Australia and New Zealand Lung Transplant Registry (ANZLUNG)
C/O South Australian Health Medical Research Institute (SAHMRI)
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Australia and New Zealand Lung Transplant Registry
Information Sheet for Patients and Families/Caregivers

Why am I being given this Information Sheet?

You are receiving a lung transplant. This means your health information can be collected by your treating transplant unit and provided to the Australia and New Zealand Lung Transplant Registry (ANZLUNG). This information sheet provides information on what ANZLUNG does, and why we are requesting information about you to be included in the registry. Participation in ANZLUNG 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 the ANZLUNG and what does it do?

The ANZLUNG is a transplant outcome clinical quality registry. ANZLUNG collects information (data) about the health of all people (adults and children) in Australia and New Zealand who have received a lung transplant.

ANZLUNG 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 lung transplantation. This centralised registry operates out of Adelaide, South Australia.

How does the ANZLUNG collect and store my information?

Your treating transplant unit will provide ANZLUNG specific information about your condition and lung transplant. If you choose to share your information with ANZLUNG, your information will provided to the registry after you have received a lung transplant. The ANZLUNG 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 the ANZLUNG collect about me?

Your hospital gives ANZLUNG your name, postcode, date of birth, gender, ethnic background (your race), and information about your health conditions (what disease you have), 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 the ANZLUNG use my information?

The information collected by the registry is used to track the number of lung transplants and outcomes of lung transplant treatment. Reports will be sent to lung transplant hospitals and a public de-identified annual report will be available each year. 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 the ANZLUNG?

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

Do I have to share my health information with the ANZLUNG?

Participation in the ANZLUNG 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 ANZLUNG at any stage.

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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 the ANZLUNG team. You can also contact ANZLUNG 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 kelly@anzdata.org.au

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

Does sharing health information with the ANZLUNG help me?
Sharing your information with ANZLUNG will not directly affect your care. Collecting information about the health and treatment of end-stage lung 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 lung failure leading to transplantation in the future.

What are the risks for me if I agree to share my information with the ANZLUNG?
The main risk is a loss of privacy if your personal and private health information which is given to ANZLUNG 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 ANZLUNG 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 the ANZLUNG kept private and safe? Who can see it?
ANZLUNG 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. ANZLUNG has strict rules around who can ask for information and how they can get it. If ANZLUNG 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 the ANZLUNG at any stage, you can talk to your transplant team. You can also contact The ANZLUNG team by phone on (08) 8128 4758 or by email kelly@anzdata.org.au
If you want to talk to someone who isn't involved with ANZLUNG, you can contact people who know about privacy and ethics at the Central Adelaide Local Health Network Human Research Ethics Committee on (08) 7117 2224 or email them at Health.CALHNResearchGovernance@sa.gov.au.

Version	Version Date	Endorsement	Outcome
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