Australian Paired Kidney Exchange (AKX) Programme

User Manual

Version 2 – August 2015

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Frequently Asked Questions

Information for patients and willing living donors

What is the Australian Paired Kidney Exchange (AKX) Programme?
The Australian Paired Kidney Exchange (AKX) Programme is a nationwide live kidney exchange programme. The goal of AKX is to increase live kidney donor transplant by identifying matches for incompatible donor/recipient pairs.

AKX is part of the Organ and Tissue Authority’s efforts to increase available organs from live donors. Approximately 30% of potential donors fail to fulfil their wish to donate a kidney to a relative of friend due to incompatible blood group or tissue matches. Long-term results from living donor kidney transports are excellent. Five years after the transplant, 88% of transplants from live donors are still functioning, compared with 80% for transplants for cadaveric (deceased) donors.

A paired kidney exchange can happen when a live donor (Donor #1), who is willing to donate to a spouse, friend or relative (Recipient #1), is unable to donate because they have an incompatible blood type or tissue type. AKX will help fund compatible donors amongst other registered pairs (such as Donor #2 and Recipient #2 as shown below), who might be a suitable match, and thus enable two compatible living donor transplants to occur.

How does AKX work?
If you have a willing but incompatible living donor, participating in the Australian Paired Kidney Exchange (AKX) Programme will increase the chance that you will be able to receive a living donor kidney transplant.

Should you agree to participate in the programme, your information will be registered in a secure computer database containing all the register donor/recipients pairs across Australia.

The computer program searches the entire available database of registered recipient/donor pairs to look for combinations that might enable a suitable kidney exchange to occur. If the computer finds a potential match doctors will arrange for the final tissue typing test for you and your willing living donor.

If no match is found in the first match run (the computer matching), you and your donor will be kept on the register and will be included in further computer match runs. If no match is found after several match runs, your kidney specialist will discuss other options that are available to you.
How can I join AKX?
To register with AKX you should contact your kidney specialist. You and your willing donor will be asked to:

◊ have the programme explained to you by a medical professional
◊ sign an Agreement to Participate form stating that you understand this programme and agree to participate
◊ provide a detailed medical history
◊ undergo a number of medical tests.

Who can participate?
If you are a patient who is eligible for a kidney transplant, and are receiving care at a transplant centre/renal unit in Australia, you may be able to participate in the programme. You must have a living donor who is willing but unable to donate to you because of an incompatible blood type of tissue type. Your donor must be willing to take part in the Programme and donate a kidney to someone else.

What happens if a match is found?
If a match is found you will be informed by your kidney specialist. Further testing will be required to confirm that the recipient and potential donor are compatible. Once the testing is completed, each donor and recipient pair will meet with their own transplant team to discuss the results and whether to proceed. After discussion, if the donor recipient pairs agree to the exchange, they will sign the appropriate consent forms for surgery.

There is no guarantee that the transplant will occur even if you are identified for a possible donor/recipient exchange. There are many health and emotional issues to be considered in the paired kidney exchange programme and the process is complex. You will receive advice and support to help to understand these issues.

What happens if no match is found?
Patients who don’t find a matching donor through the exchange programme still have the chance of receiving a kidney transplant. If patients are eligible for the deceased donor waiting list, they will remain on the deceased donor transplant waiting list. The chance of finding a successful match for exchange should increase as more donor/recipient pairs join the programme. If no match is found in your first match run, you can remain on the register and re-enter subsequent match runs. However if no suitable pair matches are found after a period of time, you may wish to consider other options after discussion with your kidney specialist.

Where would the transplant take place?
If all parties agree to an exchange, and are medically compatible, the two transplant surgeries take place at two different transplant centres. Each donor/recipient pair remains at their own transplant centre. Both operations occur at the same (even if the other transplant is in another state). In this way, both donors are sure that each has proceeded with the surgery. Each recipient receives their kidney on the same day as their willing living donor partners donates.

Can I contact the other couple?
No. Strict privacy and confidentiality will be maintained for each donor/recipient pair. This is one of the reasons we endeavour to use different hospital sites for the two pairs of donors and recipients. The National Health and Medical Research Council (NHMRC) Organ and Tissue Donation by Living Donors – Guidelines for Ethical Practice for Health states that anonymity between donors and recipients should be maintained to avoid possible future repercussions for either party.

Can I change my mind after I have joined the programme?
Donors and recipients can change their minds at any time leading up to and including the day of surgery. The donor operations are coordinated to take place at exactly the same time so that neither party is disadvantaged if one member of a donor pair chooses to withdraw from the exchange donation at the last minute.
What is the chance of finding a match?
The chance of finding a suitable match depends on a number of factors. The more donor/recipient pairs registered on the programme database, the greater the chance of finding a match.

