

# ANZDATA Information Sheet and Consent Form for Parent or Caregiver



## What is ANZDATA?

ANZDATA is a team of people working in Adelaide that asks all hospital teams in Australia and New Zealand to share health information about kids and grown-ups with kidney problems. Doctors at your child's hospital and hospital teams around New Zealand share health information about the treatment they give each patient and send this to ANZDATA each year. This health information is about the medicines and dialysis or transplant treatments given to each child and adult in New Zealand. ANZDATA is funded by the Australian and New Zealand governments.

ANZDATA helps your hospital team learn about the best ways to look after kids and grown-ups with kidney disease. ANZDATA has been going for over 40 years. Nearly all children and adults in New Zealand treated with dialysis or a kidney transplant have shared their treatment information with ANZDATA. ANZDATA is based at the South Australia Medical and Health Research Institute in Adelaide in Australia. The health information kept by ANZDATA is stored in a secure computer network in Australia.

Whether you agree to let your child's health information be shared with ANZDATA is your choice. If you don't want health information about your child shared with ANZDATA, you don't have to give a reason and it won't affect the care you or your child receives. You can change your mind at any time.

## Why is my child being asked to give information to ANZDATA?

Your child is being asked to share health information with ANZDATA because he or she is having dialysis treatment or has a kidney transplant at Starship Hospital.

## How does health information about my child get shared with ANZDATA?

You and your child don't need to do anything extra as part of ANZDATA. Your hospital team will send health information about your child's care to ANZDATA each year. Your team may ask you or your child some questions about treatment each year. There are no wrong or right answers to any of our questions. You do not have to answer any question you do not want to answer. It is completely up to you.

## What will happen if I agree to share my child's health information with ANZDATA?

Your hospital team will fill out a form about your child's kidney care once every year. You don't have to help them fill out the form. If anything new happens to your child during that year, the hospital team may fill out extra forms. This would happen if your child got a kidney transplant or got a dialysis infection.

## Does health information about my child have to be shared with ANZDATA?

NO. You can choose for the health information about your child to be shared with ANZDATA or not. Also, you can change your mind at any time, even if you have already said yes already. We think ANZDATA is an incredibly helpful resource to help improve treatments for people with kidney disease. The more children who take part, the more valuable ANZDATA is to answer important questions about treatments and kidney disease.

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If you decide that you would prefer that the health information for your child is not shared with ANZDATA, this will have no effect on your child's care. Your child will still get all the treatments they need.

## **Will sharing health information with ANZDATA help my child?**

ANZDATA may or may not help your child. Children who have already shared information to ANZDATA in the past will have helped your hospital team improve the way they give kidney care to other children. We hope we might learn new things that can help people who have the same kidney problems as your child.

## **Who will know about my child sharing information with ANZDATA?**

Everything you say to your hospital team about your child will be kept private. We will not tell anyone else about the information you have shared about your child. When we tell other people about what we learned from ANZDATA, we will not tell them your child's name or the name of anyone else who has shared health information with ANZDATA.

## **What if there is a problem about sharing information with ANZDATA?**

If you are worried about anything to do with ANZDATA, please ask your child's 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 have any questions or concerns about ANZDATA at any stage, you can talk to anyone involved in your child's care.

You and your family can also talk with anyone at the Office of the Privacy Commissioner (phone 0800 803 909 Monday-Friday between 10.00 am and 3.00 pm or through the website [www.privacy.org.nz](http://www.privacy.org.nz)).

# ANZDATA Registry

## Consent Form for Parent or Caregiver



Please tell us if you need an Interpreter

Please tick to indicate you consent to the following	Yes	No
I have read, or have had read to me, in my first language (including NZ sign language) the information I have been given about ANZDATA.	<input type="checkbox"/>	<input type="checkbox"/>
I have been given sufficient time to think about whether I will share my child's health information with ANZDATA.	<input type="checkbox"/>	<input type="checkbox"/>
I have had a chance to talk about ANZDATA with my child's healthcare team.	<input type="checkbox"/>	<input type="checkbox"/>
I have had the opportunity to involve whānau/ family support or a friend to help me ask questions and understand about ANZDATA and I am satisfied with the answers I have been given.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that sharing my child's health information with ANZDATA is my choice and that I can withdraw my child's information from ANZDATA at any time without this affecting my child's medical care.	<input type="checkbox"/>	<input type="checkbox"/>
I consent to ANZDATA staff collecting and processing my child's health information.	<input type="checkbox"/>	<input type="checkbox"/>
If I decide to withdraw my child's health information from ANZDATA, I agree that the information collected about my child up to the point when my child is withdrawn may continue to be processed.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that sharing my child's health information with ANZDATA is confidential and that no material, which could identify my child personally, will be used in any reports or publications from ANZDATA.	<input type="checkbox"/>	<input type="checkbox"/>
I know who to contact if I have any questions about ANZDATA in general.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if my child can give assent that they will be asked to sign an assent form. When my child is old enough and able to give consent, they will be asked to do so.	<input type="checkbox"/>	<input type="checkbox"/>
I have received a copy of this signed consent form.	<input type="checkbox"/>	<input type="checkbox"/>

### Declaration by parent:

I consent for my child's health information to be shared with ANZDATA.

**Parent's or caregiver's name:**

**Signature:**

**Date:**        /        /

### Declaration by member of research team:

I have given a verbal explanation about ANZDATA to the parent or caregiver and have answered the parent's or caregiver's questions about it.

I believe that the parent or caregiver understands ANZDATA and has given informed consent to share their child's health information with ANZDATA.

**Clinician's name:**

**Signature:**

**Date:**        /        /