

Supplemental Material

**Interpretation of multivariable linear regression model results presented in Table 3**

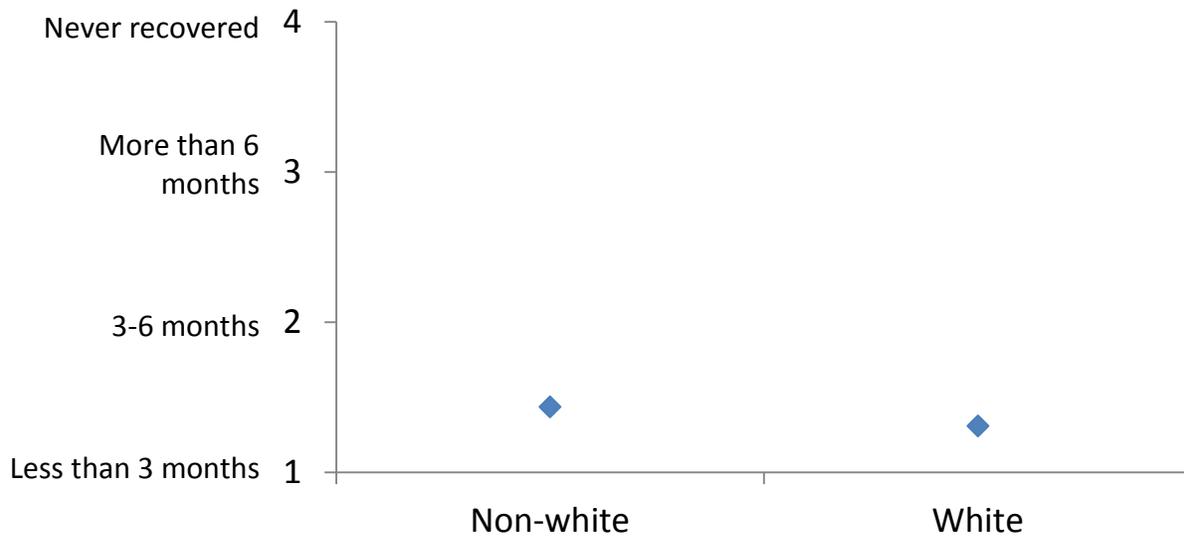
When dichotomous or categorical covariates are modeled as dummy variables, a one-unit difference is the difference between being in the effect group or the reference group. For instance, when we modeled race, white race was the effect group (modeled with the number 1) and non-white race was the reference group (modeled with the number 0). The effects for race, because they are modeled as dummy variables, are therefore interpreted as the difference between white and non-white.

Other covariates were continuous, or measured with multi-point scales and treated as continuous. For example, we examined age and years since donation. Each of these variables was evaluated per 10 years, meaning the regression coefficient of age describes someone who donated at age 30 versus someone who donated at age 40, or likewise a 55-year-old donor versus a 65-year-old donor.

Outcomes of the linear regression models were multi-point scales. For instance, the outcome of overall recovery time was measured as 1 = less than 3 months, 2 = 3 to 6 months, 3 = more than 6 months, and 4 = never recovered. A one-unit increase in this scale would be the difference between any two adjacent categories, such as the difference between 'less than 3 months' and '3 to 6 months.'

Linear regression results are interpreted according to the general formula: Holding  $X_2$  constant, an increase of 1 unit in  $X_1$  is associated with an increase of # in Y. In this scenario, Y is the outcome,  $X_1$  is the effect being interpreted, and  $X_2$  is a covariate that was also included in the model, but is not being interpreted in the sentence. For instance, in the model predicting the outcome (Y) overall recovery time, we included two covariates: race ( $X_1$ ) and surgical procedure ( $X_2$ ). We can interpret the effect of race in this model as: Holding surgical procedure constant, white donors had an overall recovery time that was shorter by 0.13 points than non-white donors. Supplemental Figure 1 shows this association in terms of the mean overall recovery time.

