

Australian and New Zealand Paired Kidney Exchange Program

Form 2: Information for Donors and Recipients



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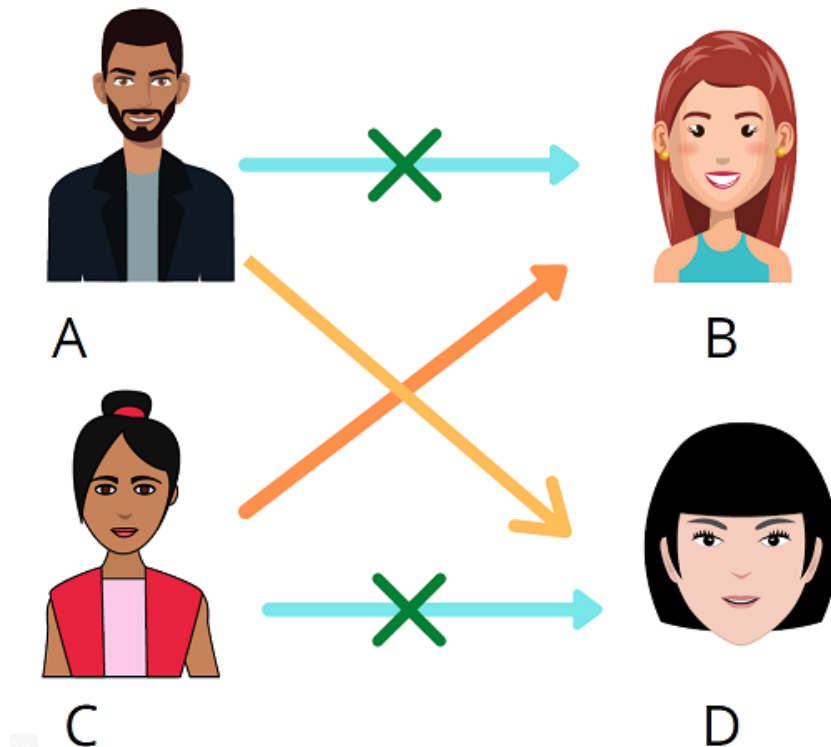
What is the Australian and New Zealand Paired Kidney Exchange Program (ANZKX)?

The Australian and New Zealand Paired Kidney Exchange Program (ANZKX) is a collaborative live kidney donor exchange program between the two countries. The primary goal of the ANZKX Program is to facilitate live kidney donor transplants by helping to match incompatible donor-recipient pairs. Participants in the ANZKX Program are individuals in need of a kidney transplant and their potential living donor, who cannot proceed to direct transplant because of incompatibility. It is also possible for donor-recipient pairs to enter the program to try to achieve better tissue matching, for a better transplant outcome.

A recipient may only enter the program if they have one (or more) willing 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, may have their kidney allocated to an individual in this living transplant program.

About 2-way chains

In a conventional paired donation (2-way exchange), two donor/recipient pairs overcome each other's incompatibility problem by simply exchanging donors. This chain is called a closed loop exchange. In the example shown below, A and B are husband and wife. B has kidney disease and is in need of a kidney transplant. Donor A is unable to give a kidney to recipient B as they have different blood groups. The transplant team that looks after A and B suggest paired kidney donation.



