Phase II or Phase III studies | | OR (95% CI) | P-value ¹ |
|---|-----------|--------------------------------------|----------|---------------------|----------------------|
| | | Yes | No | | |
| Ethnicity | | | | | |
| Caucasian/white | 197 (66%) | 178 (90%) | 19 (10%) | 1.00 | 0.321 |
| 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 | | | | | |
| High school or GED, or less | 71 (24%) | 63 (89%) | 8 (11%) | 1.00 | 0.370 |
| 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 | | | | | |
| Less than \$25,000 | 102 (34%) | 85 (83%) | 17 (17%) | 1.00 | 0.019* |
| \$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 | | | | | |
| Northeast | 34 (12%) | 29 (85%) | 5 (15%) | 1.00 | 0.746 |
| 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 | | | | | |
| Very healthy | 55 (19%) | 45 (82%) | 10 (18%) | 1.00 | 0.186 |
| Healthy | 142 (48%) | 128 (90%) | 14 (10%) | 2.03 (0.84–4.9) | 0.115 |
| Somewhat healthy | 83 (28%) | 72 (87%) | 11 (13%) | 1.45 (0.57–3.71) | 0.432 |
| Not very healthy/not at all healthy | 16 (5%) | 16 (100%) | 0 (0%) | Perfect correlation | |
| In control over own healthcare | | | | | |
| No | 43 (15%) | 37 (86%) | 6 (14%) | 1.00 | 0.613 |
| Yes | 244 (85%) | 216 (89%) | 28 (11%) | 1.25 (0.48–3.23) | 0.644 |
| Currently taking HIV medication | | | | | |
| No | 6 (2%) | 6 (100%) | 0 (0%) | Perfect correlation | 1.000 |
| Yes | 291 (98%) | 256 (88%) | 35 (12%) | 1.00 | |
| Percentage of life living with HIV diagnosis | | | | | |
| Up to 25% | 115 (39%) | 106 (92%) | 9 (8%) | 1.00 | 0.194 |
| 26–50% | 133 (46%) | 113 (85%) | 20 (15%) | 0.48 (0.21–1.1) | 0.083 |
| More than 50% | 44 (15%) | 39 (89%) | 5 (11%) | 0.66 (0.21–2.1) | 0.484 |
| Ever volunteered for an HIV treatment study | | | | | |
| No | 162 (55%) | 137 (85%) | 25 (15%) | 1.00 | 0.047* |
| Yes | 131 (45%) | 121 (92%) | 10 (8%) | 2.21 (1.02–4.79) | 0.045* |
| Ever volunteered for an HIV cure study | | | | | |
| No | 270 (92%) | 235 (87%) | 35 (13%) | 1.00 | 0.088 |
| Yes | 22 (8%) | 22 (100%) | 0 (0%) | Perfect correlation | |
| Generally interested in HIV cure research | | | | | |
| No | 5 (2%) | 0 (0%) | 5 (100%) | Perfect correlation | <0.001*** |
| Yes | 285 (98%) | 259 (91%) | 26 (9%) | 1.00 | |

¹ 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.