**Figure 1. Mean overall recovery time for non-white and white donors, holding education constant**



The reason we include the phrase “holding surgical procedure constant” in the interpretation is that some white donors and some non-white donors had laparoscopic surgeries, and some white and non-white donors had open surgeries. The model provides the effect of race independent of the effect of laparoscopic surgery. The surgical effect is interpreted as: holding race constant, donors with a laparoscopic surgery had an overall recovery time that was shorter by 0.10 points than donors with an open surgery.

When interpreting 95% confidence intervals, intervals that include 0 are not statistically significant, while intervals that do not include 0 are statistically significant using the criterion  $p < 0.05$ .

Following is a description of mean (average) differences that may help interpretation of the rest of the linear regression results.

- In the model predicting recovery time for daily activities, which was measured on a 4-point scale from “less than 3 months” (1) to “never recovered” (4)...
  - White donors had a recovery time shorter by 0.16 points than non-white donors, holding educational attainment constant. The effect of race indicates that the typical recovery time for daily activities among white donors was 1.08 points (on the 4-point scale), compared to a typical recovery time of 1.24 points among non-white donors.
  - Donors with a graduate degree had a recovery time for daily activities that was shorter by 0.08 points than donors with less than a high school degree (4 units lower on the scale of educational attainment). The typical recovery time for daily activities among donors with less than a high school education was 1.12 points (on the 4-point scale), compared to a typical recovery time of 1.04 points among donors with a graduate degree.
- In the model predicting recovery time compared to expectations, which was measured on a 5-point scale from “much shorter than I expected” (1) to “much longer than I expected” (5)...

- Relative to their expectations, 20-year-old donors reported recovery time of 2.96 points. This 2.96 mean on a 1-5 scale is close to 3, which is the response “about as long” as expected. Typical donors’ reports were relatively stable at 30 years old, 40 years old, and 50 years old (all above 2.90). The age-squared term models the sharper decrease in recovery time compared to expectations for older donors. Sixty-year-old donors reported recovery time relative to expectations of 2.66 points, while 70-year-old donors reported recovery time compared to expectations of 2.35 points. This mean is closer to the response “somewhat shorter” than expected than it is to the response “about as long” as expected.
- Mean recovery time compared to expectations was 2.81 points for male donors compared to 2.96 points for female donors.
- Typical recovery time compared to expectations was 2.99 points for donors with an open procedure compared to 2.72 points for donors with a laparoscopic procedure. (The magnitude of this difference was smaller after adjusting for age and sex.)
- In the model predicting support from friends and family, which was measured on a 5-point scale from “strongly disagree” (1) to “strongly agree” (5)...
  - On average, donors only 10 years out from their donation were close to “strongly agreeing” that family or friends supported them (4.61 points), while individuals who donated 40 years ago were closer to the “agree” response (4.36 points). (The magnitude of this difference was smaller after adjusting for relationship to recipient and emotional complications.)
  - Donors who were related to their recipient reported family and friend support of 4.60 points compared to 4.48 points among donors who were not related to their recipient. (When adjusting for time since donation and emotional complications, the difference between related and unrelated donors was larger, at 0.17 points.)
  - Donors with an emotional, psychological, or substance abuse complication reported family and friend support of 4.21 points compared to 4.60 points among donors without an emotional complication.
- In the model predicting support from health care providers, which was measured on a 5-point scale from “strongly disagree” (1) to “strongly agree” (5)...
  - Twenty-year-old donors reported support from health care providers of 3.41 points, compared to 3.80 points among 60-year-old donors. (The magnitude of this difference was smaller after adjusting for sex, medical complications, and emotional complications.)
  - Men reported support of 3.73 points, compared to 3.57 points among women.
  - Donors with a medical complication reported support from health care providers of 3.34 points compared to 3.70 points among donors without an emotional complication. (The magnitude of this difference was smaller after adjusting for age, sex, and emotional complications.)
  - Donors with an emotional, psychological, or substance abuse complication reported support from health care providers of 2.87 points compared to 3.66 points among donors without an emotional complication. (The magnitude of this difference was smaller after adjusting for age, sex, and medical complications.)

