**Today’s date (month/day/year): \_\_\_\_\_\_/\_\_\_\_\_\_\_/\_\_\_\_\_\_\_\_**

**Study ID #: \_\_\_\_\_\_\_\_\_\_\_\_\_**

The purpose of this survey is to understand what you know about HIV-positive to HIV-positive organ donation and transplantation, and your opinions about them. Thank you for taking the time to complete this survey. Please remember that you can skip any items you do not want to answer.

**Transplant Information**

* 1. **Do you know anyone who is currently receiving dialysis treatment for kidney disease?**
     1. Yes
     2. No
     3. Not sure
  2. **Do you know anyone who has received an organ transplant?**
     1. Yes
     2. No
     3. Not sure
  3. **Do you know anyone who is on an organ transplant waiting list?**
     1. Yes
     2. No
     3. Not sure
  4. **Do you think there is currently a shortage of organs for transplantation in the United States?**
     1. Yes
     2. No
     3. Not sure
  5. **Do you know that until recently in 2016, transplanting organs from donors with HIV was illegal?**
     1. Yes
     2. No
     3. Not sure
  6. **Have you heard of the new law that made it legal to transplant organs from donors with HIV under research studies?** 
     1. Yes
     2. No
     3. Not sure
  7. **If yes, where did you hear about this law? Please mark all that apply**

□ My doctor and/or other healthcare providers

□ The news (e.g. newspapers, TV, etc…)

□ Social media (Facebook, Twitter, etc…)

□ Academic journals

□ Word of mouth

□ Community groups

□ Other:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**This new law is called the HOPE Act (HOPE stands for HIV Organ Policy Equity), which makes it legal for people with HIV to donate organs to other people with HIV under research studies. We would like to hear your opinion about the law.**

* 1. **Do you think that using HIV-positive organs for transplantation into patients with HIV/AIDS should be studied in research?**
     1. Definitely should
     2. Probably should
     3. Not sure
     4. Probably should not
     5. Definitely should not
  2. **Do you think using HIV-positive organs for transplantation will help reduce discrimination against people living with HIV/AIDS?**
     1. Definitely yes
     2. Probably yes
     3. Not sure
     4. Probably no
     5. Definitely no
  3. **Do you think people with HIV/AIDS should have the choice to donate organs to other people with HIV/AIDS?**
     1. Definitely yes
     2. Probably yes
     3. Not sure
     4. Probably no
     5. Definitely no
  4. **We want to learn more about the reasons why people think using HIV-positive organs for transplantation into patients with HIV/AIDS should or should not be studied in research:**

**11.1. Do you think using HIV-positive organs for transplantation is safe for the HIV-positive recipient?**

a) Definitely yes b) Probably yes c) Not sure d) Probably not e) Definitely not

**11.2. Do you think HIV-positive organs would work as well as HIV-negative organs?**

a) Definitely yes b) Probably yes c) Not sure d) Probably not e) Definitely not

**11.3. Do you think using HIV-positive organs for transplantation would lower the number of people waiting for organs?**

a) Definitely yes b) Probably yes c) Not sure d) Probably not e) Definitely not

**11.4. Do you think using HIV-positive organs would help people who need organ transplantation to get an organ faster?**

a) Definitely yes b) Probably yes c) Not sure d) Probably not e) Definitely not

**11.5. Do you think by using HIV-positive organs for transplantation, HIV-positive patients would help other people in need of organ transplants by freeing up HIV-negative organs for someone else?**

a) Definitely yes b) Probably yes c) Not sure d) Probably not e) Definitely not

**11.6. Do you think the person who receives an HIV-positive organ for transplantation would get a different type of HIV virus that might be harder to treat than what he/she currently has?**

a) Definitely yes b) Probably yes c) Not sure d) Probably not e) Definitely not

**11.7. Do you think the person who receives an HIV-positive organ for transplantation would get other infections besides HIV/AIDS?**

a) Definitely yes b) Probably yes c) Not sure d) Probably not e) Definitely not

* 1. **Please list any other reasons influencing your opinion on whether organs from donors with HIV should be used for transplantation into people with HIV/AIDS that were NOT listed above:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**There are two types of organ donors: deceased donors and living donors. A deceased donor is someone who donates their organs to others after they have passed away. Some organs (e.g. kidney, liver) can be donated while the donor is alive because the remaining organ or parts of an organ can still work after he/she donates. A living donor is someone who donates their organs to others while they are still alive.**

* 1. **If you ever needed an organ transplant in the future, would you CONSIDER accepting an HIV-positive organ from an HIV-positive DECEASED donor?**
     1. Yes, I would consider
     2. No, I would not consider
     3. Not sure
  2. **If you ever needed an organ transplant in the future, would you CONSIDER accepting an organ from a LIVING donor regardless of HIV status?**
     1. Yes, I would consider
     2. No, I would not consider
     3. Not sure
  3. **If you ever needed an organ transplant in the future, would you CONSIDER accepting an HIV-positive organ from an HIV-positive LIVING donor?**
     1. Yes, I would consider
     2. No, I would not consider
     3. Not sure
  4. **If you needed a transplant, what other information would you want before making a decision about accepting an HIV-positive organ? Please mark all that apply.**

