

# Public Attitudes toward Disclosure of Information of Donors and Recipients

## Disclosures by donors and recipients in kidney transplantation

The University of Chicago and Beth Israel Hospital (Boston) are conducting a survey to explore how different stakeholders feel about sharing health and social information between potential living donors and kidney transplant candidates.

Currently, at most transplant centers, potential donors and recipients are evaluated by separate teams of health care providers. In order to protect patient confidentiality, the transplant teams do not disclose or share information about the recipient to the donor. Nor do they disclose information about the donor to the recipient EXCEPT if the donor fits a high-risk category for HIV/AIDS. If the donor is "high risk", the team informs the recipient but does not share specific details.

This study seeks to determine whether donors and recipients (and friends and family) support the current practice that transplant teams not share information -- or whether there is support for some information-sharing by transplant teams. The University of Chicago and Beth Israel Hospital (Boston) would like to know what you think should be shared by the transplant team when the donor and recipient know each other, and what should be shared by the transplant team when they do not.

Your participation is voluntary. It is expected that this survey will take 15 minutes to complete and you can skip any questions you wish. Your responses will be understood as your agreement to participate. All answers will be kept confidential.

If you have any questions, you may contact Dr. Lainie Ross at [Lross@uchicago.edu](mailto:Lross@uchicago.edu) or by phone at 773-702-6323 or the University of Chicago Institutional Review Board at 773-702-6205.

We thank you in advance.

**The research oversight committee requires that all participants be 18 years of age or older.**

**Are you 18 years or older?**

- Yes
- No

## What should Donors Know about Potential Recipients?

We will begin by asking you what information you believe living donors should be told about their recipients. Most living donors donate to a family member, but some donate to a friend, colleague, or stranger.

**Who should share information about the potential kidney transplant recipient with the potential living donor?**

- The potential recipient
- The transplant team
- Both the potential recipient and the transplant team
- No one

# Public Attitudes toward Disclosure of Information of Donors and Recipients

**Do you agree or disagree with the following statement: The transplant team should tell potential living donors, before the transplant takes place, information about the recipient's health that could affect the transplant outcome?**

- Strongly agree
- Moderately agree
- Moderately disagree
- Strongly disagree

**Please state whether you agree with the following statements: The transplant team should tell potential living donors...**

	Strongly agree	Moderately agree	Moderately disagree	Strongly disagree
How long the potential recipient would have to wait for a deceased donor transplant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general terms only, that the potential recipient has health problems that could affect how long the kidney is expected to function	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the potential recipient has diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the potential recipient has HIV/AIDS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the potential recipient has heart disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the potential recipient has problems with taking medications as prescribed or in keeping medical appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the potential recipient has a past history of drug abuse or dependence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the potential recipient has a past history of alcohol abuse or dependence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the potential recipient is a current smoker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the potential recipient has a past history of depression, anxiety, bipolar disorder, or other psychiatric disturbance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How long the potential recipient is expected to live with and without a kidney transplant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the potential recipient engages in high-risk sexual activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the potential recipient has a criminal record	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**How long does a kidney need to function in a transplant recipient to make a living donation worthwhile?**

Period of time

**Would it be okay for a potential living donor to contact a potential transplant recipient's friend, partner, or spouse to get more information about the transplant recipient?**

- Yes
- No

**Would it be okay for a potential living donor to go on the Internet (e.g. Facebook or Google) to get more information about the transplant recipient?**

- Yes
- No

# Public Attitudes toward Disclosure of Information of Donors and Recipients

## What should Potential Transplant Recipients Know about Prospective Living D...

### Who should share information about the potential living donor with the potential kidney transplant recipient?

- The prospective donor
- The transplant team
- Both the prospective donor and the transplant team
- No one

### Do you agree or disagree with the following statement: The transplant team should tell potential transplant recipients, before the living donor transplant takes place, information about the potential living donor's health that could affect the transplant outcome?

- Strongly agree
- Moderately agree
- Moderately disagree
- Strongly disagree

### Please state whether you agree with each of the following: The transplant team should tell potential transplant recipients...

	Strongly Agree	Moderately Agree	Moderately Disagree	Strongly Disagree
The donor's kidney function	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the donor is a current smoker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the donor has a history of alcohol abuse or dependence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the donor has a history of drug abuse or dependence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the donor has a past history of depression, anxiety, bipolar disorder or other psychiatric disturbance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the donor engages in high-risk sexual activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The donor's sexual orientation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The donor's marital status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The donor's employment status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The donor's religion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the donor has a criminal record	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### Would it be okay for a potential transplant recipient to contact a potential living donor's friend, partner, or spouse to get more information about the living donor?

