



James Lind Alliance Priority Setting Partnership in

Kidney Transplantation

SURVEY

Why we need your help

We are asking for your help because we want to improve care and outcomes for people waiting for, or who have had, a kidney transplant, or who have been living kidney donors. We know that many people have important unanswered questions about kidney transplantation and donation and we want to find out what they are. We want to use these questions to set priorities for research that will improve care for this group of patients.

Who you are

We would like the following groups of people to submit questions to our survey:

- Adults and children on the waiting list for a kidney transplant and their carers/parents
- Adults and children who have previously received a kidney transplant and their carers/parents, even if this transplant has failed
- People who have donated a kidney as a living donor
- Medical doctors, nurses and professionals allied to medicine with clinical experience of kidney transplantation

What we are asking you to do

Please think about your own experiences and let us know about any questions regarding the management of kidney transplant patients and living donors that you have not been able to find answers for.

To help us better understand these questions, we will also ask for a little information about you. This section of the survey is optional.

If you prefer, you can also complete this survey online at:

<http://www.transplantpsp.org/kidney/survey>

What will happen to your question(s)

All the question(s) we get from everyone who takes part in this survey will be gathered together. The questions that we haven't yet got the answers to will be published in the UK Database for Uncertainties of Effects of Treatment (UK DUETS).

We will bring together groups of patients, carers, family members and other healthcare professionals to look at these questions and identify the most important ones. You can be involved in this, if you like.

This will result in a 'top 10' list of research topics which we will use to influence future decisions about research. For example it could help decide which research projects should get funding.



Your Unanswered Questions

Previous 'Priority Setting Partnerships' have found that the most useful format for such a survey is for respondents to write short, simple questions that they would most like to be answered.

There have been similar surveys on other medical conditions or settings. Here are some example questions from similar surveys used in other medical conditions:

- Are breathing exercises helpful in controlling asthma?
- What is the evidence for gargling with aspirin to relieve a sore throat?
- How safe is it for my breast-fed baby if I take antidepressants?

What unanswered questions about kidney transplantation and living donation would you like to see answered by research?

Question 1:

Question 2:

Question 3:

About You

We want to make sure that we have a broad representation of people contributing ideas to this survey. In order to ensure that we meet this aim, we would be grateful if you would complete the following questions about yourself. *All responses are optional.*

1. What is your gender?

- Male Female

2. How old are you?

- Less than 18 years 18-24 years 25-34 years
 35-44 years 45-54 years 55-64 years
 65-74 years 75 or more years

3. Where do you live?

- East Midlands East of England London
 North East North West Northern Ireland
 Scotland South East South West
 Wales West Midlands Yorks and Humber
 Other (*please specify*)

4. What is your ethnic group?

- | | |
|---------------------|--|
| White | <input type="checkbox"/> English/Welsh/Scottish/Northern Irish/British |
| | <input type="checkbox"/> Irish |
| | <input type="checkbox"/> Gypsy or Irish Traveller |
| Mixed ethnicity | <input type="checkbox"/> White and Black Caribbean |
| | <input type="checkbox"/> White and Black African |
| | <input type="checkbox"/> White and Asian |
| Asian/Asian British | <input type="checkbox"/> Indian |
| | <input type="checkbox"/> Pakistani |
| | <input type="checkbox"/> Bangladeshi |
| | <input type="checkbox"/> Chinese |
| African/Caribbean | <input type="checkbox"/> African |
| | <input type="checkbox"/> Caribbean |
| Other ethnic group | <input type="checkbox"/> <i>Please specify</i> |
| Prefer not to say | <input type="checkbox"/> |

5. Which best describes you?

- I am on the kidney transplant waiting list (and have never received a transplant).
Please answer question 6.
- I am the recipient of a kidney transplant (even if it has failed).
Please answer question 7.
- I am the carer of someone on the transplant waiting list.
Please answer questions 6 and 8.
- I am the carer of a kidney transplant recipient.
Please answer questions 7 and 8.
- I am a live donor.
Please answer question 9.
- I am a healthcare professional.
Please answer question 10.
- Other (*please specify*).....

6. If you (or the person you care for) are on the transplant waiting list.

How long have you (or the person you care for) been on the kidney transplant waiting list?

- Less than 6 months 6 months to 1 year 1-2 years
- 2-3 years 3-4 years 4-5 years
- More than 5 years Unsure

7. If you (or the person you care for) have received a transplant.

7a. How long ago did you (or the person you care for) receive your transplant?

If you have had more than one transplant, please tell us about the last one

- Less than 6 months 6 months to 1 year 1-2 years
- 2-3 years 3-4 years 4-5 years
- 5-6 years 6-7 years 7-8 years
- 8-9 years 9-10 years More than 10 years

7b. How many previous transplants have you (or the person you care for) received?

- 1 previous transplant 2 previous transplants 3 previous transplants
- 4 or more previous transplants

7c. Is your (or the person you care for) last kidney transplant still functioning?

- Yes – I am not currently on dialysis
- No – I am on dialysis

8. If you are a carer (or family member).

What is your relationship to the patient?

- Parent Child Other relative
 Friend Other (*please specify*)

9. If you are a live donor.

9a. Who did you donate a kidney to?

- Your spouse/partner Another relative A friend
 A stranger (altruistic donor) Other (*please specify*)

9b. How long ago did you donate your kidney?

- Less than 6 months 6 months to 1 year 1-2 years
 2-3 years 3-4 years 4-5 years
 More than 5 years

10. If you are a healthcare professional.

10a. Which best describes your role?

- Nephrologist/physician Transplant surgeon Anaesthetist
 Radiologist Pharmacist Technician
 Clinical scientist Nurse/transplant co-ordinator
 Other (*please specify*)

10b. How long have you held this role?

- Less than 6 months 6 months to 1 year 1-2 years
 2-3 years 3-4 years 4-5 years
 More than 5 years

Thank you for your responses.

Please return your survey by the 15th December 2014 to:

Kidney Transplant PSP c/o Sandra Regan
NIHR Oxford Biomedical Research Centre
Joint Research Office - Block 60
Churchill Hospital
Headington
Oxford OX3 7LE

If you have any questions or comments about this survey, please contact us by e-mail at **kidney@transplantpsp.org** or by phone on **01865 223298**.