Australia and New Zealand Heart Transplant Registry (ANZHTR)
C/O South Australian Health Medical Research Institute (SAHMRI)
SAHMRI Building, Level 4 South
PO Box 11060
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Ph: +61 8 8128 4758
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AUSTRALIA AND NEW ZEALAND HEART TRANSPLANT REGISTRY
INFORMATION SHEET FOR ADOLESCENTS

What is the Australia and New Zealand Heart Transplant Registry?

Doctors who look after young persons and grown-ups with heart disease got together as a team to learn more about what the best treatments are for young persons who have a heart transplant.

The hospital team that looks after you shares information about your transplant treatment with the Australia and New Zealand Heart Transplant Registry.

ANZHTR replaces a previous heart and lung transplant registry which ceased operations in 2018. To ensure we continue to learn about the best ways to care for young persons and grown-ups who need a heart transplant, the Australian government has funded this registry to continue to monitor heart transplantation. Data will be stored securely by the registry indefinitely, for the lifetime of registry operations This centralised registry operates out of Adelaide, South Australia.

Why am I being asked to share information with the Australia and New Zealand Heart Transplant Registry?

You are being asked if we can share some of your treatment information with the Australia and New Zealand Heart Transplant Registry because you are waiting for or have received a Heart transplant.

The Australia and New Zealand Heart Transplant Registry stores information about you and your heart treatment in a secure computer network in Adelaide, South Australia. The Australia and New Zealand Heart Transplant Registry 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 heart disease.

Your parents or carers and your hospital team will tell you more about sharing your health information with the Australia and New Zealand Heart Transplant Registry.

You can talk to your heart doctor any time you have questions about your care and the Australia and New Zealand Heart Transplant Registry.

What will happen if I agree to share my information with the Australia and New Zealand Heart Transplant Registry?

Your hospital team will provide information about when you are listed on the waiting list and when you receive a heart transplant. You don't need to do anything; your hospital team will provide this information. The information collected by the registry is used to track the numbers of heart transplants and outcomes of heart transplant treatments. Reports will be sent back to heart transplant hospitals.

What information does ANZHTR collect about me?

Your hospital will give ANZHTR your name, postcode, date of birth, gender, ethnic background (your race), and information about your health condition (what disease you have), how long you have waited for a transplant and the type of transplant you receive.
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.

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Do I have to share my health information with the Australia and New Zealand Heart Transplant Registry?

No. You can choose to share your information with the Australia and New Zealand Heart Transplant Registry or not. You can change your mind at any time, even if you have already said yes.

Even if your parents or carers say yes, you can still say no. If you decide not to share your health information with the Australia and New Zealand Heart Transplant Registry, that is your decision. It does not affect the treatment you receive in anyway. All you have to do is tell your parents or carers 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 the Australia and New Zealand Heart Transplant Registry help me?

Sharing health information with the Australia and New Zealand Heart Transplant Registry may help your hospital team improve the way they provide 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 heart problems as you.

Who will know about my information in the Australia and New Zealand Heart Transplant Registry?

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 the Australia and New Zealand Heart Transplant Registry. When we tell other people about what we learned from the Australia and New Zealand Heart Transplant Registry, 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. The Australia and New Zealand Heart Transplant Registry takes protecting your privacy very seriously and does everything it can to stop that from happening. In very rare situations, there may be a legal requirement to pass your information to an authorised third party. We have an obligation to inform you of this possibility, in the rare circumstance this may occur.

What if there is a problem?

If you are worried about anything to do with the Australia and New Zealand Heart Transplant Registry, please ask your heart 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 giving your information to the Australia and New Zealand Heart Transplant Registry at any stage, you can talk to your heart doctor, nurse or other team member. You can also speak with someone at the registry by contact the Australia and New Zealand Heart Transplant Registry by phone on (08) 8128 4758 or by email anzhtr@anzdata.org.au

If you want to talk to someone who isn't involved with the Australia and New Zealand Heart Transplant Registry, you can contact people who know about privacy and ethics at the Women's and Children's Health Network Human Research Ethics Committee on (08) 8161 6521 or email them at HealthWCHNResearch@sa.gov.au

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