□ Information on the risks of organ transplantation

□ Information on the risks of accepting an HIV-positive organ

□ Information on the benefits of organ transplantation

□ Information on the benefits of accepting an HIV-positive organ

□ Stories about the experiences of other HIV-positive donors

□ Stories about the experiences of other HIV-positive recipients

□ Information from my doctor and/or other healthcare providers

□ Information on the costs of organ transplantation

□ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**In this section, we will ask you a few questions about organ donation and your opinion on whether you would be WILLING TO DONATE your organs as a person currently living with HIV/AIDS.**

* 1. **Are you currently registered as an organ donor?**
     1. Yes
     2. No
     3. Not sure
  2. **Have you talked about whether you want to be an organ donor with anyone?**
     1. Yes
     2. No
  3. **If yes, Which of these people have you talked to about whether you want to be an organ donor? Please mark all that apply.**

□ Partner/Spouse

□ Children that are over 18 years old

□ Children that are under 18 years old

□ Parents

□ Brother(s)/Sister(s)

□ Other relatives

□ Close friends

□ Employer

□ Other; please specify­­­­­­­­­­­­­­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

* 1. **Now that people living with HIV/AIDS are allowed to donate organs to other people living with HIV/AIDS under research studies, would you be willing to be a DECEASED organ donor?**
     1. Definitely yes
     2. Probably yes
     3. Not sure
     4. Probably no
     5. Definitely no
  2. **We want to learn more about the reasons why you are willing or not willing to be a DECEASED organ donor:**

**21.1. Do you have religious beliefs about organ donation that encourage or discourage you from being willing to donate?**

a) Definitely yes b) Probably yes c) Not sure d) Probably not e) Definitely not

**21.2. Do you think donating organs would add financial burden to you and your family if you choose to be a deceased donor?**

a) Definitely yes b) Probably yes c) Not sure d) Probably not e) Definitely nor

**21.3. Do you think you would trust the medical system to handle the donating process appropriately if you choose to be a deceased donor?**

a) Definitely yes b) Probably yes c) Not sure d) Probably no t e) Definitely not

**21.4. Do you think your organs would function as well in the recipient despite your past medical illnesses besides HIV if you choose to be a deceased donor?**

a) Definitely yes b) Probably yes c) Not sure d) Probably not e) Definitely not

**21.5. Do you think your organs would be taken before you are dead if you choose to be a deceased donor?**

a) Definitely yes b) Probably yes c) Not sure d) Probably no t e) Definitely not

**21.6. Do you think your body would be disfigured before your funeral if you choose to be a deceased donor?**

a) Definitely yes b) Probably yes c) Not sure d) Probably no t e) Definitely not

* 1. **Now that people living with HIV/AIDS are allowed to donate organs to other people living with HIV/AIDS under research studies, would you be willing to be a LIVING organ donor?**
     1. Definitely yes
     2. Probably yes
     3. Not sure
     4. Probably no
     5. Definitely no
  2. **We want to learn more about the reasons why you are willing or not willing to be a LIVING organ donor:**

**23.1. Do you have concerns about going through surgery that discourage you from being willing to donate?**

a) Definitely yes b) Probably yes c) Not sure d) Probably no t e) Definitely not

**23.2. Do you think donating organs would make your health worse if you choose to be a living donor?**

a) Definitely yes b) Probably yes c) Not sure d) Probably no t e) Definitely not

**23.3. Do you think your HIV treatment would be changed if you choose to be a living donor?**

a) Definitely yes b) Probably yes c) Not sure d) Probably no t e) Definitely not

**23.4. Do you think that you would be at higher risk for poor health after donating because of your HIV status if you choose to be a living donor?**

a) Definitely yes b) Probably yes c) Not sure d) Probably no t e) Definitely not

* 1. **Please list any other reasons influencing your decision on whether you are willing to be an organ donor, either living or deceased, that were NOT listed above:**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

* 1. **What information could help you make a decision about becoming an organ donor? Please mark all that apply.**

□ Information on the risks of becoming an organ donor

□ Information on the benefits of becoming an organ donor

□ Understanding the need for organ donation

□ Stories about the experiences of HIV-positive donors

□ Stories about the experiences of HIV-positive recipients

□ Information from my doctor and/or other healthcare providers

□ Information on how much donating will cost

□ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Medical History**

* 1. **Have you ever been diagnosed with chronic kidney disease (CKD)? If no, skip to #28.**
     1. Yes
     2. No
     3. Not sure
  2. **If yes, when? (month/year) ­­­­\_\_\_\_\_\_\_\_/\_\_\_\_\_\_\_\_\_**
  3. **Have you ever been diagnosed with chronic liver disease or cirrhosis? If no, skip to #30.**
     1. Yes
     2. No
     3. Not sure

