



NATIONAL ASTHMA RESEARCH AGENDA

The top asthma research priorities according to people with asthma, carers, healthcare professionals and policy makers



Asthma Australia thanks all participants who contributed to the project.

CONTRIBUTING AUTHORS

- Michele Goldman
- Professor Peter Gibson
- Anthony Flynn
- Rose Bell
- Anne McKenzie AM
- Sundram Sivamalai
- Eleanor Majellano
- Lauren Vaughan

PROJECT AMBASSADORS



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EXECUTIVE SUMMARY

THE PROBLEM

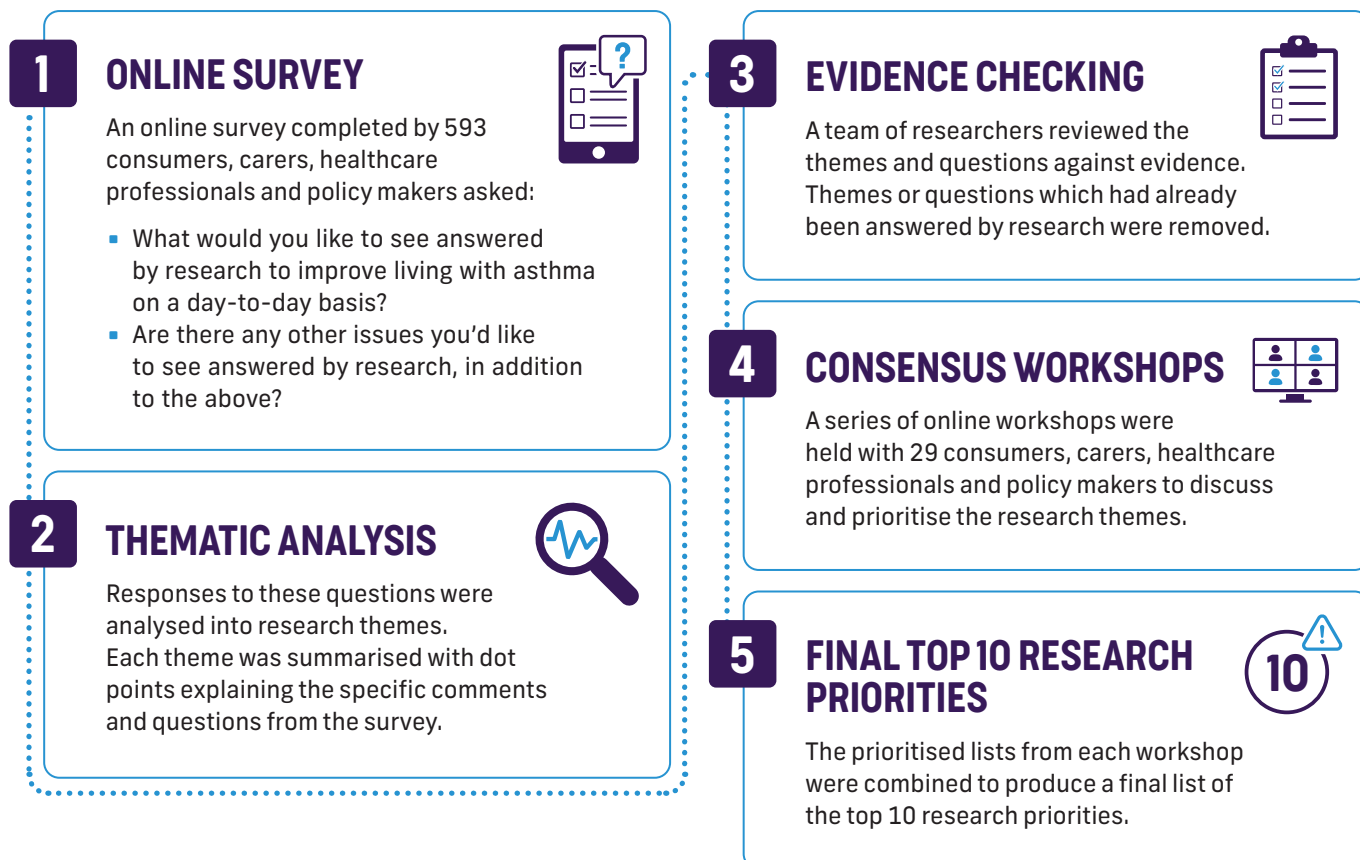
The 2018 National Asthma Strategy (NAS) highlighted the need for a National Asthma Research Agenda to help **“focus, coordinate and translate quality health research into policy and practice.”** The NAS identified research as a key enabler of progress in Australia but emphasised there is a lack of overarching strategic direction.

