# What risk of death would people take to be cured of HIV and why? A survey of people living with HIV

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## Abstract

People living with HIV (PLWHIV) can reasonably expect near-normal longevity, yet many express a willingness to assume significant risks to be cured. We surveyed 200 PLWHIV who were stable on antiretroviral therapy (ART) to quantify associations between the benefits they anticipate from a cure and their risk tolerance for curative treatments. Sixty-five per cent expected their health to improve if cured of HIV, 41% predicted the virus would stop responding to medications over the next 20 years and 54% predicted experiencing serious medication side effects in the next 20 years. Respondents' willingness to risk death for a cure varied widely (median 10%, 75th percentile 50%). In multivariate analyses, willingness to risk death was associated with expected long-term side effects of ART, greater financial resources and being employed (all $P < 0.05$) but was not associated with perceptions of how their health would improve if cured.

Keywords: HIV, medication, risk taking, treatment

## Introduction

HIV has been transformed from a deadly infection to a chronic disease for most individuals with access to antiretroviral therapy (ART) [1]. However, controlling the virus with ART does not eradicate the disease, and there are long-term harms of living with the virus in a latent state [2]. As such, there remains real value in the development of a cure. Research into this area often carries risk of harm for study participants who otherwise would be expected to live nearly normal lives both in terms of quality and length [3–5].

Despite this risk, there is a growing body of research showing a desire among people living with HIV (PLWHIV) on stable therapy to participate in curative trials [6–19]. A 2016 global study found that 95% were interested in participating in cure studies and 59% were willing to take 'substantial risks' [20]. Similar enthusiasm has been seen in the USA, with a recent survey finding that a majority of respondents desire to participate in cure studies [17]. Less research, however, has focused on quantifying this desire or on understanding participants' motivations to undergo risky but potentially curative therapies, if such treatments existed.

To date, few studies have explored attitudes towards HIV cure in the context of decision sciences. Specifically, we know of no studies that have explored the health-related utility of PLWHIV *vs* the utility they expect from a cure. Decision researchers commonly measure such attitudes using instruments such as the standard gamble, which asks participants what risk of death they would accept for a health improvement [21,22]. The standard gamble is derived from economic axioms of rational choice [23,24]. In decision and cost-effectiveness analyses, health-related utilities are measured on a 0–1 scale, with 1 being equivalent to experiencing perfect health, that is, no reduction in utility from health problems. According to decision analytic theories, persons willing to accept a 10% chance of death to rid themselves of a health problem are signifying that they believe the health condition is reducing their utility by 0.1. In addition, these theories hold that the greater improvement people expect to receive from an HIV cure, the higher their willingness to accept a risk of death should be.

In this study, we have explored the willingness of PLWHIV to undergo a potential HIV cure, even if that cure carries a risk of death. We explored these perceptions not in the context of a clinical trial, but in the hypothetical context of an existing cure. By focusing on a non-trial setting, we were able to distinguish people's beliefs about how an HIV cure would benefit their lives from their willingness to accept risks to benefit other people than themselves. In addition, we explored their underlying reasons for accepting such risks.

## Methods

We surveyed a convenience sample of PLWHIV at clinics associated with two hospitals in Boston, the Massachusetts General

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Hospital and Brigham and Women's Hospital. Participants were 18 years or older, living with HIV for at least 6 months, on anti-HIV therapy (aside from one 'elite controller' who had no detectable viral load despite being off therapy), had stable CD4 T cell counts and were able to read English. Clinical staff approached consecutive eligible individuals from June 2015 to February 2016 for people scheduled to receive outpatient HIV care. Those who completed the survey were given a $10 gift card for their time. Because the participants were not identifiable, this project received an exemption from the Partners Human Research Committee, which serves as the Institutional Review Board for both hospitals.

### Health-related utility

To evaluate whether survey participants believed a cure would affect their current state of health, we used two measures of health-related utility. The first (current health rating) asked respondents to mark their current health status, with '0' being 'equivalent to dead' and '100' representing 'best health for someone your age' [25].