* 1. **If yes, when? (month/year) ­­­­\_\_\_\_\_\_\_\_/\_\_\_\_\_\_\_\_\_**
  2. **Have you ever been on dialysis? If no, skip to #32.**
     1. Yes
     2. No
  3. **If yes, how long have you been on dialysis? \_\_\_\_\_\_ year(s) and \_\_\_\_\_\_\_\_ month(s)**
  4. **Have you ever been diagnosed with Hepatitis C? If no, skip to #34.**
     1. Yes
     2. No
     3. Not sure
  5. **If yes, when? (month/year) ­­­­\_\_\_\_\_\_\_\_/\_\_\_\_\_\_\_\_\_**

**HIV Information**

* 1. **Do you agree with this statement: “I feel knowledgeable about HIV”?**
     1. Strongly agree
     2. Agree
     3. Neither agree nor disagree
     4. Disagree
     5. Strongly disagree
  2. **Do you know your most recent HIV viral load value? If no, skip to #38.**
     1. Yes
     2. No
  3. **What is your most recent viral load value? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**
  4. **When was this measurement taken? (month/year) ­­­­\_\_\_\_\_\_\_\_/\_\_\_\_\_\_\_**
  5. **Do you know your most recent CD4 cell count? If no, skip to #41.**
     1. Yes
     2. No
  6. **What is your most recent CD4 cell count? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**
  7. **When was this measurement taken? (month/year) ­­­­\_\_\_\_\_\_\_\_/\_\_\_\_\_\_\_**
  8. **Have you ever been diagnosed with an “opportunistic infection?” (Some examples of “opportunistic infections” include: candida esophagitis, PCP, and toxoplasmosis)**
     1. Yes
     2. No
     3. Not sure
  9. **How long have you known you have HIV? \_\_\_\_\_\_ (years) and \_\_\_\_\_\_\_\_ (months)**
  10. **Please list all medications you are currently taking related to treating HIV:**
      1. ­­­­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ f)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
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  11. **Does anyone besides yourself know about your HIV status?**
      1. Yes
      2. No
  12. **If yes, which of these people know about your HIV status? Please mark all people who know:**

□ Partner/Spouse

□ Children that are over 18 years old

□ Children that are under 18 years old

□ Parents

□ Brother(s)/Sister(s)

□ Other relatives

□ Close friends

□ Employer

□ Other; please specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

* 1. **Where do you get your information on new findings in HIV treatment? Please mark all that apply.**

□ My doctor and/or other healthcare providers

□ The news (e.g. newspapers, TV, etc…)

□ Social media (Facebook, Twitter, etc…)

□ Academic journals

□ Word of mouth

□ Community groups

□ Other:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Demographic Information**

* 1. **What is your age? \_\_\_\_\_\_\_ years**
  2. **Please indicate the highest level of education you have COMPLETED:**
     1. Less than high school
     2. High school or GED
     3. Associate’s degree
     4. Bachelor’s degree
     5. Graduate degree
     6. Other (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
  3. **Are you currently employed?**
     1. Full-time
     2. Part-time
     3. Disabled
     4. Unemployed
     5. Retired
     6. Decline to answer
  4. **On average how many people lived in your house during the last 12 months? \_\_\_\_\_\_\_\_person(s)**
  5. **What is your combined household annual income?**
     1. <$15,000
     2. $15,000 - $29,999
     3. $30,000 - $34,999
     4. $35,000 - $49,999
     5. $50,000 - $74,999
     6. $75,000 - $89,999
     7. $90,000 - $99,999
     8. $100,000 - $149,000
     9. $150,000 - $299,999
     10. >$300,000
     11. Decline to answer
  6. **What type of insurance do you currently have?**
     1. None
     2. Medicaid, Medicare, or other government insurance
     3. Health insurance at work
     4. Other; please specify:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
  7. **What is your current gender identity? Please mark all that apply:**

□ Male

□ Female

□ Transgender

□ Genderqueer, gender non-conformant, neither exclusively male nor female

□ Additional Gender Category/(or Other), please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_

□ Decline to Answer

* 1. **What sex were you assigned at birth on your original birth certificate? Check one:**
     1. Male
     2. Female
     3. Decline to Answer
  2. **Do you consider yourself to be:**
     1. Heterosexual or straight
     2. Gay or lesbian
     3. Bisexual
     4. Other: \_\_\_\_\_\_\_\_\_\_\_\_\_
  3. **What race best describes you? Please mark all that apply:**

□ American Indian/Alaska Native

□ Asian

□ Black/African American

□ Native Hawaiian/Other Pacific Islander

□ White/Caucasian

□ Other, please specify:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

* 1. **Do you consider yourself Hispanic or Latino?**
     1. Yes
     2. No
  2. **What is your marital status?**
     1. Single
     2. Married
     3. Cohabiting
     4. Divorced
     5. Widowed
     6. Decline to answer

This concludes our survey. Thank you for your time!