



## **The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)**

Information for patients and families/whānau

### ***What is the ANZDATA Registry for?***

The ANZDATA Registry (known as ANZDATA for short) collects medical information about all people who have dialysis or transplant treatment in New Zealand and Australia.

ANZDATA is a very important way for hospitals to find out about the quality of dialysis and transplant care they provide. ANZDATA can guide ways to improve kidney care.

ANZDATA was started by kidney specialists about 40 years ago and is funded by the Australia and New Zealand governments and Kidney Health Australia.

### ***Who is ANZDATA for?***

ANZDATA is used by the government, doctors and nurses and researchers to help improve healthcare services. For example, ANZDATA can learn about whether specific patients in New Zealand could receive better access to a kidney transplant.

### ***Why is it helpful to share your health information with ANZDATA?***

If most or all people with dialysis or transplant treatment in New Zealand share their health information with ANZDATA, then this can make a difference to the health of all patients in kidney care. ANZDATA is much more useful when most people share their information.

### ***What information is shared about patients with ANZDATA?***

Patients are included in ANZDATA when they start dialysis or have a kidney transplant. Some of your personal information is shared with ANZDATA including your hospital, name, postcode, age, whether you are male or female, and all the ethnicities you identify with. The medical information you have shared with ANZDATA includes any complications (such as cancer or infections), some of your blood test results, and the dates that you start or stop dialysis or transplant care. Information about your job, income, medical insurance, telephone number, or address are NOT shared with ANZDATA.

### ***What happens to the information shared with ANZDATA?***

The information shared with ANZDATA is entered into paper forms by your local healthcare team or typed into a secure computer database. This information is sent to the South Australia Health and Medical Research Institute (SAHMRI) in Adelaide, Australia where it is stored. The information is kept privately in a secure computer network.

The ANZDATA information is then used to write reports for governments and hospitals about the quality of dialysis and transplant care. These reports are free to access on the ANZDATA website ([www.anzdata.org.au](http://www.anzdata.org.au)).

### ***Is personal information ever released?***

Information about each person who has shared information with ANZDATA is NOT released to the public or anyone else without approval from an ethics committee. The information that is released to healthcare services or researchers does not include your personal information. If researchers wish to use ANZDATA, they do not receive information that tells them who you are.

### ***Can personal information shared with ANZDATA be seen by patients?***

You can request to look at the information about you in ANZDATA. You can ask for your information to be corrected. Any information that you would like not to be shared can be removed. You can let your kidney specialist know if you would like to look at your information or if you would like to correct/change/remove information about you.

### ***Are children included in ANZDATA?***

Yes. Children will be told about ANZDATA in a way that they can understand. Their parents and caregivers will be given information about ANZDATA and be asked for permission.

### ***Is there someone who patient and families can talk to privately about ANZDATA?***

Yes. If you have any queries about ANZDATA, you can talk to your kidney specialist or nurse, or your family doctor. If you have concerns about ANZDATA, you can also talk to your kidney specialist or family doctor (GP), or you can contact the Office of the Privacy Commissioner ([www.privacy.org.nz](http://www.privacy.org.nz) or 0800 803909 Monday to Friday 10.00 AM-3.00 PM).