The second, the EuroQol Five-Dimension Questionnaire (EQ-5D), is a standardised instrument for measuring health-related utility [26]. The five questions concern mobility, self-care, performance of usual activities, pain/discomfort and anxiety/depression. For each question, one of three responses can be given, ranging from non-issue to significant impairment (e.g. 'I have no problems in walking about', 'I have some problems walking about' or 'I am confined to bed'). We combined responses into a single index score ranging from 0 to 1 [27].

### Willingness to take risk for a cure

As described earlier, we measured participants' tolerance for risk associated with an HIV cure using the standard gamble method of utility elicitation [25]. To do so, we presented each participant with a scenario: 'Medical experts are currently trying to develop new treatments and potential cures for HIV in the hopes of completely removing HIV from the body. If successful, individuals who are cured will no longer need to take HIV medications. Suppose medical experts have developed a successful treatment, but the new treatment is risky. Some people who receive the treatment will die because of a fatal side effect; the rest will be cured of HIV'. In defining HIV cure, we purposely left ambiguity about whether the cure would eradicate the virus or, instead, lead to medication-free remission, out of recognition that this distinction is not always clear to individuals or providers. Then we asked two risk questions: (1) 'If there was a 1 in 100 chance you would die by taking this HIV treatment, and a 99 in 100 chance you would survive and be cured of HIV, would you take this treatment?' (2) 'If there was a 99 in 100 chance you would die by taking this HIV treatment, and a 1 in 100 chance you would survive and be cured of HIV, would you take this treatment?' To promote comprehension, both were accompanied by a pictograph showing 100 cartoon figures; the number expected to survive and be cured was highlighted in bold. For each question, respondents could answer 'definitely no', 'probably no', 'don't know', 'probably yes' or 'definitely yes'. These two questions are designed to familiarise participants with the standard gamble question – the extreme values help people recognise whether their risk tolerance lies between 1% and 99% or, instead, on one of those extremes [28].

Finally, we assessed the maximal risk they would take: 'If asked to take a treatment that included a chance of causing death, what is the largest chance of death (0–100 out of 100) would you accept in order to be cured of HIV?'

### Predicted chance of negative health outcomes with and without a cure

According to theories of rational choice, people accept risks only when they anticipate potential benefits of an action. Thus, accepting risks for an HIV cure should relate to people's beliefs about how a cure would affect either their health or some other aspect of their lives. To assess their beliefs about the health effects of a cure, we asked respondents to predict how being cured would affect their likelihood of incurring several negative health outcomes (heart attack, cancer, injury and death) over the next 20 years, compared with continuing their current HIV treatment (1='reduced a lot', 3='no change' and 5='increased a lot'). Heart attack and cancer were included because they are two of the most commonly cited harms associated with chronic infection and thus could plausibly be affected by a cure. Alternatively, risk of injury should not change with a cure and was included to assess the plausibility of respondents' predictions.

We also assessed the participants' long-term concerns regarding ART by asking them to estimate the percent of people who would experience one of two events over the next 20 years: (1) their HIV infection will stop responding to medical treatment and they will develop AIDS, and (2) they will experience serious side effects from their HIV medications. Finally, to measure their beliefs about how a cure would affect their health, we repeated the health rating utility measure described previously, but this time asked the respondents to predict their health status in 5 years, first continuing their current treatment regimen (health in 5 years with HIV) and then if cured of HIV (health in 5 years with HIV cure). These questions allowed us to measure people's perceptions of how their health would differ with and without a cure.