- In the model predicting feeling that no one paid attention, which was measured on a 5-point scale from “strongly disagree” (1) to “strongly agree” (5)...
  - Donors with a medical complication reported more agreement that they felt no one paid attention, with an average of 2.03 points compared to 1.71 points among donors without an emotional complication. (The magnitude of this difference was smaller after adjusting for emotional complications.)
  - Donors with an emotional, psychological, or substance abuse complication reported more agreement that no one paid attention, with an average of 2.48 points compared to 1.74 points among donors without an emotional complication. (The magnitude of this difference was smaller after adjusting for medical complications.)
- In the model predicting feeling closer to the recipient, which was measured on a 5-point scale from “strongly disagree” (1) to “strongly agree” (5)...
  - Twenty-year-old donors reported agreement that they felt closer to their recipient of 3.89 points, compared to 4.20 points among 60-year-old donors.
  - Donors with an emotional, psychological, or substance abuse complication reported agreement that they felt closer to their recipient of 3.47 points compared to 4.04 points among donors without an emotional complication. (The magnitude of this difference was smaller after adjusting for medical complications.)
  - Donors who were unrelated to their recipient and not a friend reported agreement that they felt closer to their recipient of 3.63 points compared to 4.19 points among donors who were a parent of their recipient, 4.16 points among donors who were children of their recipient, 3.92 points among siblings, 4.19 points among spouses, 4.06 points among friends, and 3.92 points among donors with another related relationship. (The magnitude of the effects of being a child, sibling, other relative, or friend of the recipient were larger after adjusting for age and emotional complications.)
- In the model predicting thinking the recipient feels indebted, which was measured on a 5-point scale from “strongly disagree”(1) to “strongly agree” (5)...
  - Donors who were unrelated to their recipient and not a friend reported agreement that their recipient felt indebted of 2.83 points compared to 2.09 points among donors who were a parent of their recipient and 2.43 points among spouses. (The magnitude of the effect of being a parent of the recipient was larger after adjusting for recipient graft function, while the magnitude of the effect of being a spouse of the recipient was smaller.)
  - Donors whose grafts were no longer functioning in the recipient reported agreement that their recipient felt indebted of 2.20 points compared to 2.60 points among donors whose grafts were still functioning.
- In the model predicting thinking the recipient doesn’t show enough gratitude, which was measured on a 5-point scale from “strongly disagree” (1) to “strongly agree” (5)...
  - Twenty-year-old donors reported agreement the recipient doesn’t show enough gratitude of 1.76 points, compared to 1.52 points among 60-year-old donors. (The

- magnitude of the effect of age larger after adjusting for medical complications, emotional complications, and relationship to recipient.)
- Donors with a medical complication reported more agreement that recipient doesn't show enough gratitude, with an average of 1.88 points compared to 1.53 points among donors without an emotional complication. (The magnitude of this difference decreases after adjusting for age, emotional complications, and relationship to recipient.)
  - Donors with an emotional, psychological, or substance abuse complication reported more agreement that recipient doesn't show enough gratitude, with an average of 2.32 points compared to 1.57 points among donors without an emotional complication. (The magnitude of this difference decreases after adjusting for age, medical complications, and relationship to recipient.)
  - Donors who were unrelated to their recipient and not a friend reported more agreement that recipient doesn't show enough gratitude, with an average of 1.74 points compared to 1.50 points among donors who were children of their recipient. (The magnitude of the effect of being a child of the recipient was larger after adjusting for age, medical complications, and emotional complications.)
- In the model predicting the donor's perception of the overall donation experience, which was measured on a 5-point scale from "poor" (1) to "excellent" (5)...
    - On average, donors only 10 years out from their donation rated their overall donation experience as 4.35 points, while individuals who donated 40 years ago rated their experience as 4.14 points. (The magnitude of this difference decreases after adjusting for medical complications, emotional complications, and recipient graft function.)
    - Donors with a medical complication reported a less positive overall donation experience, with an average of 3.89 points compared to 4.44 points among donors without a medical complication. (The magnitude of this difference decreases after adjusting for time since donation, emotional complications, and recipient graft function.)
    - Donors with an emotional, psychological, or substance abuse complication reported a less positive overall donation experience, with an average of 3.29 points compared to 4.38 points among donors without an emotional complication. (The magnitude of this difference decreases after adjusting for time since donation, medical complications, and recipient graft function relationship to recipient.)
    - Donors whose grafts were no longer functioning in the recipient reported a less positive overall donation experience, at 4.25 points compared to 4.42 points among donors whose grafts were still functioning. (The magnitude of this difference decreases after adjusting for time since donation, medical complications, and emotional complications.)
  - In the model predicting willingness to donate again, if possible, which was measured on a 5-point scale from "definitely not" (1) to "definitely yes" (5)...
    - On average, donors only 10 years out from their donation were more willing to donate again, rating 4.79 points, while individuals who donated 40 years ago rated their experience as 4.70 points. (The magnitude of this difference decreases after adjusting for race, relationship to recipient, medical complications, and emotional complications.)

