

IV-1 CURE RESEARCH: WHAT DO YOU THINK?

Thank you for your interest in this study.

The purpose of this questionnaire is to learn about your views on HIV-1 cure research. While there is no HIV cure at the moment, researchers in laboratories around the world are trying to develop one. It is important for researchers to understand community views on HIV cure research in order to develop one that will eventually be acceptable for those that will use it.

This is an anonymous and voluntary survey.

In this section we would like to learn a little bit about you. Please remember that participation is voluntary and all information you provide is anonymous.

1. *Do you identify as?*
 - Women
 - Man
 - Transgender man
 - Transgender women
 - Travesti
 - Non-binary
 - Other _____

2. *What is your sexual orientation?*
 - Bisexual
 - Gay
 - Questioning
 - Straight
 - Asexual
 - I don't identify with any of these
 - Other _____

3. *How old are you today?*

4. *What is your race?*
 - White
 - Mixed
 - Black
 - Asian
 - Indigenous

5. *What is the highest level of education you have had the chance to complete?*
- Less than high school
 - High school or equivalency
 - Skilled training
 - Some college
 - Undergraduate degree
 - Some graduate school
 - Graduate degree
6. *Which best describes your current employment status? Please select all that apply.*
- Full-time work
 - Looking for work
 - No paid work by choice
 - Part-time work
 - Retired
 - Seasonal work
 - Student
 - Informal work (e.g., street-based sales)
 - Sex worker
 - Other _____
7. *Which part of the city do you live in, or if you live outside of São Paulo, which city do you live in?*
8. *How would you describe your health status over the past month?*
- Very Healthy
 - Healthy
 - Somewhat healthy
 - Not very healthy
 - Not healthy at all
9. *Do any of the following describe you? Please select all that apply.*
- I am living with HIV
 - I have family or friends living with HIV
 - My partner / spouse is living with HIV
 - I feel I am at risk for HIV
 - I work in the field of HIV
 - None of these apply to me
10. *Have you ever heard about research to cure HIV/AIDS?*
- Yes
 - No

11. *What does a cure for HIV mean to you. Please select all that apply.*

- No more HIV treatment needed temporarily
- No more HIV treatment needed ever
- No risk of transmitting HIV to others
- Negative HIV test
- HIV completely eliminated from the body
- There is no risk of HIV/AIDS-related complications or other effects of HIV
- Other _____

12. *Do you think anyone has ever been cured of HIV?*

- Yes
- No

13. *How many years will it take to make an HIV cure that's available to the public?*

- I think there is a cure available now
- Within 5 years
- 6 to 10 years
- 11 to 20 years
- More than 20 years
- Probably never
- I'm not sure

14. *Have you ever participated in any health studies? These might be about HIV-1 or anything health-related. Please select all that apply.*

- Online questionnaire research (answering questions online only)
- Interviews (answering questions in person or on a phone call)
- Focus group discussions (where a group of people talk about a topic)
- Study where only blood draws were taken
- Long term study (where I came back to the clinic more than one time)
- None of these
- Other _____

15. *Have you ever participated in any HIV prevention studies? Please select all that apply.*

- HIV-1 prevention studies with medications
- HIV-1 prevention studies without medications
- HIV-1 prevention studies with behavioral treatments (like condom use, learning to ask partners about HIV status)
- Surveys about HIV prevention
- Studies that involve totally new treatments or approaches ("first-in-human" studies)
- Studies about drug safety
- Studies about whether drugs work to prevent HIV-1
- None of these
- Other _____

16. How willing would you be to take part in HIV cure research that involved each of the following?

	Very Willing	Willing	Not sure	Unwilling	Very Unwilling	Does not apply	I don't understand
Surveys or questionnaires online	<input type="checkbox"/>						
Interviews in person or by phone	<input type="checkbox"/>						
Focus group discussions	<input type="checkbox"/>						
Blood draws	<input type="checkbox"/>						
Tissue biopsies (taking out a small lymph node, for example)	<input type="checkbox"/>						
Procedures where selected cells are separated out while the rest of your blood is returned to you through a vein in your arm (leukapheresis, apheresis)	<input type="checkbox"/>						
Medications that can reactivate HIV-1 that has become dormant inside your body/cells (latency reversing agents)	<input type="checkbox"/>						
Modification of some of your genes (gene editing) in your immune cells	<input type="checkbox"/>						
Transplantation of your own stem cells (autologous transplant)	<input type="checkbox"/>						
Transplantation of someone else's stem cells (allogenic transplant)	<input type="checkbox"/>						
Therapeutic vaccines (to control HIV-1 in people already living with HIV-1)	<input type="checkbox"/>						
Taking you off your medications for at least a month or more (treatment interruption)	<input type="checkbox"/>						
Use of broadly neutralizing antibodies, infused into a vein in your arm or under the skin	<input type="checkbox"/>						
Use of unique proteins or T cells	<input type="checkbox"/>						
Totally new treatments that have never been tested in people	<input type="checkbox"/>						
Studies to see if new drugs are safe (early safety studies)	<input type="checkbox"/>						
Studies to see if new drugs work (efficacy studies)	<input type="checkbox"/>						