### Stigmatisation and financial status

The effects of an HIV cure might not be limited to health but could affect other aspects of the participants' lives. To begin exploring such factors, we added two questions related to non-health outcomes known to be influenced by HIV. Previous studies have shown that PLWHIV are affected by stigma and by the financial burdens of managing their illnesses [29,30]. To evaluate perceptions of social stigma, we asked, 'How much do you consider yourself stigmatised by the people who are aware of your HIV status?' (1='not at all stigmatised' and 5='extremely stigmatised'). To evaluate financial status, we asked the participants whether their current household's financial situation was best characterised as one of the following: 'After paying the bills, you still have enough money for special things that you want'; 'You have enough money to pay the bills, but little money to buy extra or special things'; 'You have money to pay for the bills, but only because you have cut back on things' or 'You are having difficulty paying the bills, no matter what you do' [31–33].

### Demographics

We collected data on participants' age, sex, education, employment status (currently employed: yes or no) and years since being diagnosed with HIV.

### Data analysis

Our primary outcome of interest is the maximum risk of death (from 0 to 100) that participants would accept to be cured of HIV. For those analyses, we excluded participants ($n=21$) who did not respond to the maximum risk of death question. In secondary analyses, we also excluded people who were inconsistent across the three risk questions: those who answered definitely yes or definitely no to either the 1% risk of death question or

the 99% risk of death question and then contradicted themselves in later responses. For example, we considered persons to be inconsistent if they said definitely no to taking a 1% risk of death and then stated a maximum risk greater than 1%. Based on these criteria, 24 of the remaining 179 respondents provided inconsistent responses, leaving 155 respondents who answered all three standard gamble questions consistently. In all other analyses, we report numbers reflecting the total number of people who answered the item in question.

### Predictors of willingness to take risk

We conducted both bivariate and multivariate regression analyses to determine which variables were associated with people's willingness to take risk for an HIV cure. We first ran analyses including all 179 participants who responded to the maximum risk question, and then again with only the 155 participants who gave consistent responses. We ran a Spearman's correlation to exclude collinear variables from our multivariate regression analysis.

## Results

### Respondent characteristics

Two hundred individuals completed the survey. Their mean age was 51.9 years (SD=10.4), with 65% male (Table 1). The median length of time since HIV diagnosis was 19 years [interquartile range (IQR)=13–24], the median length of time on ART was 15 years (IQR=9–20) and 58% had received at least some college education. The average EQ-5D score for our population was 0.79 (SD=0.20, scale ranges from 0 to 1). The average current health score was 77.6 (SD=16.7, scale ranges from 0 to 100), which, if interpreted as a health-related utility score, yields a value of 0.78, very similar to that provided by the EQ-5D.

### Willingness to take risk

When asked if they would take a '1 in 100' chance of death to be cured, 73% answered that they 'definitely' or 'probably' would, and 16% stated they probably or definitely would not. When asked if they would take a '99 in 100' chance of death, 26% said they definitely or probably would, while 63% answered they probably or definitely would not.

For the question on the 'largest chance of death (0–100) you would accept in a cure trial', the median response was 10% (Figure 1). While 18% (32 of 179) said that they would not take any risk of death in pursuit of a cure, more than a quarter (26%) said they would accept a greater than 50% chance of death.

### Concerns surrounding the long-term efficacy of antiretrovirals

The median estimated probability that the virus would stop responding to medications was 30% (IQR=10–50), with 41%

**Table 1.** Characteristics of PLWHIV completing a survey on HIV cure (*N*=200)

| Characteristics | All participants |
|---|---|
| Age (years), mean (SD) | 51.9 (10.4) |
| Sex | |
| Female/male (%) | 35.4/64.6 |
| Education, *n* (%) | |
| Some high school | 31 (16.6) |
| High school graduate | 48 (25.7) |
| Some college | 61 (32.6) |
| College graduate | 36 (19.3) |
| Postgraduate degree | 11 (5.9) |
| Employed, *n* (%) | 83 (42.8) |
| Household financial situation after paying bills, *n* (%) | |
| Still have money | 55 (30) |
| Little spare money | 64 (35) |
| Cutback on things | 30 (16) |
| Difficulty no matter what | 34 (19) |
| Years since HIV diagnosis, median (IQR) | 19 (13–24) |
| Years on HIV medications, median (IQR) | 15 (9–20) |
| Utility scores | |
| Current health (0–100), *M* (SD) | 77.6 (16.7) |
| EQ-5D (0–1), *M* (SD) | 0.79 (0.20) |

IQR: interquartile range; PLWHIV: people living with HIV.