- White donors were more likely to donate again, at 4.79 points than non-white donors at 4.67 points. (The magnitude of this difference was larger after adjusting for time since donation, relationship to recipient, medical complications, and emotional complications.)
- Donors who were related to their recipient were more likely to donate again, at 4.79 points compared to 4.72 points among donors who were not related to their recipient. (When adjusting for time since donation, race, medical complications, and emotional complications, the difference between related and unrelated donors was larger.)
- Donors with a medical complication were less likely to donate again, rating this as an average of 4.69 points compared to 4.81 points among donors without a medical complication. (The magnitude of this difference was larger after adjusting for time since donation, race, relationship to recipient, and emotional complications.)
- Donors with an emotional, psychological, or substance abuse complication were less likely to be willing to donate again, with an average of 4.33 points compared to 4.81 points among donors without an emotional complication. (The magnitude of this difference was weaker after adjusting for time since donation, race, relationship to recipient, and medical complications.)
- In the model predicting financial burden, which was measured on a 5-point scale from “no burden” (1) to “extreme burden” (5)...
  - Twenty-year-old donors reported greater financial burden, at 1.39 points, compared to 1.21 points among 60-year-old donors. (The magnitude of this difference was smaller after adjusting for education, medical complications, and emotional complications.)
  - Donors with less than a high school education reported a greater financial burden, of 1.41 points, compared to 1.20 points among donors with a graduate degree. (The magnitude of this difference was smaller after adjusting for age, medical complications, and emotional complications.)
  - Donors with a medical complication reported greater financial burden, rating this as an average of 1.48 points compared to 1.26 points among donors without a medical complication. (The magnitude of this difference was larger after adjusting for age, education, and emotional complications.)
  - Donors with an emotional, psychological, or substance abuse complication reported greater financial burden, rating this with an average of 1.98 points compared to 1.27 points among donors without an emotional complication. (The magnitude of this difference was weaker after adjusting for age, education, and medical complications.)

