Form 2: Information for Donors and Recipients

Version 4
August 2019
Information for Donors and Recipients

What is the Australia and New Zealand Paired Kidney Exchange Program (ANZKX)?

The Australia and New Zealand Paired Kidney Exchange Program (ANZKX) is a collaborative live kidney donor exchange program between Australia and New Zealand.

Who can join ANZKX?

The goal of ANZKX is to increase live kidney donor transplants in Australia and New Zealand by helping to match incompatible donor-recipient pairs.

Participants in the ANZKX Program include:

- individuals in need of a kidney transplant and their potential living donor, who cannot proceed to direct transplant because of an incompatible blood type or tissue match, or other incompatibility;
- donor-recipient pairs aiming to achieve better tissue matching.

Donors up to 72 years of age may be accepted in ANZKX if they meet the minimum acceptable level of kidney function to be eligible for this 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 ANZKX recipient.

Pre-emptive recipients (those who have not yet commenced dialysis) may also be eligible to participate in ANZKX if they are suitable for transplantation. A recipient alone may not enter ANZKX. A recipient may only enter the program if they have one (or more) willing donor(s).
**How does ANZKX Work?**

ANZKX seeks to identify donor-recipient pairs in Australia and/or New Zealand in the same situation (incompatibility or poor tissue matching) 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 overcome each other’s incompatibility problem by simply exchanging donors. The pictorial example below shows how each willing donor fulfils his or her wish to donate a kidney which is then exchanged and transplanted into an unknown, compatible recipient. Donors and recipients usually undergo transplant procedures at their own hospitals although occasionally the option of moving to another centre or state might be discussed.

Paired donations can also be arranged involving three or more otherwise incompatible donor-recipient pairs, as shown in the diagram below.

Paired donations can also be initiated by a non-directed (altruistic) donor. This can result in a longer 'chain' of transplants than would have been possible with a normal donor-recipient pair match run. Non-directed (altruistic) donor chains result in an ANZKX donor who is the last link in the chain. The kidney from this final donor is donated to a suitable recipient on the deceased donor waiting list.

**What are the benefits and risks of participating?**

Many patients who enter ANZKX will be matched and will be able to give/receive a transplant, however the chance of a match varies according to tissue type compatibility and other factors.

There is no guarantee that you will receive a match or any benefit from participating in ANZKX.
The risks and benefits of the donation and transplantation operations will be discussed with you in detail by the appropriate transplant centre, to help you decide whether to proceed. The risks and benefits are no different to living kidney donation from a directed donor.

Participation in ANZKX is voluntary. A participant can withdraw at any time without giving a reason. Agreeing to participate in this program does not commit you in any way to any operation, unless you choose to proceed.

No money can be paid to you for donating a kidney or participating in ANZKX.

**What if I refuse to participate or later withdraw my agreement?**

Refusal to participate in the ANZKX Program will result in no penalty or loss of benefits to which you would be otherwise entitled. Choosing not to join or leaving the ANZKX Program will not affect your chance of receiving a kidney through the deceased donor waiting list.

**If I agree to participate, what is the procedure?**

**Evaluation and assessment**

Before entering the ANZKX Program, donors undergo a full medical evaluation, including psychological assessment by their transplant centre. The medical suitability of each donor will be tested using agreed medical criteria. The safety of the donor and the suitability of the kidneys potentially involved in a paired kidney exchange will be determined by the transplant unit performing the assessment. Part of this process includes the completion of the Donor Declaration Form and tests to exclude transmissible disease prior to surgery.

**Match runs**

The ANZKX Program works by entering medical and other details of incompatible donor/recipient pairs into a computer database. At approximately four-month intervals, the database searches for possible compatible donor-recipient pairs (a 'match run'). Matching can also be performed between these times when certain donors, such as non-directed altruistic donors, are entered. The computer program used for match runs has a way of prioritising matches that takes into account the number of transplants facilitated, the blood groups of recipients and how difficult individuals are to match. It also considers the location of recipients to determine whether a match is logistically feasible. Geographic separation (which includes, but is not solely determined by, donor and recipient location in different countries) can prevent a match. You can discuss this further with your local transplant centre if you would like more information regarding this process.

**If a recipient is matched**

Your doctor will notify you if a pair has been identified with whom a kidney exchange may be possible. A tissue match (crossmatch test) is then performed and a copy of the donor CT images is sent to the recipient surgeon for review. If the results of these are acceptable and all parties consent to proceed then surgical dates are negotiated between the participating transplant centres. All donor operations will occur on the same day as agreed by the participating transplant units. When exchanges are solely occurring within Australia the donor surgical start times are usually simultaneous.