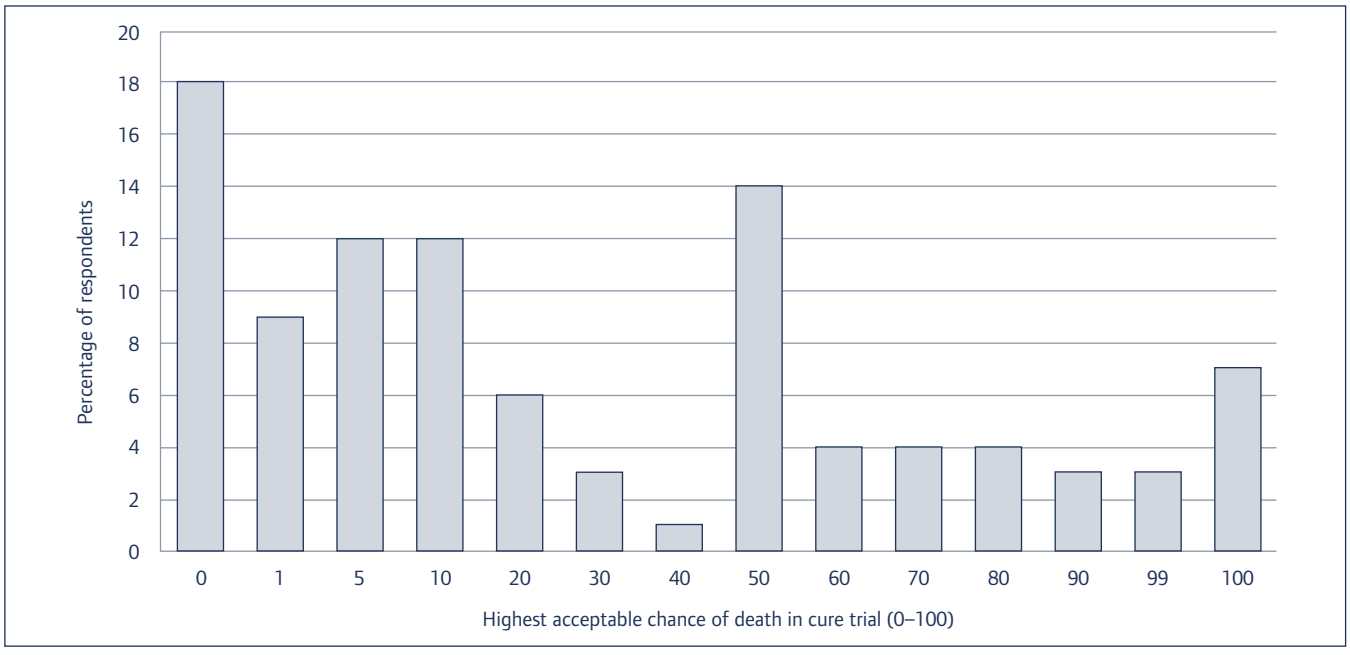


**Figure 1.** Stated risk tolerance on a continuous scale. The *x*-axis is not proportional to highlight responses of interest

of the respondents estimating this risk to be at or greater than 50% (Figure 2). Similarly, the median estimated probability that participants would experience serious side effects from medications was 50% (IQR=15–70).

### Stigmatisation

Nearly 80% (154 of 196) of the participants reported some degree of stigma, with a third reporting that they were either 'very' (19%) or 'extremely' (15%) stigmatised.