Asthma Australia aimed to establish a research agenda based on the needs of people with asthma, carers, healthcare professionals and policy makers. This aims to understand and support investment in the areas that are most important and valuable to the end users of asthma research.

We want to know what really matters to people who live with asthma, who care for someone with asthma, or who treat people with asthma.

THE METHODS AND PARTICIPANTS

We followed an adapted James Lind Alliance Priority Setting Partnership process. This included:



THE NATIONAL ASTHMA RESEARCH AGENDA: TOP 10 LIST

-  **Asthma in children**
-  **COVID-19 and asthma**
-  **Asthma care and self-management**
-  **Diagnosis and medication**
-  **Managing asthma attacks**
-  **Causes, prevention and features of asthma**
-  **Mental health**
-  **Asthma and ageing**
-  **Severe asthma**
-  **Asthma and other health conditions**

The final National Asthma Research Agenda describes the top 10 research priorities. Whilst the overarching themes may appear broad, this is a powerful and rich list with the potential to influence research investment and get more out of our collective efforts in asthma. Each theme captures a range of specific questions and narrative, gathered through the online survey.



WHAT NEXT AND HOW TO GET INVOLVED

We hope the National Asthma Research Agenda will influence research funding and policy decisions in Australia; support increased investment in and attention to priority issues identified by the end users of asthma research; and facilitate conversations about the necessary research investment to address these priorities.

We look forward to working with research organisations and funding bodies across Australia to realise the potential of this important work.

To hear more about the project, or discuss how you can use these priorities, please contact research@asthma.org.au

INTRODUCTION

BACKGROUND

Research at Asthma Australia

Asthma Australia has a long history in supporting and funding asthma research. We maintain the only dedicated asthma research funding program in Australia which aims “to invest in progressive approaches to make, translate and implement new discoveries that improve the lives of people with asthma”.

One of our driving principles of the National Asthma Research Program is to champion consumer centred research. That is to support and invest in research informed by, involving, and focused on priorities important to people with asthma.

Call for the development of a National Asthma Research Agenda

The 2018 National Asthma Strategy (NAS) outlined a comprehensive approach to improve asthma diagnosis and management in Australia.¹ It highlighted areas for action to bridge the gap between evidence and practice, and reduce the burden of asthma in Australia.

The NAS identified research as a key enabler of progress in asthma and one of Australia’s key strengths. However, it emphasised there is a lack of overarching strategic direction for asthma research in Australia, resulting in a fragmented approach. This can lead to research waste and devalue the research effort.² It also identified polarising views among Australian asthma researchers about research priorities.

“No single body is dedicated to promoting collaboration and ‘joining the dots’ in the asthma and broader airways disease community”.

National Asthma Strategy

The NAS called for the development of a national research agenda. This would be an internationally relevant and nationally coordinated agenda to *“focus, coordinate and translate quality health research into policy and practice.”*

Previous priority setting projects

A process to establish priorities for research areas has been successfully undertaken in other areas using the James Lind (JLA) Alliance Priority Setting Partnership process.

The JLA is a not-for-profit organisation in the United Kingdom. They have led the development of a Priority Setting Partnership Process which aims to *“bring patients, carers and clinicians together to identify and prioritise the unanswered questions or evidence uncertainties that they agree are most important for research to address”*.³ This process seeks to address the risk that vested interests inappropriately influence what gets researched, which may be in tension with what consumers and their service providers need and want.

