

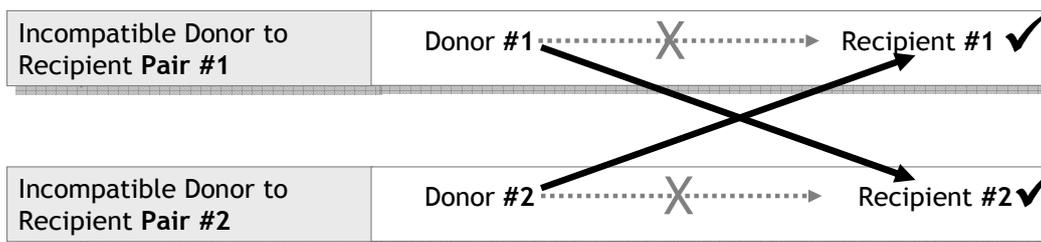


AGREEMENT TO PARTICIPATE FOR DONORS AND RECIPIENTS

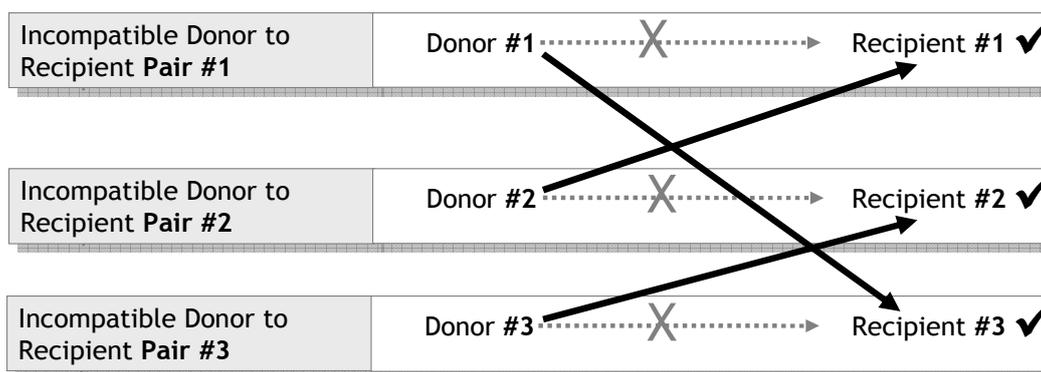
What is the Australian Paired Kidney Exchange Program (AKX)?

The Australian paired Kidney eXchange Program (AKX) is a nationwide live kidney donor exchange program. The goal of the Australian Paired Kidney Exchange Program is to increase live kidney donor transplants by helping incompatible donor-recipient pairs. Participants in the Australian Paired Kidney Exchange Program include individuals who wish to donate a kidney to a known potential recipient at an Australian transplant centre, such as a partner, family member or close friend, but cannot do so because of an incompatible blood type or tissue match, or other incompatibility. The Australian Paired Kidney Exchange Program seeks to identify donor-recipient pairs in the same situation and to organise an exchange of the donors' kidneys to achieve two compatible transplantations.

In a conventional paired donation (2-way exchange), two donor/recipient pairs surmount each other's incompatibility problem by simply exchanging donors. The pictorial example shows how each willing donor could fulfil their wish to donate a kidney that would be exchanged and transplanted into an unknown recipient. Both the recipients would undergo transplant procedures at their own hospitals.



Paired donations can also be arranged involving three (3-way exchange) or more pairs, as shown in this diagram.



The Australian Paired Kidney Exchange Program has been established to help find another registered pair who might be a match with you and your donor. By exchanging donors, two compatible matches would be created.

A recipient may only enter the program if they have one (or more) willing but incompatible donor/s. A recipient alone may not enter the Program.

Non-directed (altruistic) kidney donors, who wish to give a kidney to any suitably matched recipient on the waiting list, may have their kidney allocated to an individual in this living transplant program.

This program is one option if you are incompatible with your proposed donor, but there is no requirement to enter the program and you may choose not to. Potential donors and recipients receive separate information sessions, so that each person can make up their own mind. The opportunity to decline or withdraw is available to the donor and the recipient up until the time the surgical procedures commence. No reason or explanation is required.

If I agree to participate, what is the procedure?

The Australian Paired Kidney Exchange Program works by entering medical and other details of willing but incompatible donor/recipient pairs into a computer database. At 3-month intervals, the database searches for possible donor-recipient pairs (a 'match run'). Your doctor will notify you at that time if another potentially compatible pair has been identified with whom a kidney exchange may be possible. A tissue match (crossmatch test) is then performed. If the crossmatch test confirms that the proposed transplants are compatible, then each donor and recipient and their respective transplant teams (for example, the surgeon and nephrologist) need to agree to proceed.