### Predictions of how HIV cure would affect health and health-related utility

When asked to estimate health status 5 years from now if cured, respondents predicted an average health rating of 89.1 (SD=12.0). When asked to predict health status in 5 years if antiretrovirals were continued, respondents predicted an average health rating of 77.7 (SD=17.3) (Figure 3). More than half of the respondents anticipated that a cure would reduce their chance of having a heart attack, being diagnosed with cancer or death in the next 20 years (55%, 57% and 59%, respectively) (Figure 4). Only 20% of the participants expected their chance of injury to change if they were cured of HIV.

### Predictors of willingness to take risk

Table 2 presents bivariate and multivariate regression analyses. In the bivariate analyses, five variables were positively associated with the maximum risk of death participants said they would be willing to take for a cure: (1) being employed, (2) having higher financial status, (3) expecting no response to their current HIV medications in 20 years, (4) expecting side effects from their medications in 20 years and (5) rating their current health-related quality of life (per EQ-5D scale) less highly. These same five variables were associated regardless of whether we analysed all respondents or only those who provided consistent answers to the three risk questions. In multivariate analyses, three variables were positively associated with people's willingness to take risk: (1) being employed, (2) having a higher financial status and (3) expecting side effects from their medications in 20 years.

## Discussion

Many PLWHIV in our study reported being willing to accept a substantial risk of death to potentially be cured of HIV. Specifically, despite being stable on ART, a quarter of our respondents were willing to accept a 50% or greater risk of death to achieve an HIV cure, and 10% were willing to accept a 90% or greater risk of death. Willingness to accept such risks was strongest among those with current jobs, greater financial security and a greater sense that they would expect long-term side effects from ART. One potential explanation for this enthusiasm to accept treatment risks is a belief that a cure would substantially improve health. A majority of participants thought that their present health not only would be maintained with a cure but also would improve, such that current health problems other than HIV would also be modestly reversed by a cure. In addition, many respondents believed that a cure would substantially reduce their risk of heart attack and cancer over the next 20 years.

Rational choice theories? Theories of rational choice hold that people should only accept risks if those risks will be outweighed by potential benefits. In other words, it would be irrational to accept a substantial risk of death to be cured of HIV if a cure would have little or no impact on one's life. However, we can

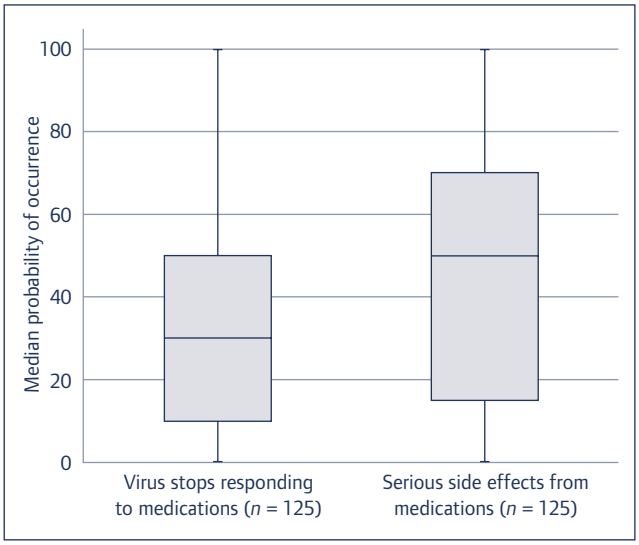


**Figure 2.** Participant expectations for their antiretroviral medications over the next 20 years. Boxes represent the interquartile range. The centre line is the median and whiskers show the range of responses

