Project Information Sheet: Participant

Scientific title of study	RRR^2: Rapid Respiratory Response in Rural and Remote Regions - an observational study of bronchiectasis using ground-breaking tools
Lay Title of study	Rapid Respiratory Response in Rural and Remote Regions
Principal Investigator	Dr Thomas Goddard
Institution	Women's and Children's Hospital
Phone Number	(08) 8161 7234 or (08) 8161 7000 (24-hr emergency)

Why are we doing this study?

Doctors want to help kids like you get better treatment for lung problems. Sometimes, when kids get a lung infection, it is hard to figure out what is causing it. This means it can take longer to get the right medicine to make them feel better.

Right now, doctors often have to guess which germs are making kids sick because the tests they use take a long time and don't always give clear answers.

This study will help us to:

- **Learn more about the germs that cause lung infections.** By studying the germs in your samples (like spit), we can figure out which ones are making you sick.
- **Find better, faster ways to help kids.** We are testing a new way of finding these germs more quickly. If it works, doctors will know the best medicine to give right away!
- **Help kids stay at home with their families.** With better ways to find germs, kids won't always need to travel far to big hospitals for testing and/or treatment.

How is this study special?

- We will use a computer to quickly check for germs in the samples you give your doctor.
- This can help us figure out what is wrong in just one day instead of waiting a week or more.

Why am I being asked to join the study?

You are being asked because you have a lung condition called bronchiectasis or another lung issue such as chronic wet cough. Doctors want to learn more from your samples so they can help kids like you get better care in the future.

How many children will be part of this study?

A total of **115 children** aged between 0-18 years will be involved in this study:

- **50 children** from the Women's and Children's Hospital in Adelaide
- **50 children** from Alice Springs Hospital
- **15 children** from Mount Gambier and Districts Health Service

What will happen if I join the study?

If you agree to join:

1. **We will use part of the samples you give your doctor** (like mucus from your lungs). These are samples you already give when you visit the doctor or hospital.
2. **We will look at the samples in our lab** to learn about the germs (like bacteria and viruses) causing the infection.
3. **You don't need to do anything extra** other than what your doctor already asks you to do.

Who will this study help?

This study might not help you feel better right now, but it could help other kids who get lung infections in the future. If the tools we're testing work well, they might become something all doctors use to help kids everywhere!

Who is running the study?

- **Lead Researcher:** Dr. Thomas Goddard
- **Hospital:** Women's and Children's Hospital, Adelaide, South Australia
- **Phone Number:** (08) 8161 7234

Who is funding the study?

The money to do this study comes from the **Women's and Children's Hospital Foundation Boom Research Grant**. This is money given to help doctors and researchers find better ways to keep kids healthy.

What will I do in the study?

If you join, we will:

- Use the spit or mucus samples you already give to your doctor as part of your care.
- Study the germs in those samples in our lab to see what's causing the infection.
- You don't need to do anything extra besides your usual visits to the doctor.

How long will it take?

We're only using samples from your regular doctor visits, so there's no extra time needed for this study.

Does it hurt and are there any risks?

No! We are just using samples you already give your doctor. No needles, no extra tests, and nothing that hurts.

Do I have to join?

No, you don't have to join if you don't want to. It's your choice! If you say no, there will be no change to your care.

If you do join but later change your mind, that's okay too. You can tell someone in the research team, or you can ask your parent or guardian to call or email the Principal Investigator to let them know. Their contact details are listed in the *'Who can I talk to if I have questions?'* section below.

What if I say yes but change my mind?

That is okay! You can stop being part of the study anytime, and no one will be upset with you. Just let a member of the research team know.

If you decide to leave the research project, the researchers will not collect any more information or samples from you. However, some of the data already collected from any previous appointments may not be able to be removed from the study. This is because, in scientific research, results need to stay the same each time they are analysed. If we remove data after it has been included, the results will change and no longer be reliable.