The JLA priority setting partnership process has previously been used to prioritise research in more than 100 areas, including asthma in the UK in 2007.⁴

THE PROJECT

Asthma Australia, as the peak asthma organisation in Australia and owner of the only dedicated asthma research funding program in Australia, was well placed to take on this task and initiated the project in 2021.

We aimed to understand the research priorities of end-users of asthma research and translate this into a National Asthma Research Agenda to inform research funding and policy decisions in Australia.

We want to know what really matters to people who live with asthma, care for someone with asthma, or treat people with asthma.

With the development of this research agenda, we hope to:

- Provide the diverse research community with a point of reference against which to prioritise and progress asthma research, and identify opportunities to collaborate
- Influence government asthma research policy priorities
- Potentially improve the sharing, collaboration and translation of research projects and research outcomes for the benefit of people with asthma
- Emphasise research which addresses the priorities emerging from this project and has potential to translate into policy and practice. We recognise that this will/can involve multiple approaches and different disciplines,
- Support investment in critical research infrastructure (databases, registries, cohorts, networks)
- Attract world-class researchers to Australia
- Attract interest of donors to increase investment in asthma research



1. National Asthma Council Australia and Asthma Australia, National Asthma Strategy, 2018, Available from: <https://d8z57tiamduo7.cloudfront.net/resources/National-Asthma-Strategy-2018.pdf>
2. Chalmers I, Bracken MB, Djulbegovic B, Garattini S, Grant J, Gülmezoglu AM, et al, How to increase value and reduce waste when research priorities are set, Lancet, 2014;383(9912):156-65
3. The James Lind Alliance, The James Lind Alliance Guidebook Version 10 2021, Available from: <https://www.jla.nihr.ac.uk/jla-guidebook/downloads/JLA-Guidebook-Version-10-March-2021.pdf>
4. The James Lind Alliance, The Priority Setting Partnerships, Available from: <https://www.jla.nihr.ac.uk/priority-setting-partnerships/>

GOVERNANCE

The project was supported with the following governance and advisory structures:

1. Project executive
 2. Project reference group
 3. Project ambassador group
-

1. Project executive

The project executive team were responsible for the design and delivery of the project. They included:

- Project Sponsor: Michele Goldman, CEO Asthma Australia
- Project Lead: Professor Peter Gibson, co-director at the Centre for Research Excellence in Treatable Traits for Asthma, Hunter Medical Research Institute (HMRI)
- Project Manager: Anthony Flynn, Senior Manager, Research, Information and Evaluation, Asthma Australia
- Project Coordinator: Rose Bell, Coordinator, Research and Evaluation, Asthma Australia
- Project Advisor: Anne McKenzie AM, Consumer Consultant, Telethon Kids Institute and The University of Western Australia
- Consumer Advisor: Sundram Sivamalai, Ethnic Communities Council of Victoria
- Qualitative Researcher: Eleanor Majellano, University of Newcastle
- Marketing and Communications Lead: Lauren Vaughan, Asthma Australia

2. The project reference group

The reference group included health professionals from across Australia, who work with children and adults, and across asthma related disciplines. There was equal representation among the reference group of people with asthma or carers.

The role of the project reference group was to provide advice to the project executive on the questions for the qualitative survey, as well as the construction of the themes analysed for presentation to the consensus workshops. The reference group also assisted in distributing the survey and were invited to attend the consensus workshops.

3. The project ambassador group

The project ambassadors have joined the project to support the translation of the project into tangible outcomes. The project ambassador group comprises leaders of peak organisations who share an interest in translated research for real impact for people with asthma, and include:

- Asthma Australia Consumer Advisors
- Consumers Health Forum (CHF)
- Lung Foundation Australia (LFA)
- Australian College of Nursing (ACN)
- New Zealand Medical Research Institute (MRI NZ)
- Asthma Foundation New Zealand (AFNZ)
- Thoracic Society of Australia and New Zealand
- Centre of Excellence in Treatable Traits
- Australian College Rural and Remote Medicine (ACRRM)
- Asthma WA (AWA)
- Asthma Foundation Northern Territory (AFNT)
- Australian Council of Social Services (ACOSS)
- Australian Research Alliance for Children and Youth (ARACY)
- School of Public Health, University of Sydney, Menzies Centre for Health Policy
- Research Australia (RA)

METHODOLOGY AND PARTICIPANTS

The project plan, adapted from the JLA priority setting partnership process comprised 5 stages, which are explained below:



STAGE 1 ONLINE SURVEY

An online survey was sent to Asthma Australia's consumer and health professional databases, and via email invitations, newsletters and social media platforms sent out by peak professional societies and organisations.