## Supplemental Material

eFigure 1. Enrollment Flow Diagram

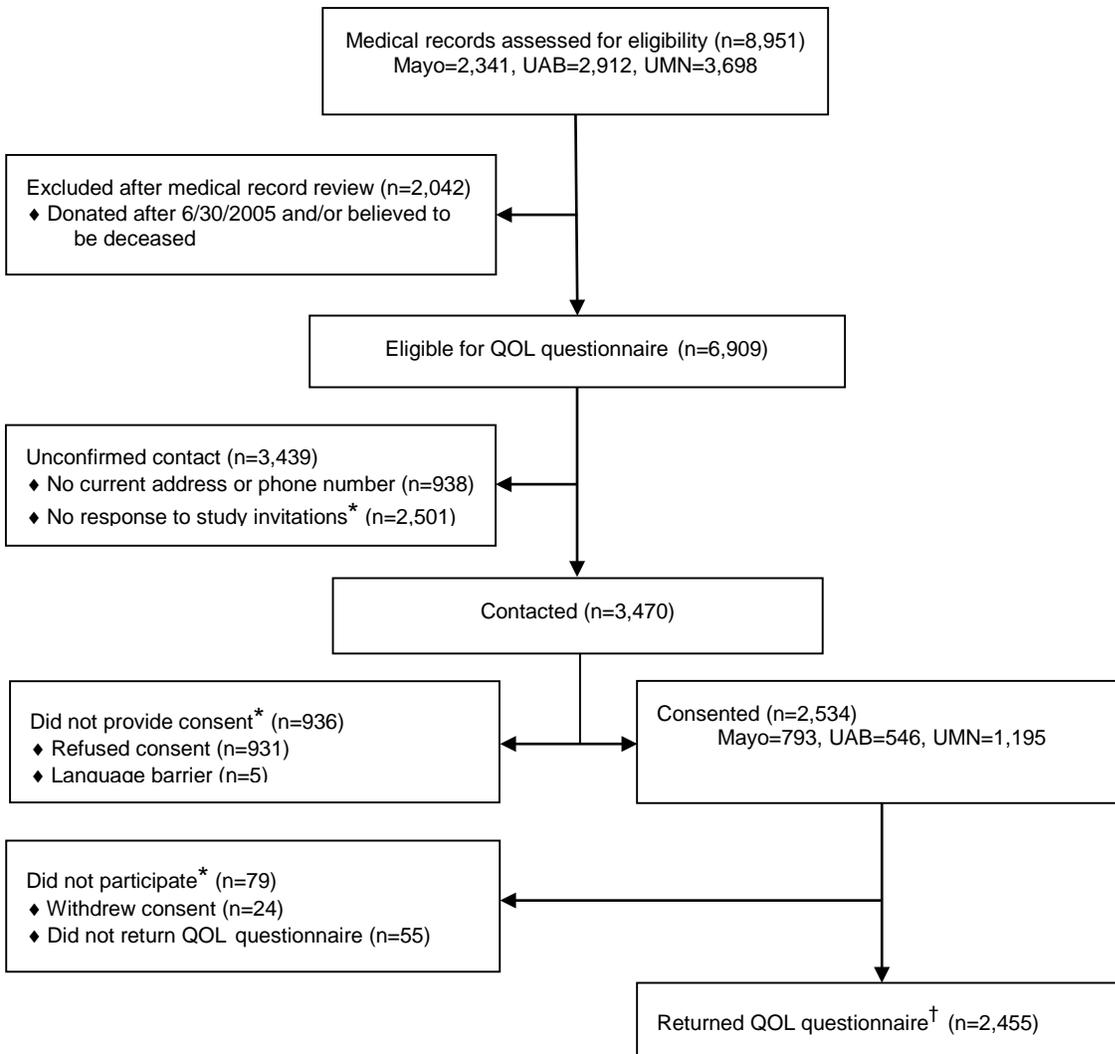
eFigure 2. Attitudes and Feelings Toward Donation

eFigure 3. Donation Experience

eFigure 4. Recipient and Donor Outcomes

eAppendix. Donor Questions on the QoL Questionnaire

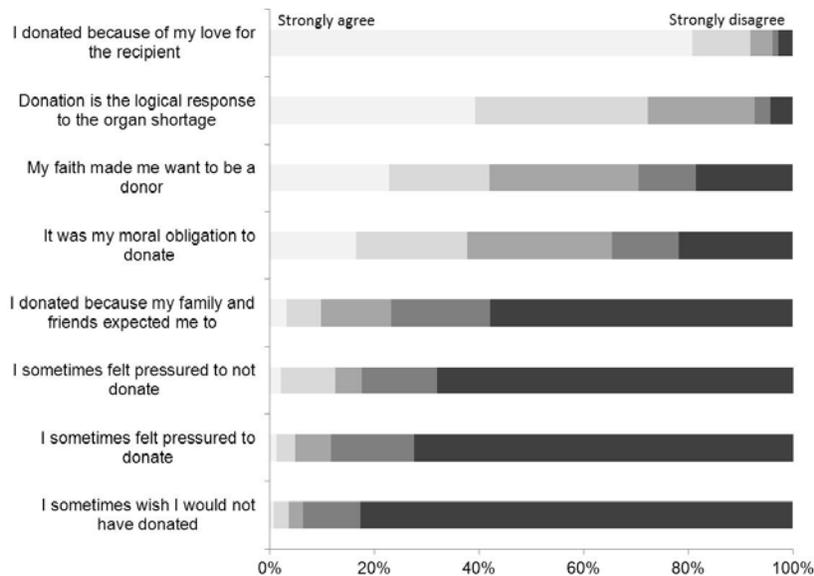
eFigure 1. Enrollment Flow Diagram. Non-participants (\*, n=3516) and participants (†, n=2455) were tested for comparability of characteristics (see text).