If a patient has more than one donor who is willing to enter the programme, they have a greater chance of finding a match. Only the donor with the best match will actually donate their kidney. Individuals with common blood types and low levels of sensitisation to other blood and tissue antigens will also have a greater chance of matching. Alternatively, your doctor may discuss other options.

What should I do next?
For more information, ask your kidney specialist. Counselling support will be available to donor/recipient pairs through the transplant centre both before and after the paired kidney exchange.

Where can I get further information?
Australian Paired Kidney Exchange (AKX) Programme
Attention: Programme Coordinator
Department of Nephrology
Fremantle Hospital

PO Box 480
FREMANTLE WA 6160

Phone 08 9431 3690
Fax 08 9431 3902

Organ and Tissue Authority
www.donatelife.gov.au
Recipient agreement to participate

I have reviewed the Australian Paired Kidney Exchange Programme Agreement to Participate (the Agreement) and conditions of participating with this patient and his/her potential donor.

<table>
<thead>
<tr>
<th>Transplant Physician/Surgeon</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transplant Coordinator (witness)</td>
<td>Date</td>
</tr>
</tbody>
</table>

(tick) I have read and understand the Agreement to Participate and conditions of participation and all my questions have been answered.

I have been fully informed about all of my other transplant options for living kidney donation from an incompatible donor.

I consent to my personal information (including my health information) being used and disclosed for the purposes explained in the Agreement.

I consent to AKX reporting personal information to ANZDATA and ANZDATA to report to the AKX Programme for the purposes explained in the Agreement.

I hereby agree not to participate in interviews with the media prior to the exchange taking place.

I hereby agree and consent to participate in the Australian Paired Kidney Exchange Programme and understand that I can withdraw my consent for participation at any time without penalty or disadvantage.

Name (print)

Address

Phone Number

Email

Signed | Date

Scan and upload onto MMEx or copy & post, fax or email to:

Australian Paired Kidney Exchange Programme
Attention: Programme Coordinator
Department of Nephrology
Prince of Wales Hospital, High Street Building
Randwick NSW 2031

Ph 02-9382 4476 Fax 02-9382 4409
E: claudia.woodroffe@sesiahs.health.nsw.gov.au
**Donor agreement to participate**

I have reviewed the Australian Paired Kidney Exchange Programme Agreement to Participate (the Agreement) and procedures with this donor and his/her potential recipient.

<table>
<thead>
<tr>
<th>Transplant Physician/Surgeon</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transplant Coordinator (witness)</td>
<td>Date</td>
</tr>
</tbody>
</table>

**Type of donor (tick applicable)**

- directed
- altruistic

**I have read and I understand the Agreement to Participate and conditions of participation and all my questions have been answered.**

**I, as a living kidney donor, have been fully informed about all other transplant options for my intended, incompatible recipient. (Not applicable if altruistic)**

**I consent to my personal information (including my health information) being used and disclosed for the purposes explained in the Agreement.**

**I consent to AKX reporting personal information to ANZDATA and ANZDATA to report to the AKX Programme for the purposes explained in the Agreement.**

**I hereby agree not to participate in interviews with the media prior to the exchange taking place.**

**I hereby agree and consent to participate in the Australian Paired Kidney Exchange Programme and understand that I can withdraw my consent for participation at any time without penalty or disadvantage.**

**I have read and I understand the Donor Declaration Form and I have answered all questions to the best of my knowledge.**

**I hereby agree to be tested for the presence of hepatitis B, hepatitis C, HIV immediately prior to organ donation if a match is found.**

---

**Name (print)**

**Address**

**Phone Number**

**Email**

**Signed**

**Date**

---

**Scan and upload onto MMEx or copy & post, fax or email to:**

Australian Paired Kidney Exchange Programme  
Attention: Programme Coordinator  
Department of Nephrology  
Prince of Wales Hospital, High Street Building  
Randwick NSW 2031

Ph 02-9382 4476  Fax 02-9382 4409  
E: claudia.woodroffe@sesiahs.health.nsw.gov.au
Hepatitis B core Antibody positive donors - Recipient Consent

Before entering the AKX Programme kidney donors undergo in-depth medical, surgical and psychological evaluations at their transplant centre. They also undergo a series of tests to minimise the risk of infectious diseases being transmitted from the donor to the recipient. There are some people who MUST NOT donate organs as they are likely to transmit infections to those who receive them.