Before entering the Australian Paired Kidney Exchange Program, donors undergo a full medical evaluation, including psychological assessment by the transplant centre. If all parties consent and the clinical evaluations are acceptable, the donor surgical procedures occur at exactly the same time, even when performed at hospitals in different states.

Participants may remain in the Program as long as they remain medically eligible and willing to participate. During this time, the recipient remains on the deceased donor waiting list.

Are there any special considerations specific to this Program?

If you consent to participate, it is important that you are aware of the following points:

1. Blood group O donors will be preferentially matched with blood group O recipients. This is to give those recipients the fairest chance of receiving a transplant since blood group O recipients frequently have to wait longer on the transplant waiting list. Highly sensitised non-O recipients, whose chances of finding an acceptable match are low will also receive preferential matching with O donors.
2. Recipients remain active on the transplant waiting list until a match run occurs. Recipients on the transplant waiting list are suspended from the list while the match run is performed e.g. up to 2 days. Match runs occur every 3 months. Recipients from matched pairs remain off the list until the transplant can occur. If tests show that the exchange is not possible, the recipients go straight back onto the waiting list.
3. It is possible that a donor/recipient pair will be matched to a suitable pair in another state. In this case the kidney will be transported to the recipient. This is because transporting kidneys does not affect the success of the transplant. Donors will not be required to travel and will have their kidney removed at the unit where they have been assessed.
4. The donor operations occur at the same hospital where donors have been evaluated with their originally intended recipient. The donor kidneys are then transported to the respective recipients' transplant centres.

5. Tests on the donor using agreed medical criteria will ensure the quality of donor kidneys involved in paired kidney exchange.
6. Older donors (up to 70 years of age) may be accepted in the paired kidney exchange program if they meet the minimum acceptable level of kidney function to be eligible for this program.
7. If a transplanted kidney fails, the recipient will be assessed and treated as appropriate. This may involve going back on the transplant wait list, receiving dialysis if required, and considering whether they have other potential donors, as would occur if any other kidney transplant failed.
8. Non-directed (altruistic) kidney donors are matched against the highly sensitised recipients in the deceased donor transplant waiting list and if no match is found, these donors are allocated into the Program, given the optimising effect on the number of transplants this brings.
 - a. When paired donations are initiated by an altruistic donor they can result in a chain of transplant where the last recipient is a person on the deceased donor transplant waiting list.
 - b. Surgical procedures with altruistic donor chains do not necessarily have to be performed simultaneously.

What information will be entered into the Australian Paired Kidney Exchange Program Database and how will the data be used?

If you agree to participate, you must consent to have information relevant to an organ exchange entered into the computer database. This information includes, but is not limited to: name, date of birth, relationship between donor and incompatible recipient, blood type, current medications and other health information. In addition, more detailed clinical information for identifying potential donor-recipient pairs will be provided by the transplant centre where you or your originally intended recipient is listed.

Data entered into the Australian Paired Kidney Exchange Program Database will be used to identify potential donor-recipient pairings to maximise the number of transplants that can be achieved. The kidney transplant team including program staff, physicians and surgeons will review possible donor-recipient pairings. The data will be stored indefinitely unless, or until, a participant asks to withdraw or is no longer medically eligible.

Will data be used for purposes other than the Exchange Program?

This data may also be used to provide information to the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). Most recipients on dialysis will already have given consent to be part of this registry. Living kidney donors also need to consent to be included in the registry. Information collected, in addition to that mentioned above, will consist of medical tests performed prior to transplantation, the exact type of surgery performed, and progress of the donor after transplantation. The ANZDATA database remains confidential and is only used to provide annual statistics on dialysis and transplantation within Australia and New Zealand. Identities of the registrants are not disclosed. Inclusion on this registry is entirely voluntary. This information will help improve the quality of the Exchange Program.

How will confidentiality be maintained?

Information collected will be entered into a database by a Program coordinator. Staff, physicians, surgeons and the Program Director will review your information. Otherwise, your information will remain confidential to the extent required by law. Access to the database will be through a secure, password protected system and all paper copies of this information will be stored in a secure location. Your information will not be shared with anyone outside the Program or the participating transplant centres without your permission.

What are the legal requirements for an organ exchange in Australia?

For paired kidney exchange to be legal, most States currently require their Minister for Health to approve the exchange in writing. Your name and some details will therefore need to be given to the Minister when the arrangements for the surgery are being finalised. The Minister for Health, or his or her designated officer, will have to be reasonably satisfied that no monetary payment or reward will be made, given or received for this exchange of kidneys, and that you are freely entering into this arrangement with full understanding of the risks and benefits involved.

What are the benefits of participating?