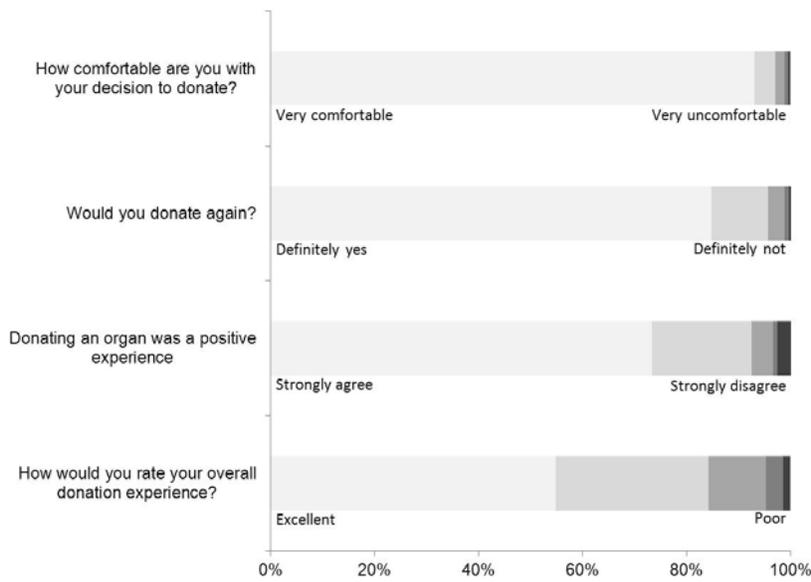
## Donor Participation

Using logistic regression, living kidney donors who were eligible to participate in the QOL study but who did not because they did not respond to study invitations, did not provide consent, withdrew consent, or did not return the QOL questionnaire (n=3,516) had lower educational attainment at donation ( $p < 0.0001$ ) and were younger at donation ( $p < 0.0001$ ) compared to donors who completed the QOL questionnaire (n=2,455). In addition, donors who did not participate in the QOL study were more likely than participants to be black or African American ( $p < 0.0001$ ), male ( $p = 0.0003$ ), and related to their recipient ( $p < 0.0001$ ). Figure previously published in Gross et al., Health-Related Quality of Life in Kidney Donors from the Last Five Decades: Results from the RELIVE Study. 2013; 13: 2924-2934.

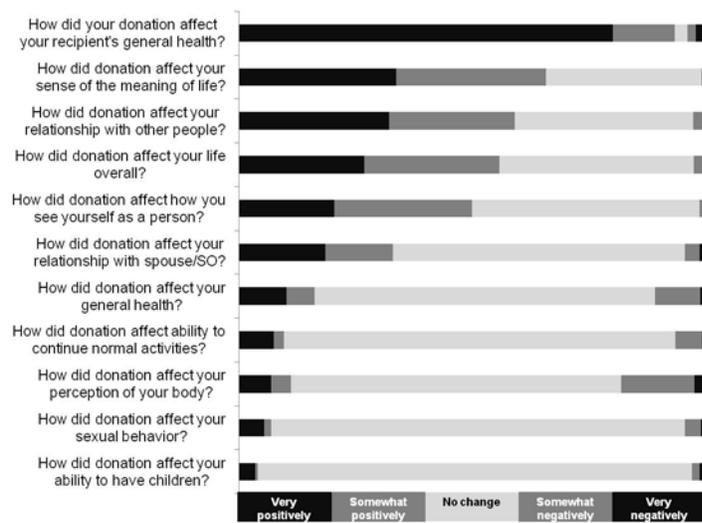
**eFigure 2. Attitudes and Feelings Toward Donation**



**eFigure 3. Donation Experience**



**eFigure 4. Recipient and Donor Outcomes**



Note that the color density scale becomes darker as answers become more extreme to emphasize the category “no change.”

