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 Adolescents

What is the ANZLUNG?

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

The hospital team that looks after you shares information about your transplant treatment with the Australian and New Zealand Lung Transplant Registry (ANZLUNG).

The ANZLUNG 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 lung transplant, the Australian government has funded this registry to continue to monitor lung transplantation. Data within the registry will be retained indefinitely. This centralised registry operates out of Adelaide, South Australia.

Why am I being asked to share information with the ANZLUNG?

- You are being asked if we can share some of your treatment information with the ANZLUNG Registry because you have received a Lung transplant.
- The ANZLUNG stores information about you and your lung treatment in a secure computer network in Adelaide, South Australia. The ANZLUNG 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 end-stage lung disease.
- Your parents or carers and your hospital team can tell you more about sharing your health information with the ANZLUNG.
- You can talk to your lung doctor any time you have questions about your care and the ANZLUNG.

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

Your hospital team will provide information about when you receive a lung 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 lung transplants and outcomes of lung transplant treatments. Reports will be sent back to lung transplant hospitals.

What information does the ANZLUNG collect about me?

Your hospital will give the ANZLUNG your name, postcode, date of birth, gender, ethnic background (your race), and information about your health condition (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.

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Do I have to share my health information with the ANZLUNG?
No. You can choose to share your information with the ANZLUNG 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 ANZLUNG, that is your decision. It does not affect the treatment you receive in anyway. All you have to do is tell your parents, carers or your doctor that you don't want to share any of your information. You will receive the best possible care whether you decide to take part or not.

Does sharing health information with the ANZLUNG help me?
Sharing health information with ANZLUNG 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 lung problems as you.

Who will know about my information in the ANZLUNG?
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 ANZLUNG. When we tell other people about what we learned from ANZLUNG, 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 ANZLUNG 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 ANZLUNG, please ask your lung 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 ANZLUNG at any stage, you can talk to your lung doctor, nurse or other team member.
You can also speak with someone at the registry by contact the ANZLUNG 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 the 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.

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