The survey included demographic questions and free-text questions asking participants:

1. What would you like to see answered by research to improve living with asthma on a day-to-day basis?
2. Are there any other issues you'd like to see answered by research, in addition to the above?

After completing the survey, participants could register their interest to take part in the consensus workshops.

PARTICIPANTS

A total of 593 people completed the survey

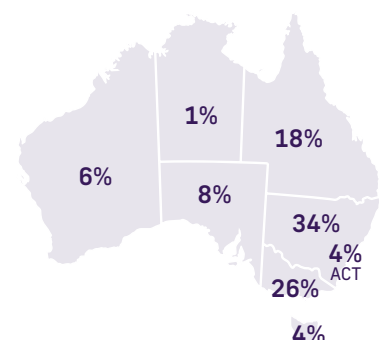
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RESPONSES

83% people with asthma
8% carers / personal connection
9% healthcare professionals / policy makers

23%  **77%** 

10% speak a language other than English at home

AGE	%
12-17	.16%
18-24	.33%
25-34	7%
35-44	21%
45-54	22%
55-64	21%
65-74	21%
75+	8%



STAGE 2

THEMATIC ANALYSIS

All free-text responses were thematically analysed by the qualitative researcher. The analysis was discussed and reviewed with the executive group. Each theme included indicative quotes and research questions, to explain the specific scope of the theme.

The thematic analysis approach is summarised below:

1st Round

Data familiarisation and generating initial codes for the 1,185 text comments

2nd Round

Searching for and reviewing themes

3rd Round

Defining and naming 24 themes

4th Round

Discussing themes with the executive committee, resulting in 20 themes

5th Round

Generating indicative questions for 20 themes

STAGE 3

EVIDENCE CHECKING

The 20 themes resulting from the thematic analysis were then checked against the available evidence. A group of research scientists from the Centre of Excellence in Treatable Traits searched the Cochrane Database of Systematic Reviews, the Cochrane Controlled Trials Register and clinical guidelines to assess the summary questions against published evidence. Where evidence was found, the content was analysed to determine the extent to which it addressed the summary question (i.e., totally, partially, or unanswered). Themes or questions were removed if found to be totally answered.

This resulted in 18 themes to be taken to the workshops for prioritisation. These 18 themes are listed below. For full details about the scope of the themes, please see Appendix A: Workshop pre-reading for participants.



Asthma in children



Diagnosis and medications



Managing asthma attacks



Severe asthma



Asthma self-management



Asthma care



COVID-19 and asthma



Asthma and pregnancy



Digital and mobile health



Asthma and other health conditions



Causes, prevention, and features of asthma



Asthma awareness and stigma



Mental health



Complementary treatments



Medication costs



Exercise and sleep



Asthma and ageing



Asthma triggers

STAGE 4

CONSENSUS WORKSHOPS

Three online consensus workshops were held between March and April 2022, with the aim to reach consensus on the top priorities for asthma research. Participants from Phase 1 who expressed their interest in participating in the workshop were contacted. Asthma Australia then reached out to its networks again, with a focus on achieving participant diversity in the workshops.

Prior to the workshops, all participants were given pre-reading materials which contained the themes and their illustrative quotes that emerged from Phase 1 (see appendix B: Workshop prereading documents).

The three workshops each focused on different participants groups. These were (1) health professional and consumers, (2) consumers from across regional/rural locations and from Culturally and Linguistically Diverse backgrounds, and (3) young people and parents of children with asthma.

The workshops were structured in two parts, see appendix C: Workshop agenda. Both sessions used small breakout room discussions and whole group discussions to ensure all participants had a chance to contribute. The two sessions included:

1. Theme discussion

Participants were given an opportunity to comment on the themes, in particular considering if any research areas were missing or groups of themes which could be collapsed.