Therefore, it is important to understand that some of the de-identified data that has already been used in publications, or presentations may not be able to be removed. However, any de-identified data already generated will not be used in any future analyses that have not yet been done, and any remaining sample will be disposed of respectfully and safely.

What do I get out of this?

You might not feel better because of the study, but the results could help other kids in the future get better care for lung infections.

Can my samples be used for other research?

If you and your parents say it is okay, samples might be used in other science projects to help other kids. But first, a group of people who are part of the hospital need to make sure the projects are safe and fair first. If you don't want your samples used in other projects, that is okay, just let us know.

What information will people see and who will see it?

If you agree to be involved in our research the team will also use information from your electronic medical records. These are the notes that your doctor writes down about your health and the care you receive. Only the doctors and researchers working on the study will see your information. They won't tell anyone your name or who you are when they talk or write about you in the study.

The information the research team will use is:

- Your age, gender, and the date and time your sample was taken.
- The language you speak at home (to help us understand where families come from).
- How well your lungs are working (from breathing tests and scans).
- What medicines (like antibiotics) you have had before and results from past germ tests.
- Some blood test results (like how your body is fighting germs or allergies).

Who will see my samples?

Any samples or information we collect from you will be kept private. When your mucus/spit sample is tested, your name will not be on it. Instead, it will be given a special study code made up of random numbers. Your sample will now be *de-identified*. This means that no one looking at your sample will know it belongs to you.

The research team will be able to use and access your samples for the study, but they will not know it is yours because it will be de-identified. Only your doctor will know which code is linked to you.

Who will look after my samples?

Your mucus/spit sample will be safely stored in a locked freezer at the hospital where you gave the sample or at Flinders University in Adelaide. Only trained researchers will be able to get into these places.

The DNA from the germs in your sample will be stored safely on special computer systems called Pawsey (for short-term storage) and the National Centre for Indigenous Genomics (NCIG) (for long-term storage). These systems keep your information private and only let the research team see your de-identified data.

Other de-identified information collected for the study, like test results or health information, will also be stored safely in a secure computer system at Flinders University. Only the research team will be able to see this de-identified information.

When the study is finished, any leftover mucus/spit sample, or DNA from your germs, will be safely and respectfully destroyed in the way that you and your parents/guardians choose. The DNA information from your germs, and other data we collect about your health, will be stored securely for 30 years (as required for research) before being deleted.

Can I find out about the results?

Yes! If you and your family would like to, you can learn about the results in a few different ways:

- Newsletters that can be sent to families directly (by email or post).
- By visiting our project website: https://fame.flinders.edu.au/rrr2/

We will also write about the study in science papers and present it at meetings in Australia and other countries. When we do this, no one will be able to tell that you were involved in the study. We will protect your privacy.

The results from your spit/mucus sample will be joined together with results from all the other kids in the study. This helps us see patterns about lung health in different places.

We will not give out individual results. Instead, we will share what we find as a whole group.

However, before any results or findings are shared, they will first be talked about with Elders and community leaders.

What happens next?

If you want to join, talk to your parents. They will help you sign the forms to show that you agree. You will also get to keep a copy of this sheet to remind you what the study is about.

Who can I talk to if I have questions?

If you or your parents have any questions about the study, you can talk to:

Name	Phone Number	Role
Dr. Thomas Goddard	(08) 8161 7234	Principal Investigator

You can also ask one of the friendly research staff, they are more than happy to answer any of your questions!

What if I have concerns about the study?

If you have any **concerns or complaints** about the study, you or your parents can call:

Location	Name	Phone Number	Email
South Australia	**Jade Jordan-Hall** (WCHN HREC Ethics Officer)	(08) 8161 6521	HealthWCHNResearch@sa.gov.au
South Australia	Aboriginal Health Research Ethics Committee	(08) 8273 7200	research@ahcsa.org.au
Northern Territory	NT Health and Menzies School of Health Research Human Research Ethics Committee	(08) 8946 8600	NTHREC@menzies.edu.au