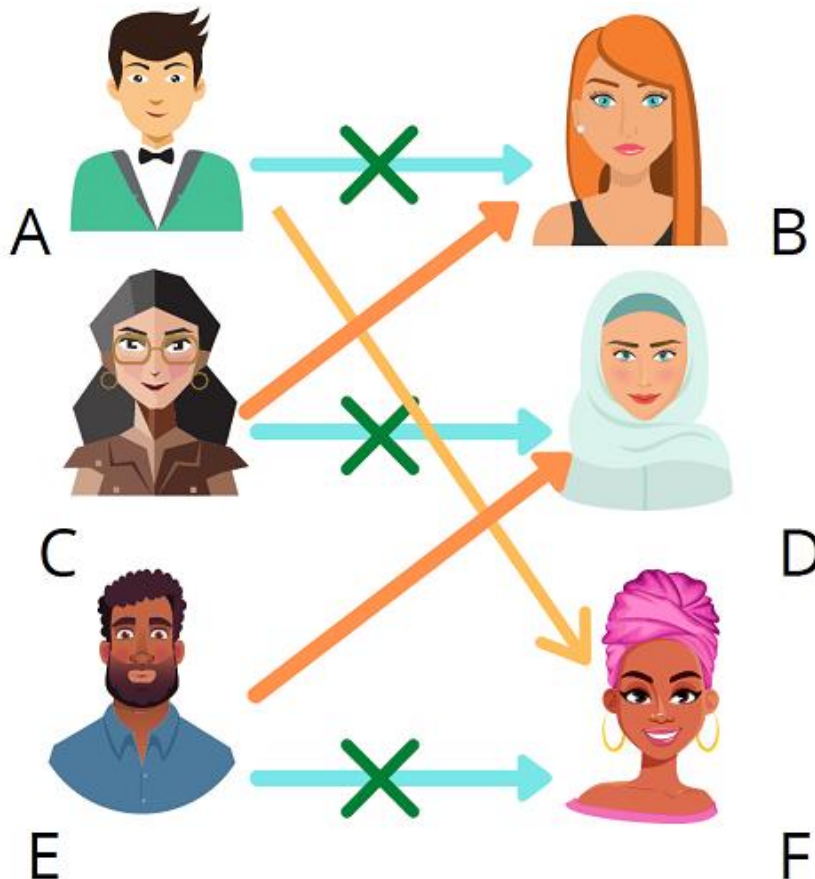
By entering the patient's details into the ANZKX program, they can find matches for pairs just like A and B. A match for A and B is found by matching with another pair, where donor C is unable to give to recipient D due to a tissue mismatch. By entering into the ANZKX program, it is found that C is compatible with B at a blood group level, and A with D at a tissue matching level. A 2-way paired kidney exchange is created by matching donor C with recipient B, and donor A with recipient D.

The ANZKX program offers the matches to the transplant team looking after B and D. If all agree it is a good match, the next step to organise the ANZKX chain to occur.

Both the donors and recipients would undergo transplant procedures at their own hospitals.

About 3-way chains

Paired donations can also be arranged involving three (3-way-exchange) or more pairs, as shown in this diagram. In this example, Donor A gives to recipient F, Donor C to recipient B, Donor E to recipient D. Chains can also be larger and involve more than 3 pairs.



What are the benefits and risks of participating?

Many patients who enter the program will be matched and will be able to be transplanted, however the chance of a match varies according to tissue type incompatibility and other factors. There is no guarantee that you will receive a match or any benefit from participating in the ANZKX Program.

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 move forward with a donor/recipient exchange. The risks and benefits are no different to living kidney donation from a donor you know.

The ANZKX Program is voluntary and any participant can withdraw at any time, until the time of surgery, without the need to give a reason. Agreeing to participate in this program does not in any way commit you to donating a kidney, or to consent to any operation.

If I agree to participate, what is the procedure?

Before entering the ANZKX Program, donors undergo a full medical evaluation, including psychological assessment by their transplant centre, and must fulfil specified criteria.

The ANZKX Program works by entering medical and other details of incompatible donor/recipient pairs into a computer database. The database identifies matches by searching for possible compatible donor-recipient pairs. This is performed continuously throughout the year.

A member of your transplant team will notify you if a match 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 are sent to the recipient surgeon for review.

If the results of the crossmatch and surgical CT review are acceptable and all parties consent, 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 unless the chain is started by a non-directed altruistic donor. When exchanges are solely occurring within Australia the donor surgical start times are usually simultaneous.

Participants may remain in the ANZKX Program as long as they remain medically eligible and willing to participate. During this time, the recipients who are on the deceased donor waiting list remain on this list. Pre-emptive recipients (those who have not yet commenced dialysis) are also eligible to participate in the ANZKX Program.

Are there any special considerations specific to the ANZKX Program?