In some cases, donors and recipients are in different locations and so are assessed at different transplant centres. In these instances donor and recipient surgery will still be carried out at the transplant centre where the donors and recipients have been evaluated. The donor kidneys will be transported to the matched recipient transplant centres.

It is possible that a donor-recipient pair will be matched to a suitable pair in another State or country. In this case the kidneys will be transported to the recipients. Donors will usually not be required to travel and will have their kidney removed at the unit where they have been assessed. In some cases however donors might be asked whether they would be willing to move to a transplant centre in another state to allow an exchange to occur that would otherwise not be possible due to logistics. This might be the case if a donor outside New South Wales or Victoria is matched with a New Zealand recipient.
If a recipient gains no match in a match run

Participants may remain in ANZKX for as long as they remain medically eligible and willing to participate. While on the ANZKX waiting list, recipients may also join and/or remain on the deceased donor waiting list.

How do international donations work?

ANZKX operates as an international program encompassing Australia and New Zealand. The larger pool of potential donors gives incompatible donor-recipient pairs in both countries an improved chance of finding a match. Australian pairs may be matched with recipients in New Zealand and vice-versa. Direct exchanges will only occur between Auckland and either Melbourne or Sydney transplant units however a chain which includes such an exchange might also involve other centres.

International exchanges operate just like ANZKX exchanges within a single country, including with regard to kidney transport and logistics. There is no preference in favour of or against either international or domestic exchanges under ANZKX. The program instead prioritises compatibility, safety and logistical considerations.

How does the ANZKX affect the deceased donor waiting list?

While on the ANZKX waiting list, recipients may also join and/or remain on the deceased donor waiting list.

Recipients who are on the deceased donor waiting list remain active on that list until an ANZKX match run occurs (i.e. approximately every four months). If no match is found, recipients remain on the deceased donor waiting list. Recipients who are matched will be taken off the deceased donor waiting list until the transplant occurs. This may be a period of six to twelve weeks. If further tests show that the exchange is not possible, the recipients will immediately go back onto the deceased donor waiting list and will be included in the next ANZKX match run.

Choosing not to join or leaving the ANZKX Program will not affect your chance of receiving a kidney through the deceased donor waiting list.

What if surgery under ANZKX is postponed or cancelled?

Surgery may be postponed or cancelled at any time in the lead-up to surgery. This may be due to unforeseen circumstances such as acute illness or, very rarely, a participant’s withdrawal from the program. In these situations the options would be discussed with the transplant teams and individual pairs involved.

If it were agreed to postpone the surgery, the matched pairs of donors and recipients would remain suspended from subsequent ANZKX match runs and (in the case of the recipients) the deceased donor waiting list until the transplant occurs.

In the event that surgery is cancelled, recipients go back onto the deceased donor waiting list and suitable donor-recipient pairs would be included in the next match runs.

What if a transplanted kidney fails?

If a transplanted kidney fails, the recipient will be assessed and treated as is appropriate and in the same way as would occur if any other kidney transplant failed. This may involve going back on the deceased donor waiting list and receiving dialysis if required.

What happens if one of the kidneys cannot be transplanted?

There is a remote possibility that a transplant may not be able to proceed as planned. Potential scenarios include in the following:

Orphaned kidney – a kidney removed from an ANZKX donor that cannot be transplanted into the matched recipient.
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 this rare circumstance the 'orphaned' kidney would be allocated to a suitable recipient on the deceased donor waiting list.

**Orphaned recipient – an ANZKX recipient that has not received a kidney from a matched donor.**

A donor may unexpectedly become unstable during the donor operation and too sick to proceed to having a kidney removed. There is also a possibility that a kidney removed from the exchange donor may not be able to be transplanted into the intended recipient for other reasons. For example, in exceptional circumstances, a kidney donated by a live donor elsewhere may be damaged before it reaches the recipient's transplant centre. This means that the intended recipient cannot receive a kidney.

In that circumstance, the 'orphaned recipient' will receive priority allocation on the deceased donor waiting list for a suitable kidney.

If the damage is obvious to the transplanting team, the kidney might not be transplanted. In this situation the same priority for allocation of the next available and suitable kidney from the deceased donor waiting list would apply.

If there is no obvious damage and kidney is transplanted, but it never worked, priority will not be given to this recipient on the deceased donor waiting list.

