

ANZDATA Patient Information Sheet and Assent Form for ages 14 to 16 years old



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 need 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 need dialysis or you have a kidney transplant.

ANZDATA stores information about you and your kidney treatment in a secure computer network at a hospital 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 anyone who cares for you if 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.

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 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.

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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.

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 information that might let them know who you.

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, your mum or dad or caregiver have any questions or concerns about ANZDATA at any stage, you can talk to a doctor or nurse at Starship:

If you want to talk to someone who isn't involved with ANZDATA, you can talk to one of your kidney team, or contact the Office of the Privacy Commissioner (phone 0800 803 909 Monday-Friday between 10.00 am and 3.00 pm or go to their website www.privacy.org.nz).



ANZDATA Assent Form for ages 14 to 16 years

Patient's name: <i>(Full name in BLOCK LETTERS)</i>	Date of Birth <i>(Month/Year)</i> / /
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Please circle all answers you agree with	Yes	No
I have read this form (or someone has read it to me).	Y	N
My hospital team has explained ANZDATA to me.	Y	N
I have had time to talk about ANZDATA with my mum and dad or the person who takes care of me.	Y	N
I understand what ANZDATA is all about.	Y	N
I know that the health information about me shared with ANZDATA will not be told to anyone who doesn't look after me in a way that shows who I am.	Y	N
I know that I can stop sharing my health information with ANZDATA and this won't change the way my hospital team look after me.	Y	N
I have asked all the questions that I want to.	Y	N
I am okay to share my health information with ANZDATA.	Y	N
Mum or Dad or the person who takes care of me will also sign a form to say they are okay for me to share my health information with ANZDATA.	Y	N

If any of your answers are no, or you don't want to share your health information with ANZDATA, then that is okay. Don't sign your name!

If you are okay to have your health information shared with ANZDATA, then please write your name and the date for today below. We will give you a copy of this signed form to take home with you.

My name:	
My signature:	Date:
Name of my mum or dad or caregiver:	Name of person who explain to me about ANZDATA:
Signature:	Signature:
Date: / /	Date: / /

Thank you for helping!