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

- 1 The medical suitability of a donor will be tested using agreed medical criteria. This is to ensure, the quality of the donor kidney for transplantation. Part of this process includes the completion of the Donor Declaration Form and tests to exclude transmissible disease prior to surgery.
- 2 Donors up to 72 years of age may be accepted in the ANZKX Program if they meet the minimum acceptable level of kidney function to be eligible for this program.
- 3 The computer program OrganMatch is used to identify matches. You can discuss this further with your local transplant centre if you would like more information regarding this process.
- 4 Recipients who are on the deceased donor transplant waiting list remain active on the list unless a match is identified, at which time they are placed on hold until the transplant is performed. If further tests show that the exchange is not possible, the recipients will immediately go back onto the deceased donor waiting list.
- 5 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 usually not be required to travel and will have their kidney removed at the unit where they have been assessed. In some cases, 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.
- 6 In some cases, donors and recipients are in different states and are assessed at different transplant centres. In these instances, donor and recipient surgery will still be carried out at the transplant centre where the donor and recipient have been evaluated.
- 7 Australian pairs may be matched with recipients in New Zealand and vice-versa, if transport and logistics allow this.



- 8 Donor travel to certain countries prior to donation can lead to concerns regarding transmission of infections. Any travel should be discussed with your transplant unit and, depending on the countries visited, some additional screening tests might be required on return.
- 9 Your transplant unit will follow the ANZKX Protocol Screening for COVID-19 to assess a donor's risk of infection.
- 10 It is possible that surgery may be postponed or cancelled at any time in the lead-up to the scheduled day of 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.

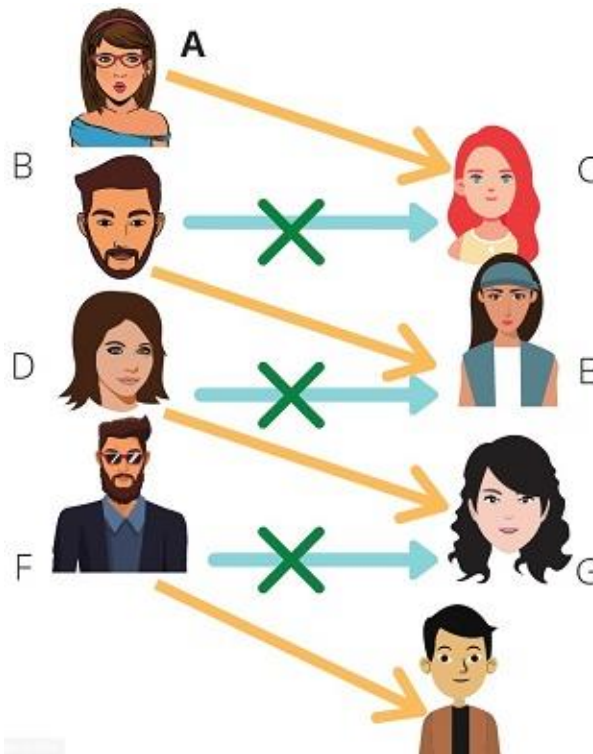
For example:

- If it was agreed to postpone the surgery, the matched recipient would remain on hold from 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 again be eligible for matching in ANZKX.
- 11 If a transplanted kidney fails, the recipient will be assessed and treated as appropriate. This may involve going back on the deceased donor waiting list, receiving dialysis if required, and considering whether they have other potential donors – as would occur if any other kidney transplant failed.

Are non-directed altruistic donors accepted in the ANZKX Program?

Altruistic (non-directed) kidney donors are accepted in the ANZKX Program as long as they satisfy the donor suitability criteria. When paired donations are initiated by an altruistic donor, they can result in a longer chain of transplants than would have been possible with a normal donor-recipient pair match run. 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.

A non-directed altruistic donor is a person who wishes to donate a kidney to someone they do not know (in this example it is donor A).



They may choose to donate through the ANZKX program. When this occurs it allows for longer chains often resulting in multiple transplants. The altruistic donor comes into the chain without a recipient who needs to be matched.

At the end of these chains, the last donor is matched with a recipient on the deceased donor transplant waiting list.

If I am matched in a chain started with a non-directed altruistic donor?

It is possible for a donor and recipient who entered ANZKX together and who are matched in a chain started by an altruistic donor to have their surgeries scheduled on different days. If the donor donates their kidney one day or more after their recipient receives a kidney this is referred to as a bridge donor. This can sometimes be to allow for different surgical dates at different transplant centres or for other reasons. This is not always the case, and this would be discussed with you by your transplant centre.

If the surgery is not on the same day, then the recipient will always receive a kidney before the donor who entered ANZKX with them donates.

