



ANZDATA Information Sheet

Introduction – Why are you being given this Information Sheet?

You are receiving dialysis or a kidney transplant. This means your health information can be collected by ANZDATA. This information sheet explains what ANZDATA does, and why information about you is being collected by ANZDATA.

What is ANZDATA and what does it do?

“ANZDATA” stands for The Australia and New Zealand Dialysis and Transplant Registry. ANZDATA collects information (data) about the health of all people (adults and children) in Australia and New Zealand who have kidney failure and have either dialysis or a kidney transplant.

ANZDATA is paid for by the Australian and New Zealand Governments, Kidney Health Australia and the Australia and New Zealand Society of Nephrology, and has one office that is located in Adelaide.

How does ANZDATA collect and store my information?

Every year, your hospital completes a survey about your health and kidney failure treatment and sends this information to ANZDATA either by computer or by post. ANZDATA keeps this information about you and your kidney treatment in a highly protected computer network in South Australia. There is a lot of security in place to protect your information.

What information does ANZDATA collect about me?

Your hospital gives ANZDATA your name, postcode, date of birth, gender, ethnic background (your race), and information about your health conditions (what diseases you have), details about the type of kidney treatment you are receiving (dialysis or transplant) and some of your test results and medications. This information is collected when you start dialysis or have a transplant, and then every year. Sometimes, extra information will be collected during the year as well if something important happens to you.

We DO NOT collect other personal details about your address, telephone number, Medicare number, medical insurance, or non-medical matters such as occupation or income.

How does ANZDATA use my information?

The information collected by ANZDATA is used for many different things. Here are the main ways we use your information.

1. Making reports with the latest information about patients with kidney failure
2. Sending reports back to each hospital and telling them how their patients are doing NOW compared to the past, and also compared to other hospitals
3. Understanding the quality, type and place of care people receive
4. Understanding the type of kidney disease people get, and how they are treated
5. Understanding how many people have kidney failure and what health care they need, so that the best health care services can be set up to look after them
6. Helping people do research so they can understand more about kidney failure and the best ways to treat it and keep patients healthier.



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What will happen if I agree to share my information with ANZDATA?

You do not have to do anything more. Your hospital team will fill out the forms and send them to ANZDATA. You can ask to see your own information at any time or get copies of the reports that ANZDATA make.

Do I have to share my health information with ANZDATA?

You can choose not to give your information to ANZDATA. If you decide not to join in, it will not affect the treatment you receive now or in the future, or your relationship with the staff caring for you. If you wish to pull out from ANZDATA, you can do so at any time without having to give a reason.

Does sharing health information with ANZDATA help me?

Sharing your information with ANZDATA will not directly affect your care. However, collecting information about the health and treatment of kidney patients helps hospitals make sure dialysis and transplantation is as safe as possible, and helps hospitals to learn new things that may help you or others with kidney failure in the future.

What are the risks for me if I agree to share my information with ANZDATA?

The main risk is a loss of privacy if your personal and private health information which is given to ANZDATA is viewed by an unauthorised person. Usually this information would only be seen by your doctors, nurses or health carers directly involved in your care. However, the information given to ANZDATA is kept as safe as possible (see next section). Your identity and personal details are not accessible to the public or anyone outside of ANZDATA. Any information released from ANZDATA is anonymous.

Is my information in ANZDATA kept private and safe? Who can see it?

ANZDATA follows Australian Government rules about keeping your information private and confidential. There are many security measures to make sure all the information is kept very safely. The computer systems are protected. Information is transferred in a safe and secure way.

Your identity (name and other personal information) is not released except to your own hospital unless there is specific ethical approval. ANZDATA has strict rules around who can ask for information and how they can get it. If ANZDATA information is used in research or in a report, it is always given anonymously (without your name).

Who do I contact for more information or if I have concerns?

If you have any questions or concerns about giving your information to ANZDATA at any stage, you can talk to your kidney doctor.

Contact ANZDATA by phone ((08) 8128 4758) or by email anzdata@anzdata.org.au

Find out more at our website www.anzdata.org.au

Contact the Royal Adelaide Hospital Human Research Ethics Committee on (08) 8222 4139 or email CALHNRResearchEthics@sa.gov.au