- Yes
- No

## Public Attitudes toward Disclosure of Information of Donors and Recipients

**Would it be okay for a potential transplant recipient to go on the Internet (e.g. Facebook or Google) to get more information about the living donor?**

Yes

No

**Donors may be excluded for many reasons including medical problems, psychosocial reasons, or because they do not want to donate but do not know how to tell their intended recipient.**

**If a living donor is excluded from donating, does the potential transplant recipient have the right to know why?**

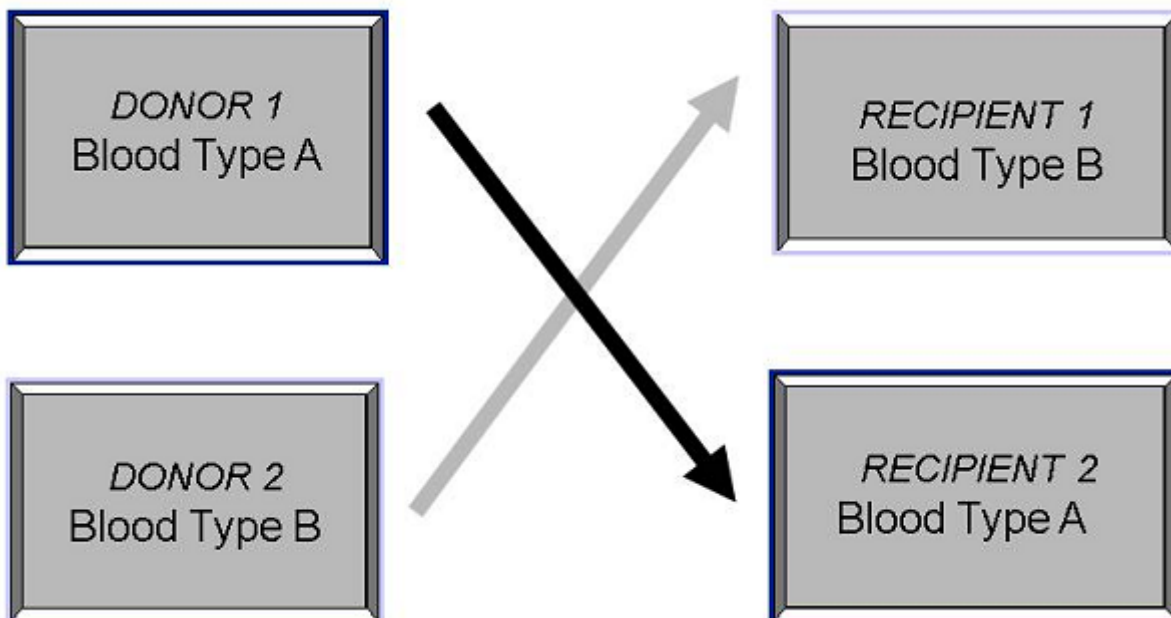
Yes

No

## Kidney Paired Exchange

**This is an example of a kidney exchange or swap. Donor 1 and Recipient 1 are siblings. Donor 2 and Recipient 2 are spouses. Donor 1 cannot donate to Recipient 1 (blood type incompatible), but can donate to Recipient 2. Donor 2 cannot donate to Recipient 2 (blood type incompatible), but can donate to Recipient 1.**

**Donor-Recipient pair 1 do not know Donor-Recipient pair 2.**



# Public Attitudes toward Disclosure of Information of Donors and Recipients

**Before agreeing to participate in an exchange, should the transplant teams tell Donor 1 and Donor 2 the following information about each other?**

	Strongly Agree	Moderately Agree	Moderately Disagree	Strongly Disagree
Exchange donor's age	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange donor's gender	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange donor's race/ethnicity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange donor's weight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange donor's kidney function	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange donor is a current smoker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange donor has a history of alcohol abuse or dependence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange donor has a history of drug abuse or dependence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange donor has a past history of depression, anxiety, bipolar disorder or other psychiatric disturbance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange donor engages in high-risk sexual activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange donor's sexual orientation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange donor's marital status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange donor's employment status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange donor's religion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange donor has a criminal record	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# Public Attitudes toward Disclosure of Information of Donors and Recipients

**Before agreeing to participate in an exchange, what should the transplant teams tell the donors about their exchange recipients? That is, should the transplant team tell Donor 1 the following information about Recipient 2? (And Donor 1 the following information about Recipient 2?)**

	Strongly Agree	Moderately Agree	Moderately Disagree	Strongly Disagree
The cause of the exchange recipient's kidney failure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether this is a primary transplant or re-transplant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange recipient's age	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange recipient's weight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange recipient's gender	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange recipient's race/ethnicity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange recipient has diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange recipient has HIV/AIDS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange recipient has heart problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange recipient has problems with taking medications as prescribed or in keeping medical appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange recipient has a past history of drug abuse or dependence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange recipient has a past history of alcohol abuse or dependence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange recipient is a current smoker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange recipient has a past history or depression, anxiety, bipolar disorder, or other psychiatric disturbance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange recipient has a short life expectancy even with the transplant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The exchange recipient's employment status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The exchange recipient's religion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange recipient engages in high-risk sexual activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange recipient's sexual orientation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exchange recipient's marital status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the exchange recipient has a criminal record	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Name and contact information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Demographics

Tell us a little about yourself. We promise to keep the information private.