Some people have in the past been exposed to the hepatitis B virus (jaundice) and have developed immunity to the infection. These people have detectable hepatitis B core (HBC) antibody. If their blood tests show no trace of detectable virus then they can be considered as an organ donor. However, these donors still carry a low risk of transmitting the virus to the person receiving their kidney.

Deceased kidney donors who test positive for the HBC antibody are frequently used as kidney donors for recipients who are willing to accept such kidneys and provide informed consent. Previous infection with or vaccination against hepatitis B in the recipient can reduce the risks of transmission of hepatitis from such a kidney transplant.

Some live kidney donors who test positive for HBC antibody want to be part of the AKX Programme, because they are incompatible to their intended recipient. If you agree, then it is possible that the donor who is matched to you will be HBC antibody positive. You may elect to accept or decline matching to such a donor. Your transplant team will explain to you what accepting a kidney from such a donor means for you.

If you agree to be assigned an organ from HBC antibody positive donor from within the AKX Programme, we kindly ask you to sign this consent form and agree that a copy is sent to the AKX Co ordinating Centre.

Please circle Yes or No

| Yes | I have been fully informed about hepatitis B core antibody (anti-HBC) positive donors and consent to accept a kidney from an anti-HBC donor. |
| No | I understand that I can withdraw my consent at any time. |

Please ONLY sign in the presence of the interviewer

Surname/family name ...............................................................
Given name.................................................................................
Date of birth ...... / ...... /............
Signature..................................................................................
Date ...... / ...... /............

Witness

Surname/family name ...............................................................
Given name.................................................................................
Signature..................................................................................
Date ...... / ...... /............
Donor Declaration Form

As part of the assessment of potential living kidney donors, the completion of the following questionnaire is necessary to identify potential factors which could lead to transmission of infection or other medical conditions. There are some people who MUST NOT donate organs as they may transmit infections to those who receive them.

To determine if your donation will be safe to the person receiving your organ, we would like you to answer some questions. These questions are vital in our efforts to eliminate diseases from the organ supply. If you do not wish to complete the questionnaire you may withdraw your consent and consideration for donation. All information remains strictly confidential in accordance with the Federal Privacy Act.

In addition to the questionnaire, all organ donors are tested for the presence of hepatitis B and C, and HIV. If your blood test proves positive for any of these conditions, or for any reason the test shows a significantly abnormal result, you will be informed. These blood tests are performed in the early stages during your medical assessment to determine your suitability for kidney donation and repeated again about 1 week prior to scheduled surgery.

Please respond by placing a cross or a tick in the relevant box. Do not circle.

To the best of your knowledge, have you:

1. Ever had a test which showed you had hepatitis B, hepatitis C, or HIV?
   - No
   - Yes
2. Ever thought you could be infected with HIV or have AIDS?
   - No
   - Yes
3. Ever used drugs by injection or been injected, even once, with drugs not prescribed by a doctor or dentist?
   - No
   - Yes
4. Ever had treatment with clotting factors such as Factor VIII or Factor IX?
   - No
   - Yes
5. In the last 12 months, had an illness with unexplained night sweats, swollen glands and a rash, with or without a fever?
   - No
   - Yes

Within the last 12 months have you:

6. Had a tattoo (including cosmetic tattooing), body and/or ear piercing, electrolysis or acupuncture?
   - No
   - Yes
7. Been injured with a used needle (needle stick injury)?
   - No
   - Yes
8. Had a blood/body fluid splash to eyes, mouth, nose or to broken skin?
   - No
   - Yes
9. Had a blood transfusion?
   - No
   - Yes
10. Been imprisoned in a prison or lock-up?
    - No
    - Yes
11. Had (yellow) jaundice or hepatitis or been in contact with someone who has?
    - No
    - Yes
12. Engaged in ANY of the following sexual behaviors (with or without a condom):
    - had male to male sex?
    - No
    - Yes
    - had sexual activity with a male or female sex worker?
    - No
    - Yes
    - been a male or female sex worker?
    - No
    - Yes
    - had sexual activity with someone you might think would answer “yes” to any of the above questions 1-11?
    - No
    - Yes

Please ONLY sign in the presence of the interviewer

Surname/family name ...........................................................

Given name.............................................................................

Date of birth ...... / ...... / ............

Signature..................................................................................

Date ...... / ...... /............

Witness

Surname/family name ..............................................................

Given name................................................................................

Signature....................................................................................

Date ...... / ...... /............