**What costs are involved?**

There is no cost to you for participating in ANZKX. No payments can be charged to you for donating a kidney or participating in ANZKX.

You may need to consider your personal sick leave arrangements if you are employed as you will need to take time off work. This should be discussed with your transplant centre.


Donors who agree to travel may be eligible for financial compensation through the Australian Government’s Supporting Living Donors Program, Australian State-based patient assistance transport schemes or the New Zealand Ministry of Health’s Compensation for Live Donors Program.

There is no compensation available and no claim can be made if a planned exchange does not proceed.

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

For paired kidney exchange to be legal in New South Wales, South Australia, Western Australia, the Northern Territory, Tasmania and the Australian Capital Territory, the Minister for Health is required to approve participation in ANZKX. Your name and some details will therefore be provided to the relevant jurisdictional Minister prior to registration in ANZKX.

Ministerial approval is not required for ANZKX participation in New Zealand, Queensland or Victoria.

**Can donors and recipients meet?**

ANZKX protects the anonymity of donor and recipient pairs by maintaining strict privacy and confidentiality for each donor/recipient pair.
Specific provisions within each of the Australian State and Territory Human Tissue Acts prohibit the disclosure of information by which the identity of an organ or tissue donor and/or transplant recipient may become publicly known. This includes names, but also other information that could lead to the identification of a person. The Human Tissue Acts operate alongside the relevant privacy legislation or privacy policies of the jurisdictions.

ANZKX staff are not permitted to facilitate meetings of donors and recipients, whether before or after transplants.


Can I speak to the media about my transplant?

To ensure confidentiality and anonymity is maintained, donors, recipients and their families should not participate in media interviews prior to the exchange taking place. Engaging with the media prior to an exchange may result in private and confidential information being divulged to the public which could jeopardise the exchange proceeding.

In the event you are contacted by the media to share your story, and you are interested in participating, you should contact the ANZKX Program Coordinator to discuss the request.

What information about you will be entered into the ANZKX 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 ANZKX computer database. This information includes, but is not limited to: name, date of birth, relationship between donor and incompatible recipient, blood type and other health information.

Identified images of the donor kidney (including CT scan) will be provided to transplanting surgeons. The sharing of this identifiable data is necessary to ensure donor and recipient safety. In accordance with relevant legislation, transplant surgeons will maintain confidentiality of your data, and will not disclose your identity to any other members of the transplant team or recipient.

The kidney transplant team including program staff, physicians and surgeons will review possible donor-recipient pairings. This de-identified information includes donor age and clinically relevant information which might be discussed with the potential recipient to help you make an informed decision about any potential transplant. The data will be stored indefinitely.

Will data be used for purposes other than ANZKX?

Data may also be used to provide information to the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). Most recipients on dialysis will have previously provided consent to be part of this registry. Living kidney donors will be asked to consent to be included in the registry. The ANZDATA database remains confidential and is voluntary. Further information about the ANZDATA registry can be found at www.anzdata.org.au.

How will confidentiality be maintained?

Information collected will be entered into a database and can be viewed by the ANZKX Program team, as well as participating transplant centre coordinators, physicians and surgeons. Otherwise, your information will remain confidential to the extent required by law. Access to the database is through a secure, password protected system and all paper copies of this information are stored securely. Your information will not be
shared with other ANZKX donor-recipient pairs, anyone outside the program or participating transplant centres without your permission.

**Who do I contact if I have questions?**

Your transplant team will discuss all the conditions of participation in ANZKX with you. It is very important that you clearly understand these conditions prior to consenting to participate in ANZKX.

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

**For further information contact:**

**ANZKX Program Director**

Department of Nephrology  
Level 1 South East  
The Royal Melbourne Hospital  
Grattan St, Parkville VIC 3050  
Phone: +61 3 9342 4261  
Fax: +613 9342 7352  

**ANZKX Program Coordinator**

Department of Nephrology  
Level 1 South East  
The Royal Melbourne Hospital  
Grattan St, Parkville VIC 3050  
Phone: +613 9342 4261  
Fax: +613 9342 7352  
Email: emma.vanhardeveld@mh.org.au

**For New Zealand enquires contact:**

**Jo Burton**

Renal Transplant Offices  
Level 15 Support Building  
Auckland City Hospital  
Grafton, Auckland  
Phone: +64 800 717777  
Fax: +64 9 3072842  
Email: job@adhb.govt.nz