## **eAppendix**

### **Donor Questions on the QoL Questionnaire**

#### DONATION EXPERIENCE

17. How would you rate your overall organ donation experience? (Mark one response.)

Excellent  Very Good  Good  Fair  Poor

18. Which of the following best represents the reason you volunteered to be a living donor?

I was asked by my recipient

I was asked by someone other than my recipient

I volunteered to donate on my own

19. Thinking about the length of time for recovering after surgery, which one of the following statements best describes your recovery time?

Much longer than I expected

Somewhat longer than I expected

About as long as I expected

Somewhat shorter than I expected

Much shorter than I expected

20. How much time did it take for you to recover from surgery?

Less than 3 months

3 to 6 months

More than 6 months

Never recovered

21. How long after donation surgery did it take you to return to your usual daily activities, such as walking, driving a car, or shopping for groceries?

Less than 3 months

3 to 6 months

More than 6 months

I never returned to my usual daily activities

22. Please answer these questions about your experience after your donor surgery.

Did you have any medical complications that resulted in additional hospitalization days or re-hospitalization after your donor surgery?  Yes  No

Did you have any medical complications that did not require hospitalization after your donor surgery?  Yes  No

Are you currently seeing a doctor or other health care provider for medical problems related to the donor surgery?  Yes  No

Did you have any emotional, psychological, or substance abuse difficulties (e.g., depression, anxiety, mood changes, etc.) that were the result of your donation?  Yes  No

Did you obtain professional help (e.g., counseling, medication, etc.) for emotional, psychological, or substance abuse concerns that were a result of your donation?  Yes  No

*If yes* Are you currently receiving treatment for this problem?  Yes  No

23. If you marked "Yes" to any of the questions above, please provide a description of your experience(s) in the space provided below.

24. Before your donation, had you ever been treated for emotional, psychological, or substance abuse difficulties?  Yes  No

If yes, please provide a description of your experience(s) in the space provided.

25. Have you had any of the following problems because of donation? (Mark one response per line.)

I was denied health insurance because of donation  Yes  No  Don't know

My health insurance premium increased because of donation  Yes  No  Don't know

I was denied life insurance because of donation  Yes  No  Don't know

My life insurance premium increased because of donation  Yes  No  Don't know

I had problems paying household/routine monthly bills because of donation  Yes  No  Don't know

I had problems paying medical bills because of donation  Yes  No  Don't know

I took unpaid medical leave from work because of donation  Yes  No  Don't know

26. Do you feel that donating your kidney caused a financial burden for you?

No burden  Little  Moderate  Great  Extreme burden

27. If you could do it over again, would you donate again?

Definitely yes  Probably yes  Not sure  Probably not  Definitely not

#### ATTITUDES ABOUT DONATION

28. The following questions involve your feelings about donating. How much do you agree or disagree with each of the following statements?

I sometimes wish I would not have donated  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

I sometimes felt pressured to NOT donate  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

Overall, donating an organ was a positive experience in my life  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

I donated because of my love for the recipient  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

I donated because my family and friends expected me to  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

My faith made me want to be a donor  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

It was my moral obligation to donate  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

Donation is the logical response to the organ shortage  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

I sometimes felt pressured to donate  Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

29. Below are some of the ways people feel after donating. How much do you agree or disagree with each of the following statements?

