

Living Kidney Donor Registry (LKDR) Information Sheet

The Australia and New Zealand Live Kidney Donor Registry (ANZLKDR) was established in 2003 to provide information about the long-term health and wellbeing of people who donated a kidney for transplantation.

People have been donating kidneys for transplantation for many years, and the risks associated with this are very low. Your transplant team will already have discussed this with you in some detail. However, there has not previously been a formal mechanism to monitor this practice at a national level in Australia or New Zealand. All kidney transplant units throughout Australia and New Zealand have been invited to participate in this project. The aim is to collect data that examine the practice of living kidney donor surgery and outcomes from the donor perspective.

The ANZLKDR Registry is run by the ANZDATA Registry. The ANZDATA Registry is a collaborative body funded by the Australian and New Zealand governments and Kidney Health Australia. The ANZDATA Registry has conducted a similar project collecting information about people receiving treatment for kidney failure with dialysis and transplantation for 30 years. In addition, the same organisation manages the ANZOD Registry, which collects information and deceased organ donors.

What information is collected about you?

Information collected by the ANZLKDR includes the medical tests performed prior to transplantation, the exact type of surgery performed and your progress after the operation. Each year after the operation, the hospital which referred you for transplantation will be asked to provide information about your blood pressure, any new medical conditions which may have developed and results of a blood and urine test to check kidney function. This does not mean you have to visit that hospital; these tests could be performed by your general practitioner, and the results sent by post, fax or email to the transplant unit.

The Registry does not collect details about your address, telephone number, medical insurance or non-medical matters such as occupation, income etc.

Is personal data ever released?

The identity of people in the database **is not released publicly nor in any reports**. Measures have been put into place to ensure the security of all collated information. Reports and other output of the Registry will contain only general information, for example, the average age of people donating a kidney in a particular State.

What is this information used for?



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The information is used primarily for quality assurance, and planning appropriate health services. ANZDATA releases reports on a variety of topics, including an Annual Report examining the rates and treatment of kidney failure in Australia and New Zealand. Information from the ANZDATA-LKDR will comprise part of these reports. We also send to each kidney unit each year a report outlining their activity. These reports also compare the outcome of the treatment they provide with that of other units throughout the two countries. Reports are also produced at a state and national level, and from time to time analyses are also produced for renal units, government health departments and industry as particular questions arise.

Can you see what personal information ANZDATA-LKDR collects and the reports that it produces?

Individuals are able to view their own information on request. You can request alterations, if you believe it is inaccurate. You may also opt not to have your treatment included in this database, and you should let your transplant team know if this is the case. You can also choose not to have some information (e.g. racial origin) recorded. However, if your information is not included in the Registry, the ability to compare results in Australia and New Zealand or to analyse the results of different treatment methods (for example different types of surgery) will be reduced.

The national reports and much other material produced by ANZLKDR and ANZDATA are available free on the Internet at www.anzdata.org.au, or they can be sent to you on request to the address above. Your transplanting team will also have copies of many of the reports.

If you wish to discuss any of the issues raised here, please let your doctor know or telephone the ANZLKDR Registry direct on 08 8128 4758. You may also write to us at ANZDATA Registry c/- SA Health and Medical Research Institute (SAHMRI), PO Box 11060, North Terrace, Adelaide, South Australia 5001 or send us an email at anzdata@anzdata.org.au



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Living Kidney Donor Registry Consent Form

I consent to inclusion of information about myself in the Australia and New Zealand Living Kidney Donor Registry.

I understand this includes information about

- my name and age (but not my address or telephone number)
- medical tests and procedures.

I understand I might be contacted each year by the transplanting hospital to check on my state of health and kidney function.

I understand I can withdraw from this Registry at any time without affecting the care either of myself or the recipient of my kidney.

I have been provided with an Information Sheet explaining the purposes of this Registry.

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Patient's signature

.....
Witness's signature

.....
Print Name

.....
Print Name