

Participant Information Sheet - Child

Title	<i>WA Paediatric Bronchiectasis Cohort Study</i>
Project Sponsor	<i>Telethon Kids Institute</i>
Coordinating Principal Investigator	<i>A/Professor Andre Schultz</i>
Location	<i>Perth Children's Hospital</i>

1. Introduction

We are inviting you to be a part of our research study. We want you to be a part of this study because you have healthy lungs. Before you decide if you want to be in this study, it is very important to read the information below.

2. Why do we want to do this research?

A research study is a way to learn more about people. We are doing a research study about a lung condition which some children have, called bronchiectasis. Bronchiectasis is when the breathing tubes in the lungs get damaged and can make you cough, cough up phlegm or feel tired and unwell. Children with bronchiectasis often need to stay in hospital when they feel sick.

There have not been many other studies before in children with bronchiectasis. We want to find out more about what is happening in the breathing tubes of the lungs when these children are well and when they are sick and need to be in hospital.

To do this, we also need information about how healthy lungs work. This is why we want you to be a part of this study.

3. What happens if you say “yes” to being in our study?

If you decide that you do want to be part of this study, we will ask you to visit Perth Children’s Hospital twice a year, over 5-years. At each visit, there are a few breathing tests we will ask you to do:

- We will ask you to do some normal breathing of 100% oxygen through a tube. This will tell us how your lungs are working. The 100% oxygen does not taste or feel any different to normal air.
- We will ask you to take some very big breaths in and out. These will be measured using a tube you hold in your mouth to see how much air you can fit in your lungs.
- We will also ask you to breathe or pant into the tube you hold in your mouth. This will tell us more about how much air you can fit in your lungs.

All together each visit will probably take about 1 hour.

4. What happens if you say “no”?

Nothing happens, no one will be angry or upset if you say no. You can say no to being in the study whenever you like. If you do not want to be in the study anymore you can let your mum, dad, or guardian know, or your doctor. We will then make sure to not get you in for any more research visits.

5. Are there any benefits in participating?

A benefit is something good that happens to you. We do not know if you will get any benefit out of this study. You will get to see how well your lungs work, which might be helping other children who have bronchiectasis.

6. Are there any risks with participating?

A risk means a chance of something bad happening to you. We do not think that there are any risks to you.

7. What happens after the study?

When we are finished with this study, we will write a report about what we have learnt. This report will have your results, but it **will not** include your name or that you were in the study.

8. What happens if I have any questions?

Questions are very important. If you do not understand something or want to know more there are lots of people you can ask. You can ask your mum or dad (or guardian), one of our researchers or your doctor.

If you do want to know more about this study, your mum or dad (or guardian) also has an information sheet you can read. You can also contact one of the research team members:

Name	Contact Number
Ms Alana Harper – Project Coordinator	08 6319 1617
Dr. Kathryn Ramsey	08 6319 1374
A/Prof Andre Schultz	08 6456 0217

This study has been approved by the Child and Adolescent Health Service Human Research Ethics Committee and is funded by the National Health and Medical Research Council (NHMRC).