



ANZDATA Information Sheet for Adolescents

What is ANZDATA?

Nearly 40 years ago, doctors who look after kids and grown-ups with kidney disease got together as a team to learn more about what the best treatments are for kids who have dialysis or a kidney transplant. They called this team “ANZDATA”.

The hospital team that looks after you shares information about your medicines and dialysis or transplant treatments with ANZDATA each year.

ANZDATA helps your hospital team learn about the best ways to look after kids and grown-ups who have kidney disease.

Why am I being asked to share information with ANZDATA?

- You are being asked if we can share some of your treatment information with ANZDATA because you have dialysis treatment or you have a kidney transplant.
- ANZDATA stores information about you and your kidney treatment in a secure computer network in Australia. ANZDATA is designed to help doctors and nurses find out which treatments are best and are safe for you and for other young people just like you with kidney disease.
- Your mum or dad, or your caregiver and your hospital team will tell you more about sharing your health information with ANZDATA.
- You can talk to your kidney doctor any time you have questions about your kidney care and ANZDATA.

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

Your hospital team will fill out a form about your kidney care once every year. You don't have to help them fill out the form. This form is sent to ANZDATA.

If you have anything new happen to you during that year, they may fill out extra forms. This would happen if you got a kidney transplant or got a dialysis infection.

Sometimes your hospital team might ask you or your mum or dad or the person who takes care of you some extra questions about your treatments.

Do I have to share my health information with ANZDATA?

No. You can choose to share your information with ANZDATA or not. Also, you can change your mind at any time, even if you have already said yes.

Even if your mum or dad or caregiver says yes, you can still say no. If you decide not to share your health information with ANZDATA, no one will be angry with you and your treatment will



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stay the same. All you have to do is tell your mum, or dad, or person taking care of you or your doctor that you don't want to share any of your information. You will still get all the treatment you need.

Does sharing health information with ANZDATA help me?

Children who have already shared their health information with ANZDATA will have helped your hospital team improve the way they give kidney care to other young people like you.

We hope we might continue to learn new things into the future that can help people who have the same kidney problems as you.

Who will know about my information in ANZDATA?

Everything you say to your hospital team will be kept private as it always is. We will not tell anyone else about the information we share with ANZDATA. When we tell other people about what we learned from ANZDATA, we will not tell them your name or the name of anyone else.

There is a risk that someone who is not supposed to could look at your information. ANZDATA takes protecting your privacy very seriously and does everything it can to stop that from happening

What if there is a problem?

If you are worried about anything to do with ANZDATA, please ask your kidney hospital team who will do their best to answer your questions.

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

If you want to talk to someone who isn't involved with ANZDATA, you can contact people who know about privacy and ethics at the Royal Adelaide Hospital on (08) 8222 4139 or email them at CALHNResearchEthics@sa.gov.au