

NATIONAL ASTHMA RESEARCH AGENDA PRIORITISATION PROJECT CHILD INFORMATION SHEET- CONSENSUS WORKSHOP

This information sheet has been put together to help you decide if you would like to take part in our research project. You should discuss the information in this sheet with your mum, dad or usual caregiver.

Investigators

- Peter Gibson (Hunter Medical Research Institute)
- Eleanor Majellano (University of Newcastle)
- Anthony Flynn (Asthma Australia)
- Rose Bell (Asthma Australia)
- Michele Goldman (Asthma Australia)
- Sundram Sivamalai (Consumer representative, Asthma Australia)
- Anne McKenzie (Consultant)

1. Why are we asking you?

We are asking you to take part in this project because you are between 12 and 17 years of age and have been told by a doctor that you have asthma. This research is not suitable for you if you are under the age of 12.

2. Why are we doing this project?

We want to create a list of priorities for research about asthma. To do this, we have heard from people with asthma, the people who care for them and their doctors what research they would like to see done about asthma. Now we want to understand what research about asthma is more important.

3. How the project works...

If you would like to participate in this research:

- You will be asked to take part in an online workshop.
- The workshop will use a program called Zoom, on a computer. It will allow you to see other people in the workshop and speak.
- Your mum, dad or usual caregiver will need to attend the workshop with you.
- In the workshop you will be asked questions and talk with other people in the workshop about what asthma research is important.
- It will go for about 3 hours.

4. Do I have to take part?

No, you don't. If you say no, that is okay, it is up to you.

If you would like to take part in this research you will need to talk about it with your mum, dad or usual caregiver. If you agree to participate, you (and your mum, dad or usual caregiver) will be asked to sign and return the Consent Form.

If you say yes, and then you change your mind later on, that is okay as well. You can leave the workshop at any point.

5. Good and bad parts of the project

We do not think there will be any bad parts about taking part in this research. However, if you have any questions you want to ask during or after taking part in the research about your asthma, you can:

- Talk to your mum, dad or usual caregiver, or
- Call Asthma Australia's free information and support service to speak with an Asthma Educator (1800 278 462).

You do not have to talk about anything you do not want to in the workshop.

We cannot promise that you will have any good things happen because of the project, but it is important that people with asthma have a say in the research about asthma. Taking part in this project will allow your voice to be heard.

Participation in this project will not cost you anything, nor will you get paid.

6. What happens to the information I tell you?

We will record the workshop, but the records will be put away and no-one but the researchers will be able to see it. All information about you is kept in a secure office and on a computer with a password.

We might share information from the project with our project partners for more analysis, but it will only be summary data and will not have anything that can identify you.

We will share overall results of the project. This might be in science journals, on the Asthma Australia website or in the media (such as TV and newspapers). When we share the results of the project it will be written so that no one will know who was in the project.

If you want to see the results of the project you can ask your mum, dad or usual caregiver to email Rose Bell (rbell@asthma.org.au), or visit this webpage [URL to be added once webpage created] after June 2022.

7. Anything else?

You need to understand why we are doing this project, and what we will be asking you to do in this project. Talk about the project with your mum, dad or usual caregiver and ask questions before you make a decision.

If you would like to know more about this project, you or your mum, dad or usual caregiver can call Rose Bell. Rose is a member of this research project and works at Asthma Australia. You can contact Rose by phone on 03 9086 7852 or email: rbell@asthma.org.au

If anything happens while you are taking part in the research, tell your mum, dad or caregiver and they will know who to talk to.

8. Who should I contact if I have any concerns about the study?

This project has been approved by the Hunter New England Human Research Ethics



Committee of Hunter New England Local Health District, Reference 2021/ETH11604. If you have any concerns about this research or a complaint about the way it was completed, please contact the Hunter New England Local Health District on 02 4921 4140.