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Ministerial approval form

<table>
<thead>
<tr>
<th>Donor name</th>
<th>Recipient name</th>
</tr>
</thead>
</table>

**(ACT, NSW, SA, NT, WA and TAS)**

Please complete section 1 of this form, attach the signed Agreement/s to Participate (not required for SA/NT) and fax, or scan and email to fax 02 9382 4409; claudia.woodroffe@sesiahs.nsw.health.gov.au. If you have any queries regarding this form, please phone the AKX Programme Coordinator on 02 9382 4476 or email as above.

**SECTION 1: Donor/Recipient Details and Declaration.** Completed by the appropriate Senior Medical Specialist and forwarded to the National Coordination Centre. The form will be returned once the Minister for Health has signed it.

<table>
<thead>
<tr>
<th>Donor Details</th>
<th>Recipient Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surname</td>
<td>Surname</td>
</tr>
<tr>
<td>First name</td>
<td>First name</td>
</tr>
<tr>
<td>Middle name</td>
<td>Middle name</td>
</tr>
<tr>
<td>Date of birth</td>
<td>Date of birth</td>
</tr>
<tr>
<td>Location of surgery</td>
<td>Location of surgery</td>
</tr>
<tr>
<td>Physician</td>
<td>Physician</td>
</tr>
<tr>
<td>Donor relationship to recipient</td>
<td></td>
</tr>
</tbody>
</table>

**Declaration**

I confirm that the donor and/or the recipient *(circle)*

* (tick) Have read and understood the Agreement to Participate and conditions of participation and all questions have been answered.

* (tick) Have been fully informed about all other transplant options for living kidney donation from an incompatible donor.

* (tick) Understand that the AKX is not an enforceable contract but a reciprocal arrangement with no monetary reward or benefit other than the exchange of kidneys.

* (tick) Are aware that they can withdraw at any time up until the surgery.

* (tick) Are aware that there are no legal remedies for the exchange not proceeding.

* (tick) Anonymity of donors and recipients will be maintained.

**Name** *(print)*

**Position**

**Signed**

**Date**
Donor name | Date of birth  
Recipient name | Date of birth

SECTION 2: Completed by the AKX Programme Coordinator and forwarded to the Minister for Health or delegate.

Exemption requested under

(tick) Section 44 #4 of the Transplantation & Anatomy Act 1978, Australian Capital Territory

Section 32 #4 of the Human Tissue Act 1983, New South Wales

Section 22F of the Transplantation and Anatomy Act, Northern Territory

Section 35 #6 of the Transplantation and Anatomy Act 1983, South Australia

Section 27 #4 of the Human Tissue Act 1985, Tasmania

Section 29 #4(a) of the Human Tissue and Transplant Act 1982, Western Australia

A copy of the signed Agreement to Participate (Donor) is attached (not required for SA/NT)

A copy of the signed Agreement to Participate (Recipient) is attached (not required for SA/NT)

Date approval requested

Requested by

SECTION 3: Approval to be signed by the Minister for Health or delegate and returned to the National Coordination Centre.

Note that approval is required within five days of receiving this request.

Approved | Y

Name (print)

Position

Signed | Date
# Tissue Typing Registration Form

<table>
<thead>
<tr>
<th>Referral Centre</th>
<th>State</th>
<th>Transplant Centre</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nephrologist</td>
<td>Phone</td>
<td>Email</td>
</tr>
<tr>
<td>Transplant nurse</td>
<td>Phone</td>
<td>Email</td>
</tr>
</tbody>
</table>

## SECTION 1: Recipient Details

- **Recipient surname**
- **Recipient first name**
- **Date of Birth**
- **NOMS recipient National ID (if known)**
- **Pre-emptive**
- **Blood Group**
- **Accept ABOi**
- **Accept anti-Hbc positive donor**

## SECTION 2: Donor Details

- **Donor surname**
- **Donor first name**
- **Date of Birth**
- **NOMS donor National ID (if known)**
- **Altruistic donor (omit sections 1 & 3)**
- **Hepatitis B core antibody positive donor**

## SECTION 3: Donor - Recipient Information

- **Relationship of incompatible donor to registered recipient**
- **Is the donor blood group incompatible with the registered recipient?**
- **Is the donor HLA antibody incompatible with the registered recipient? (ie. positive cross-match?)**
- **Is the donor compatible with the registered recipient?**

## SECTION 4: This form completed by

- **Full name (please print)**
- **Signature**
- **Date form submitted**
- **Hard copies of validated Blood Group and Virology results attached (donor and recipient)**
- **Reason for AKX entry**
- **Please indicate for which quarterly AKX match run this pair (or altruistic donor) will be ready**

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