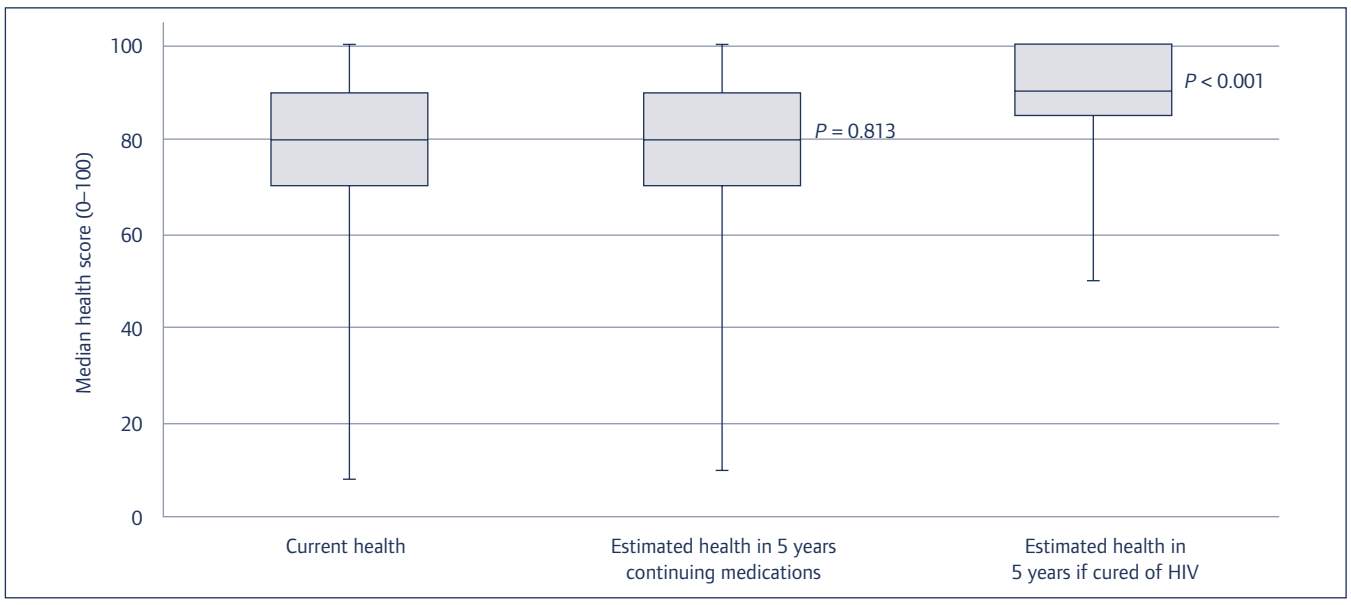


**Figure 3.** Current health and predicted health in 5 years, with and without a cure. Boxes represent the interquartile range. The centre line is the median and the whiskers show the range of responses. The *P*-values indicate whether there is a significant change in the distribution of scores between current and predicted health in 5 years