I felt depressed for a while after the surgery  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

Once the surgery was over, no one really paid much attention to me  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

There was a lot of support available to me after the surgery from the health care providers  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

My family or friends supported me throughout the donor surgery  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

30. On a scale of 1 to 10 where 1 is "Not at all informed" and 10 is "Extremely informed," how well informed do you feel now about organ donation?  1 Not at all informed  2  3  4  5  6  7  8  9  10 Extremely informed

31. How comfortable are you now with your decision to donate? Would you say you are:

- Very comfortable with the decision
- Somewhat comfortable with the decision
- Neutral
- Somewhat uncomfortable with the decision
- Very uncomfortable with the decision

32. How did your donation affect the following areas of your life?

Your general health  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your perception of what your body looks like  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your sexual behavior  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your ability to have children  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your ability to continue the normal activities you did before the donation  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

How you see yourself as a person  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your sense of the meaning of life and what is important to you  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your relationship with your spouse or significant other  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your relationship with other people involved in the donation  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

Your life overall  Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively

#### DONATION-RELATED RELATIONSHIPS

33. Is the recipient you donated to still alive?

- Yes  No  Don't know/not applicable

*If yes* How much do you agree or disagree with the following statements?

Since I donated, I feel closer to the recipient  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

Sometimes I think the recipient feels like he/she is in debt to me  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

I sometimes feel like the recipient does not show me enough gratitude  Strongly agree  Agree  Unsure  Disagree  Strongly disagree

34. How did your donation affect your recipient's general health?

- Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively  
 Don't know/not applicable

35. How did your donation affect your relationship with the recipient?

- Very negatively  Somewhat negatively  No change  Somewhat positively  Very positively  
 Don't know/not applicable

36. Is the organ you donated still functioning in the recipient?

- Yes  Yes, but with current problems with function  No  Don't know/not applicable

37. Did the person who received your donated organ have medical complications after their surgery?

- Yes  
 No  
 Don't know/not applicable

*If yes* How severe were their complications?

- Mild  Moderate  Severe  Very severe

#### ABOUT YOU

38. What is the highest grade or level of school you have completed?

- 8<sup>th</sup> grade or less  
 Some high school  
 High school graduate or GED  
 Vocational, Technical, or Business School  
 Some college or Associates Degree (including Community College)  
 Four year college graduate (Bachelor's Degree)  
 Graduate or Professional School  
 Other, specify:

39. Are you currently...

- Married  Living with someone in a marriage-like relationship  Separated  Divorced   
Widowed  Never been married

40. Were you working for pay at the time of donation?

- Yes  No – Skip to question 41

If yes, please rate how supportive your employer was of organ donation by marking the box that best describes the level of support.

- Not very supportive  
 Not supportive  
 Neutral or unsure  
 Supportive  
 Very supportive

If you were working at the time of donation, how much time elapsed after surgery before you were able to return to your pre-donation work status?

- Less than 1 week  1 to 2 weeks  3 to 4 weeks  5 to 6 weeks  More than 6 weeks   
Unable to return to work due to complications from donation  Did not return to work by choice

41. Which of the following best describes you now?

- Working full-time for pay (35 or more hours a week)  
 Working part-time for pay

Not working for pay at present → Are you... (Mark all that apply.)

- A full time homemaker
- A seasonal worker
- Looking for a job
- Retired
- In school
- None of the above

42. Are you Hispanic or Latino?

- Yes
- No
- Not sure/Don't know

43. Which of the following best describes you?

- White or Caucasian
- Black or African American
- American Indian or Alaskan Native
- Asian or Pacific Islander
- Something else? Describe:

44. Do you have any life insurance coverage?

- Yes  No

45. Are you CURRENTLY covered by any of the following types of health insurance or health coverage plans?

Insurance through a current or former employer or union (yours or another family member)   
Yes  No

Insurance purchased directly from an insurance company (yours or another family member)   
Yes  No

Medicare, for people age 65 and over, or people with certain disabilities  Yes  No

Medicaid, Medical Assistance, or any kind of government-assistance plan for those with low incomes or a disability  Yes  No

TRICARE or other military health care  Yes  No

VA (including those who have ever enrolled for or used VA health care)  Yes  No

Indian Health Services  Yes  No

Any other health insurance or health coverage plan, please specify:

46. Did someone help you complete this survey?

- Yes  No

*If yes* How did that person help you?

- Read the questions to you
- Wrote down the answers you gave
- Answered the questions for you
- Translated the questions into your language

47. Do you have further comments about organ donation?