

**STUDY NAME: NATIONAL ASTHMA RESEARCH AGENDA PRIORITISATION PROJECT
PARTICIPANT INFORMATION SHEET**

Introduction

You are invited to participate in this research project about future priorities for asthma research.

Researchers from the Hunter Medical Research Institute and staff from Asthma Australia would like to hear from you about what asthma research you would like to see in the future. It is important that future asthma research priorities are informed by end-users of research (including people with asthma, carers, healthcare professionals and policy makers).

The research team conducting this research project include:

- 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)

This project is funded by Asthma Australia.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve.

This Participant Information Statement provides background information about the project and what your participation will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

If you have questions about anything that you don't understand or something you want to know more about please contact the research team using the details at the end of this sheet.

1. What is the research being done?

The purpose of this research is to understand from end-users of research (including people with asthma, carers, healthcare professionals and policy makers) what the priorities are for future asthma research.

This will lead to the development of a National Asthma Research Agenda, which will help to prioritise asthma research for funding and to advocate for increased asthma research.

2. Who can participate in the research?

To take part in this survey you must meet the following criteria:

- Aged 12 years and over and have asthma,
- A parent or carer of a child with asthma,
- A professional who works in direct health service provision for people with asthma, or
- A public health professional who has role in or responsibility for public health planning for chronic respiratory disease.

This research is not suitable for you if you:

- Are staff of companies in pharmaceuticals
- Work exclusively in research
- Are younger than 12 years
- Are a parent or carer of a child with asthma younger than 1 year

3. What would you be asked to do?

If you agree to participate in this study, you will then be asked to participate in an online workshop via the Zoom video conferencing platform. During this workshop you would participate in discussion about priorities for asthma research. These priorities have been informed by an online survey.

The online workshop will go for approximately 3 hours.

4. What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Your decision whether to participate or not, will not affect your current or future relationship with the researchers or anyone at the Hunter Medical Research Institute.

If you do decide to participate, you can leave the workshop at anytime if you no longer want to participate.

5. How much time will it take?

If you decide to participate, you will join one workshop for approximately 3 hours. There may be some materials provided to read before the workshop, which could take up to an hour of your time.

6. What are the risks and benefits of participating?

We cannot guarantee that you will receive any benefits from taking part in this study, but it is important that future research about asthma is informed by end-users of research (including people with asthma, carers, healthcare professionals and policy makers). Participating in this research will allow your experiences to be heard and contribute to the future priorities for asthma research.

We do not foresee any risks to you in taking part in this workshop. However, if at any point the discussion during the workshop raises any issues for you about your asthma or the asthma of someone you care for, you are free to leave the workshop. A member of the research team will reach out to see if you require any assistance. You can also call Asthma Australia's free information and support service to speak with an Asthma Educator (1800 278 462).

7. How will your privacy be protected?

We will collect your name, contact details and some basic demographic information to ensure you are eligible to participate in the workshops. There will also be identifying information contained in the consent form. However, these will only be used to manage the online workshops and will not be used in any analysis or reporting about the project.

We will record the workshops which will be held on a video conferencing platform, Zoom. These recordings will be stored in secure online servers and only accessible by the project

team. The data will be stored securely for a minimum of 5 years from completion of the research and managed/stored in accordance with the University's Research Data and Materials Management Guideline or any successor Guideline.

There will be no identifying data from the workshops used in any reporting about the project. De-identified data, and summary results may be transferred to partner groups for further analysis, for communication and publication of results, and for implementation of results.

You will also be identifiable to other participants in the workshop.

8. How will the information collected be used?

The results of this study will be published through papers in scientific journals. Once published, the results will also likely be shared through media and disseminated by stakeholders including Asthma Australia.

All results will be published at an aggregate level, and you will not be able to be identified.

This study will not collect any identifying information or contact details. If you would like a copy of a summary of the results, please email XXXX [insert email address] after [insert approximate date of availability] or by visiting the results webpage [XXXX] after [date].

9. What do you need to do to participate?

Please read this Participant Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, please contact the researcher.

If you decide to participate in the workshop, please complete the consent form provided and return to Rose Bell (contact details below).

10. Further information

If you would like more information, please contact:
Rose Bell
Research and Evaluation Coordinator, Asthma Australia
Phone: 03 9086 7852
Email: rbell@asthma.org.au

11. Complaints about this research

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 2021/ETH11604.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, please contact the HNE Research Office, Hunter New England Local Health District, Level 3, POD, HMRI, Lot 1 Kookaburra Circuit, New Lambton Heights NSW 2305. Telephone: 02 4921 4140. Email: HNELHD-ResearchOffice@health.nsw.gov.au and quote the reference number: 2021/ETH11604.