### Your Age

In years

In years

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## Your Gender

- Male  Female

## Your Ethnicity

- Hispanic or Latino  Not Hispanic or Latino

## Your Race

- African American or Black  
 Asian or Southeast Asian  
 Caucasian or White  
 Native American /Pacific Islander/Eskimo  
 Multiracial  
 Other

## What is your highest level of education?

- Finished some high school  
 Graduated high school/GED  
 Some college studies (no degree)  
 2 year associate degree  
 4 year college degree  
 Some graduate studies (no graduate degree)  
 Graduate degree (masters level)  
 Graduate degree (doctoral level)

# Public Attitudes toward Disclosure of Information of Donors and Recipients

## Which category best describes you?

- Living donor (already donated)
- Potential living donor
- Living Kidney donor transplant recipient
- Potential living kidney donor transplant recipient
- Deceased donor kidney recipient
- Potential deceased donor kidney recipient (I'm on the wait list)
- Deceased and living donor transplant recipient
- Individual with kidney disease (but not yet in need of dialysis or transplant)
- Family member or friend of a potential kidney donor
- Family member or friend of a person who needs a transplant
- Health care provider
- Interested public

## Donor Demographics

### To whom did you donate or to whom do you plan to donate?

- Parent
- Sibling
- Half or step-sibling
- Spouse
- Child
- Grandparent
- Second degree relative (aunts, uncles, cousins)
- Relatives of your spouse/partner
- close friend
- Church or club members
- Colleague at work
- Stranger
- Other (paired exchange, chain)



# Public Attitudes toward Disclosure of Information of Donors and Recipients

**Have you shared any of the following information about yourself with your intended recipient? PLEASE NOTE: We are not asking you whether you smoke, but whether you have shared /plan to share your current smoking status with your intended recipient.**

	Shared/ plan to share	Did not share/ do not plan to share
Your age	<input type="radio"/>	<input type="radio"/>
Whether you are a current smoker	<input type="radio"/>	<input type="radio"/>
Whether you have a past history of drug abuse or dependence	<input type="radio"/>	<input type="radio"/>
Whether you have a past history of alcohol abuse or dependence	<input type="radio"/>	<input type="radio"/>
Whether you have a past history of depression, anxiety, bipolar disorder, or other psychiatric disturbance	<input type="radio"/>	<input type="radio"/>
Your religion	<input type="radio"/>	<input type="radio"/>
Whether you engage in high-risk sexual activity	<input type="radio"/>	<input type="radio"/>
Your sexual orientation	<input type="radio"/>	<input type="radio"/>
Whether you have a criminal record	<input type="radio"/>	<input type="radio"/>

**How well do you know your recipient or your intended recipient?**

- Very well
- Moderately well
- Not well
- Not at all

## Transplant Recipient/ Potential Recipient Demographics

# Public Attitudes toward Disclosure of Information of Donors and Recipients

## Who donated (or plans to donate) a living kidney graft to you?

- Parent
- Sibling
- Half or step-sibling
- Spouse
- Child
- Grandparent
- Grandchild
- Second degree relative (aunts, uncles, cousins)
- close friend
- Church or club acquaintance
- Business acquaintance
- Stranger
- Other (paired exchange, chain)

**Have you shared any of the following information about yourself with your intended living donor? PLEASE NOTE: We are not asking you whether you smoke, but whether you have shared /plan to share your current smoking status with your intended donor.**

	Shared/plan to share	Did not share/ do not plan to share
Your age	<input type="radio"/>	<input type="radio"/>
Whether you are a current smoker	<input type="radio"/>	<input type="radio"/>
Whether you have a past history of drug abuse or dependence	<input type="radio"/>	<input type="radio"/>
Whether you have a past history of alcohol abuse or dependence	<input type="radio"/>	<input type="radio"/>
Whether you have HIV/AIDS	<input type="radio"/>	<input type="radio"/>
Whether you have a past history of depression, anxiety, bipolar disorder, or other psychiatric disturbance	<input type="radio"/>	<input type="radio"/>
Whether you have a problem with taking medications as prescribed or in keeping medical appointments	<input type="radio"/>	<input type="radio"/>
Your religion	<input type="radio"/>	<input type="radio"/>
Whether you engage in high-risk sexual activity	<input type="radio"/>	<input type="radio"/>
Your sexual orientation	<input type="radio"/>	<input type="radio"/>
Whether you have a criminal record	<input type="radio"/>	<input type="radio"/>

# Public Attitudes toward Disclosure of Information of Donors and Recipients

**How well do you know your living donor or your intended living donor?**

- Very well
- Moderately well
- Not well
- Not at all

## THANK YOU

**Thank you for your participation. If you would like to give us any additional information, please comment in the box below.**