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
Adelaide, South Australia 5001
Ph: +61 8 8128 4758
Email: anzhtr@anzdata.org.au

AUSTRALIA AND NEW ZEALAND HEART TRANSPLANT REGISTRY
INFORMATION SHEET FOR PATIENTS AND FAMILIES/CAREGIVERS

Why am I being given this Information Sheet?

You are receiving a heart transplant. This means your health information can be collected by your treating transplant unit and provided to the Australia and New Zealand Heart Transplant Registry (ANZHTR). This information sheet provides information on what ANZHTR does, and why we are requesting information about you to be included in the registry. Participation in ANZHTR is voluntary. If you do not want to take part, you do not have to, and you can choose to "opt-out". You will receive the best possible care whether you decide to take part or not.

What is ANZHTR and what does it do?

ANZHTR is a transplant outcome clinical quality registry. ANZHTR collects information (data) about the health of all people (adults and children) in Australia and New Zealand who have received or are waitlisted to receive a heart transplant.

ANZHTR replaces the previous Australian and New Zealand Cardiothoracic Transplant Registry which ceased operations in 2018. The Australian government has funded this registry to continue to monitor the safety and quality of heart transplantation. This centralised registry operates out of Adelaide, South Australia.

How does ANZHTR collect and store my information?

Your treating transplant unit will provide ANZHTR specific information about your condition and heart transplant including the time you were listed for transplantation.
ANZHTR keeps this information about you in a highly protected computer network in South Australia. Your information will be stored securely by the registry indefinitely, for the lifetime of registry operations.

What information does ANZHTR collect about me?

Your hospital gives ANZHTR your name, postcode, date of birth, gender, ethnic background (your race), and information about your health conditions (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.

How does ANZHTR use my information?

The information collected by the registry is used to track the numbers of heart transplant and outcomes of heart transplant treatment. Reports will be sent back to heart transplant hospitals.
Your identity (and other personal information) may be released to researchers for the purpose of research projects only after the research project has been approved by a Human Research Ethics Committee.

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

You do not have to do anything more. Your hospital team will provide the information to ANZHTR. You can ask to see your own information at any time or get copies of the reports that ANZHTR produces.

Do I have to share my health information with ANZHTR?

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Participation in ANZHTR is voluntary. You do not have to do anything - your treating transplant hospital will provide your data on your behalf. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from ANZHTR at any stage.

If you would prefer not to participate in the registry, you can tell a member of your transplant team, your doctor or nurse who will inform ANZHTR. You can also contact ANZHTR directly and advise us that you do not wish to participate in the registry. You can contact the registry by phone on (08) 8128 4758 or by emailing anzhtr@anzdata.org.au.

Your decision to take part or not to take part, or withdraw, will not affect your routine care, your relationship with your doctor or your care in any way.

Does sharing health information with ANZHTR help me?

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

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

The main risk is a loss of privacy if your personal and private health information which is given to ANZHTR 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 ANZHTR is kept as safe as possible (see next section). Your identity and personal details are not accessible to the public. 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.

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

ANZHTR 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 (and other personal information) may be released for the purpose of research projects approved by a Human Research Ethics Committee. ANZHTR has strict rules around who can ask for information and how they can get it. If ANZHTR information is used in research or is published 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 ANZHTR at any stage, you can talk to your transplant team. You can also contact ANZHTR 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 ANZHTR, 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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