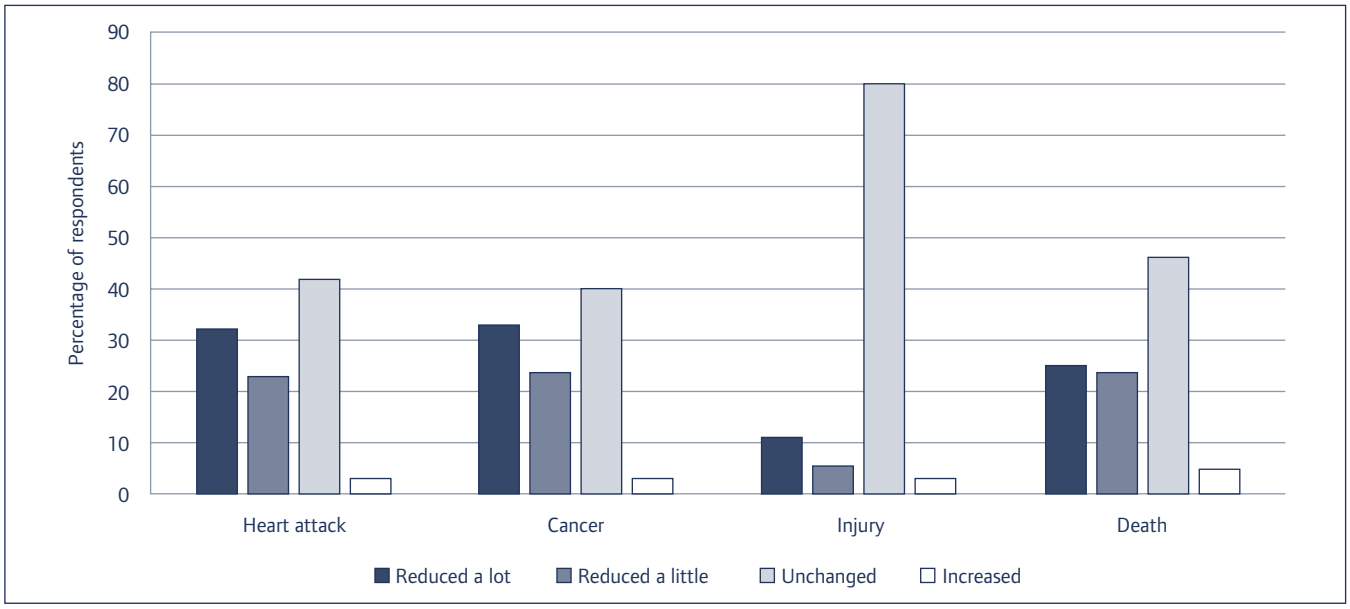


**Figure 4.** Expected change in likelihood of negative health event occurring in the next 20 years if cured of HIV ($n=193$)

**Table 2.** Predictors of willingness to risk death for an HIV cure

| Characteristic | Willingness to take risk – bivariate analysis* | | | | Willingness to take risk – multivariate analysis* | |
|---|---|---|---|---|---|---|
| | All ($n=179$) | | Consistent answers ($n=155$) | | All ($n=179$) | |
| | Coefficient | *P* | Coefficient | *P* | Coefficient | *P* |
| Current health rating (0–100) | –0.305 | 0.060 | –0.326 | 0.055 | | |
| General health (1–5) | 0.480 | 0.863 | –0.217 | 0.942 | –3.647 | 0.260 |
| EQ-5D index score | **–43.631** | **0.001** | **–44.183** | **0.001** | –25.171 | 0.166 |
| Change in health with cure compared with current | 0.251 | 0.150 | 0.340 | 0.059 | | |
| Difference in health without cure in 5 years | –0.019 | 0.922 | 0.057 | 0.774 | –0.015 | 0.945 |
| Expect side effects in 20 years | **0.186** | **0.044** | **0.199** | **0.042** | **0.206** | **0.049** |
| Expect no response in 20 years | **0.281** | **0.002** | **0.276** | **0.006** | | |
| Stigma | –1.259 | 0.524 | –2.688 | 0.199 | 2.680 | 0.270 |
| Finances | **7.156** | **0.005** | **9.088** | **0.001** | **6.226** | **0.050** |
| Subjective numeracy scale | –1.366 | 0.519 | –3.536 | 0.115 | 0.765 | 0.750 |
| Years with HIV | –0.292 | 0.353 | –0.581 | 0.074 | –0.340 | 0.348 |
| Years on HIV medications | –0.054 | 0.876 | –0.397 | 0.281 | | |
| Risk of heart attack | 2.482 | 0.398 | 0.758 | 0.814 | | |
| Risk of cancer | 1.275 | 0.660 | –0.219 | 0.944 | | |
| Risk of injury | –4.707 | 0.257 | –8.624 | 0.084 | | |
| Risk of death | 3.605 | 0.221 | 0.590 | 0.857 | | |
| Age | 0.127 | 0.621 | 0.043 | 0.874 | | |
| Sex | 2.539 | 0.647 | 4.391 | 0.450 | 7.986 | 0.221 |
| Education | –4.382 | 0.070 | –4.645 | 0.069 | | |
| Employment | **12.655** | **0.018** | **12.960** | **0.019** | **15.015** | **0.022** |

*Values in bold indicate statistical significance of $P<0.05$.
EQ-5D: EuroQol Five-Dimension Questionnaire.