Dates for surgery are negotiated by transplant units and take into consideration staffing, theatre logistics as well as the donor and recipient's personal circumstances.

The ANZKX program aims to minimise the time a donor should wait for surgery to within 1 week where possible although this will sometimes be longer.

What if I withdraw my agreement to participate?

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

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, even if donors have agreed to simultaneous operations. There are potential scenarios that may result in the following:

Orphaned kidney – this refers to 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 ('orphaned kidney'). In this rare circumstance the kidney would be allocated to a suitable recipient on the deceased donor waiting list.

Orphaned recipient – this refers to 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. This means that the intended recipient cannot receive a kidney ('orphaned recipient'). In that circumstance, the 'orphaned recipient' will receive priority allocation on the deceased donor waiting list for a suitable kidney.
- In exceptional circumstances, a kidney donated by a live donor elsewhere may suffer irreversible damage before it reaches the recipient's transplant centre.
- 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 as outlined above.



- If there is no obvious damage and the 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 the ANZKX Program. 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.

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

The Australian Government provides the Supporting Living Organ Donors Program to ensure that cost is not a barrier for living organ donors. Further information can be found at: <https://www.health.gov.au/our-work/supporting-living-organ-donors-program>

The New Zealand government also provides various types of support for donors resident in New Zealand. Further information can be found at: <https://www.health.govt.nz/your-health/conditions-and-treatments/treatments-and-surgery/organ-donations-and-transplants/live-organ-donation>

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 the ANZKX Program. Your name and some details will therefore be provided to the relevant jurisdictional Minister prior to registration in the ANZKX Program. Ministerial approval is not required in other Australian states or in New Zealand.

Can Donors and Recipients Meet?

The ANZKX Program 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 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 information that could lead to the identification of a person, not necessarily just the names of donors and recipients.

While the provisions are different in each state or territory Human Tissue Act, they all have the same intent: to maintain confidentiality and protect the identity of those who donated organs and tissues, and the identity of those who receive transplants. 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 following transplants.

The Australian Organ and Tissue Authority (OTA) has more information regarding contact between donor families and recipients available in the resources section of the DonateLife website: www.donatelife.gov.au

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 about another person being divulged to the public, which could jeopardise the exchange proceeding.

If you participate in media interviews post-transplant we ask that you do not give the date of the exchange but rather give a timeframe, for example, during the winter of 2021 or in the second half of 2021, to ensure anonymity is maintained.

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 best way to proceed with the request. The ANZKX Program Coordinator will also liaise with the Organ and Tissue Authority Communications team who are able to provide support with the media story.

Can I post details of my transplant on social media before or after surgery?

While we are keen to promote the positive outcomes the ANZKX program facilitates, we must be careful to balance the promotion of the program with the need to maintain anonymity for our donor and recipient pairs.

To maintain confidentiality and anonymity of all donor recipient pairs in a chain, pairs should refrain from posting specific details (e.g. date, location) about their surgery.

If a significant breach of confidentiality was to occur, ANZKX staff would need to consider whether the chain whose details had been posted should proceed.

If donor and recipient pairs wish to post on social media about their transplant after surgery, we ask that pairs should respect the anonymity of others involved in the chain, and hence not to include dates and specific identifying details about their surgery. Please contact the ANZKX Program Coordinator if you would like some further clarification of what is deemed 'identifying' information.

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 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 local state and territory 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. However, under no circumstances is this data provided to participating donor-recipient pairs. Your transplant team will give you as much information as is possible for you to make an informed decision about any potential transplant. The data will be stored indefinitely.

Will data be used for purposes other than the 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 in a secure location. 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 the ANZKX Program with you. It is very important that you clearly understand these conditions prior to consenting to participate in the ANZKX Program.

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

For further information contact:

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VERSION CONTROL			
Version	Date	Author	Comments
V 1.0	Jul 2019	ANZKX Team	AKX transitioned to ANZKX.
V 2.0	Feb 2021	ANZKX Team	Match run structure changed to continuous matching.
V 3.0	Nov 2021	ANZKX Team	Addition of social media.
V 4.0	May 2023	ANZKX Team	Updated paired exchange graphics, removed references to 'Good Samaritan' donor, and added information regarding bridge donors.