17. People agree to take part in research for a number of different reasons. How important is each of the following in motivating you to take part in HIV cure research studies? You can check multiple answers.

	Very Important	Somewhat Important	Not Sure/ Do not know	Barely Important	Not Important	Does not apply
Getting additional knowledge about HIV infection	<input type="checkbox"/>					
Having access to medical doctors and researchers	<input type="checkbox"/>					
Having access to study nurses	<input type="checkbox"/>					
Feeling good about contributing to HIV-1 cure research	<input type="checkbox"/>					
Hope that my health will improve	<input type="checkbox"/>					
Because I care about my community	<input type="checkbox"/>					
Learning about new treatment options	<input type="checkbox"/>					
Having laboratory work without costs	<input type="checkbox"/>					
Being offered a meal at the study site	<input type="checkbox"/>					
Payment for participation in a study	<input type="checkbox"/>					
Receiving money for gas, parking, or transportation	<input type="checkbox"/>					
Caring about future generations	<input type="checkbox"/>					
Contributing to scientific knowledge	<input type="checkbox"/>					
Potential for longer, healthier life for myself	<input type="checkbox"/>					
Potential for longer, healthier life for others	<input type="checkbox"/>					

18. *As with any new treatment being researched, treatments to cure HIV will have risks. How likely will any of the following potential risks discourage you from participating in a research study? You can check multiple answers. You can check multiple answers.*

	Very likely to discourage	Some-what likely to discourage	Not likely to discourage	Not discouraging	I don't know	Does not apply
Toxicities or adverse side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Potential for development of drug resistance to current and approved treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Potential for the virus coming back if antiretroviral treatment is stopped	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Activation of cancer-causing genes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Graft-versus-host disease (or GVHD) (a possible complication from allogeneic (foreign) stem cells transplants, although rare)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Invasive study procedures (such as biopsies)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having to be followed for many years for safety and outcomes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurologic side effects (for example, headache, dizziness, fatigue)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gastrointestinal side effects (for example, nausea, vomiting, diarrhea)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological side effects (for example, depression, vivid or strange dreams)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV-related side effects (for example, increased risk of opportunistic infections)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dermatologic side effects (for example, hair loss, rashes, itching, sores)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Musculoskeletal side effects (for example, muscle aches, soreness, trouble walking)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Allergic reactions (for example, trouble breathing, hives)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Risk of giving HIV to my sexual partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unknown side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain or discomfort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having to stay in the hospital overnight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking time away from family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking time away from work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Long study visits (more than 4 hours)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. Please indicate your level of agreement with the next statements. As with the rest of this questionnaire, there are no right or wrong answers; we are interested in your opinions.

	Strongly Agree	Agree	Neutral/ Not Sure	Disagree	Strongly Disagree
If the cost on HIV-1 cure is high, it will prevent people from taking it	<input type="checkbox"/>				
People living with HIV-1 are discriminated against	<input type="checkbox"/>				
The dangers of the new cure may be too high	<input type="checkbox"/>				
Current antiretroviral treatment is very good; we do not need a cure	<input type="checkbox"/>				
If a cure were available, people will not try to stay HIV negative using prevention methods like condoms or PrEP	<input type="checkbox"/>				
More education about cure research is needed before a cure will be accepted by the community	<input type="checkbox"/>				
I do not think there will ever be a cure for HIV	<input type="checkbox"/>				
A cure that would stop the need for all treatment would be desirable	<input type="checkbox"/>				
I can trust my health care provider's decisions on which medical treatments are best for me	<input type="checkbox"/>				
All things considered, I completely trust my health care provider	<input type="checkbox"/>				

Thank you for taking the time to complete this questionnaire! We will compile the data and present for publication to continue stimulating research in this area and including transgender voices in these important studies.