ask: how realistic are people's expectations of an HIV cure and would they align with our current understanding of a potential cure's likely benefits? In other words, we can ask whether a person's willingness to accept risk for a cure is driven by inaccurate beliefs about how a cure would affect either their current or future health-related quality of life. For example, approximately one-third of our respondents believed that an HIV cure would substantially reduce their future risk of heart attack. While an antiretroviral medication such as abacavir may increase the likelihood of a cardiovascular event over a lifetime, the absolute risk

of such an event occurring is substantially lower than the risk of death proposed in our hypothetical cure scenarios [34]. Similarly, HIV infection has been shown to increase cancer rates, but the true risk in the age of combination ART has not been well defined [35]. Nevertheless, approximately one-third of our respondents believed an HIV cure would substantially reduce the risk of cancer, raising questions about whether their beliefs about the benefits of an HIV cure are partially misinformed.

Another reason to pursue a potentially risky cure would be to avoid experiencing a decline in the effectiveness of ART therapy over time. Indeed, many of our respondents expressed scepticism regarding the continued tolerability and effectiveness of their current treatments. As has been demonstrated previously, reduction in uncertainty is one of the primary benefits people anticipate an HIV cure would provide [19]. Nevertheless, mortality from treatment failure is uncommon [36]. One study on the three original antiretrovirals found that the likelihood of triple therapy failure was less than 10% at 10 years, and 90% of those who experienced failure were alive 5 years later [37]. These worries about medications can lead to psychological distress, and concerns surrounding the likelihood of antiretroviral failure appear to be exaggerated in our population.

While our survey primarily explored people's perceptions of how an HIV cure would affect their health, the benefits of cure go beyond health. We only explored two such non-health outcomes related to HIV: stigma and financial well-being. The vast majority of respondents (79%) stated that they experience at least some stigmatisation from HIV. These findings are similar to those of a global study from 2012 that found 78% of HIV-positive people experienced some kind of stigmatisation associated with their status [38]. While the data presented here cannot be used to directly infer whether stigma influenced risk tolerance, freedom from stigma could be a motivating factor for trying a risky cure. Similarly, PLWHIV experience disease-related expenses that potentially reduce their financial well-being. Moreover, in fact, financial well-being was one of the few measures we collected that was associated with people's willingness to accept risks for a cure.

Our study had several limitations. First, survey responses were collected from a convenience sample at two hospital-based clinics in the same city and were not generalisable to a broader population. For example, a younger population more recently infected with HIV could have different perceptions of the risks and benefits of a cure versus respondents like those in our study, most of whom had experienced lengthy suppression of the virus with antiviral therapy. Second, participants indicated their willingness to take risk from a hypothetical cure. Third, the survey focused on an ambiguous definition of 'cure', describing that a cure would mean people would not need to take medications but not clarifying whether it would involve eradication of the virus or, instead, medication-free remission [2]. Future surveys should include questions on remission, its meaning and its desirability to individuals. Fourth, a substantial number of participants had difficulty with the risk measure, resulting in a high rate of inconsistent responses. These difficulties could explain the lack of association between the risk measure and their beliefs about how a cure would affect their long-term health. Of note, previous research has also found problems with people's ability to comprehend standard gamble utility questions [39]. It is likely that survey elicitations of that measure will not accurately capture people's risk attitudes. Fifth, our study is correlational, not experimental. Thus, we can test which responses on our survey are correlated with respondents' willingness to risk death for a cure. However, we cannot state whether any of those relationships are causal. Sixth, we included measures of stigma and financial security, but not many other important life domains that are potentially affected by HIV. Future research should explore what PLWHIV believe about how cure would affect other life domains.

In summary, many people are willing to accept a relatively high risk of death to achieve an HIV cure despite being stable on ART. Further research should continue to explore the reasons for such willingness, employing measures of risk tolerance that are easier for people to understand and testing the extent to which people's willingness to incur risks for a cure are influenced by misperceptions of how a cure would change their lives.

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### Conflict of interest

None declared.

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