There is no guarantee that you will receive any benefit from participating in the Program. However, the more donor/recipient pairs that enter the Program, the more likely it is that you will be part of a pair identified for a possible exchange. If successful, recipients receive a live kidney donation, and donors receive the emotional benefit of donating a kidney to an individual in need. Some feel that this is helping not just one but two or even more recipients to successful transplantation.

The risks and benefits of the donation operation and the transplant operation will be discussed with you in detail by the appropriate transplant centre if, and when you consent to move forward with a donor-recipient exchange. The risks and benefits are no different to living kidney donation from a directed donor.

Agreeing to participate in this Program does not in any way commit you to donate a kidney or to consent to any operation. You may withdraw from the Program at any point without the need to give a reason.

What happens if one of the kidneys cannot be transplanted?

There is an extremely remote possibility that one of the transplants may not be able to proceed as planned, even if donors have agreed to simultaneous operations. This has never occurred in 3,500 living directed kidney transplants to date in Australia. However, it is possible that:

- A recipient may suddenly become too sick to proceed at the time of transplant and the transplant procedure needs to be abandoned, although the donor has already had a kidney removed in readiness (so-called 'orphaned kidney'). As a donor, you will be asked to consider whether, in this rare circumstance, you would be prepared for that kidney to be allocated to someone suitable on the transplant waiting list; or
- A donor may unexpectedly become unstable during the donor operation and too sick to proceed to having a kidney removed. This means that the intended recipient cannot receive a kidney (a so-called 'orphaned recipient'). In that circumstance, the 'orphaned recipient' will receive priority for a suitable kidney from a deceased donor in due course.

What are the alternatives?

Refusal to participate in the Program will result in no penalty or loss of benefits to which you are otherwise entitled. Choosing not to join the AKX program will not affect your chance of receiving a kidney through the national deceased donor transplant wait list.

Can Donors and Recipients Meet?

Sharing information and meeting your donor or recipient can cause problems even if there are good medical results. Therefore the AKX program protects the anonymity of donor and recipient pairs. Strict privacy and confidentiality is therefore maintained for each donor/recipient pair.

It is not possible for staff involved in the Program to facilitate meeting of donors and recipients after the transplants. Donors and recipients should avoid seeking publicity through the media or other means, as this could jeopardise anonymity.

What costs are involved?

There is no cost to you for participating in the Program, although you may need to consider sick leave if you are employed as you will need to take time off work. This should be discussed with your transplant centre.

No payments can be charged, or paid to you for donating a kidney or participating in the Program, and there is no compensation available if a planned exchange does not go ahead.

Reimbursement of reasonable medical expenses can be obtained in most States. This should be discussed with your transplant centre.

Who do I contact if I have questions?

If you have questions at this stage, please call your Living Donor Coordinator at your local transplant centre.

You can also contact the Program Co-coordinator of the Australian Paired Kidney Exchange Program in Perth on Ph 08-9431 3690



Australian Government

Australian Organ and Tissue Donation
and Transplantation Authority

Australian paired Kidney eXchange (AKX)

Recipient Consent Form

RECIPIENT PARTICIPATION CONSENT FORM

I have reviewed the Australian Paired Kidney Exchange Program “Agreement to Participate” form and procedures with this patient and his/her potential donor.

Transplant Coordinator: _____ Date: _____

Transplant Physician/Surgeon: _____ Date: _____

- I have read this form 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 hereby consent to participate in the Australian Paired Kidney Exchange Program and understand that I can withdraw my consent for participation at any time without penalty or disadvantage.

Name (print): _____

Address: _____

Phone No.: _____

Email: _____

Signed: _____ Date: _____

Australian Paired Kidney Exchange Program
Attention: Program Co-coordinator

Copy & send to: Department of Nephrology
Fremantle Hospital, FREMANTLE WA 6160
Ph 08-9431 3690
Fax 08-9431 2101



Australian Government

Australian Organ and Tissue Donation
and Transplantation Authority

Australian paired Kidney eXchange (AKX)

Donor Consent Form

DONOR PARTICIPATION CONSENT FORM

I have reviewed the Australian Paired Kidney Exchange Program “Agreement to Participate” form and procedures with this donor and his/her potential recipient.

Transplant Coordinator: _____

Date: _____

Transplant Physician/Surgeon: _____

Date: _____

Type of donor: directed altruistic

- I have read this form and all my questions have been answered.
- I have been fully informed about all of my other transplant options as a living kidney donor to an incompatible recipient
- I hereby consent to participate in the Australian Paired Kidney Exchange Program and understand that I can withdraw my consent for participation at any time without penalty or disadvantage.

Name (print): _____

Address: _____

Phone No.: _____

Email: _____

Signed: _____

Date: _____

Australian Paired Kidney Exchange Program

Attention: Program Co-coordinator

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