2. Theme prioritisation

Participants were led through a consensus exercise to rank all themes in priority order, including any changes previously made to themes.

Across the workshop, participant voting was used to agree to changes. More than half of participants had to agree to a change for it to occur.

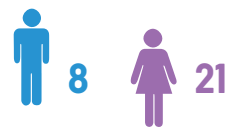
PARTICIPANTS

A total of 29 people participated in the workshop

29

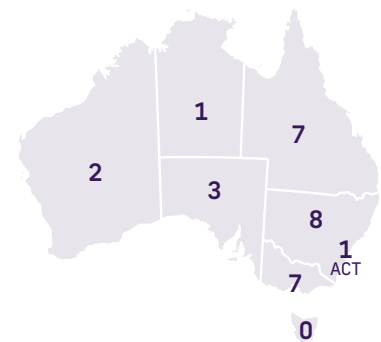
PARTICIPANTS

- 19 people with asthma
- 2 parents / carers of children with asthma
- 5 healthcare professionals
- 3 service providers / policy makers



8
from a regional
area of Australia

AGE	NO.
18-24	1
25-34	2
35-44	2
45-54	10
55-64	6
65-74	8



After the workshops, all participants were asked to complete an online feedback questionnaire. Of the 29 attendees, 16 completed the feedback survey. Most participants reported they felt satisfied with the workshop (75%) and that their priorities for asthma research were listened to (94%). For further details, see appendix D: Workshop Feedback.

STAGE 5

FINAL TOP 10 RESEARCH PRIORITIES

Each workshop produced a ranked list of the themes. These were combined using Microsoft Excel to provide an average rank for each theme.

The following decisions were made by the executive group to determine the final list:

- Any proposed new themes or collapsed themes were included in the final list if they were proposed in more than one workshop. New themes which only appeared in one workshop would be included in the final outcomes, but not receive a ranking.
- Where more than one theme was collapsed in a workshop into one larger theme, each individual theme was given an equal rank.
- Where more than one theme received an equal ranking in the combined scores, the theme which consistently appeared in the top 10 priorities across all three workshops (common theme) received a higher ranking.

The following table shows the complete ranked list. Themes highlighted in purple were consistently ranked in the top 10 across all three workshops, noting two of the seven common themes were collapsed in to one theme for the final list.

RANK	THEME
1	A. Asthma in children
2	C. COVID-19 and asthma
3	N/H. Asthma care and self-management
4	G. Diagnosis and medication
5	M. Managing asthma attacks
6	J. Causes, prevention and features of asthma
7	E. Mental health
8	L. Asthma and ageing
9	B. Severe asthma
10	D. Asthma and other health conditions
11	R. Asthma triggers
12	O. Digital and mobile health
13	I. Asthma and pregnancy
14	K. Complementary treatments
15	Q. Medication costs
16	P. Asthma Awareness and stigma
17	F. Exercise and sleep

New theme A

Health professional training, standards and quality of care

New theme B

Cost of disability aids (e.g. air filters)

OUTCOMES

THE NATIONAL ASTHMA RESEARCH AGENDA

The final National Asthma Research Agenda describes the top 10 research priorities, developed through a rigorous consensus process with end users of asthma research.

Whilst the overarching themes may appear broad, this is a powerful and rich list with the potential to influence research investment and get more out of our collective efforts in asthma. Each theme captures a range of specific questions and narrative, gathered through the online survey.

- 1**  **Asthma in children**
- 2**  **COVID-19 and asthma**
- 3**  **Asthma care and self-management**
- 4**  **Diagnosis and medication**
- 5**  **Managing asthma attacks**
- 6**  **Causes, prevention and features of asthma**
- 7**  **Mental health**
- 8**  **Asthma and ageing**
- 9**  **Severe asthma**
- 10**  **Asthma and other health conditions**



PRIORITY 1

ASTHMA IN CHILDREN

This theme relates to the prevention, treatment, impacts and causes of asthma in children and the factors that influence whether they 'outgrow' it. It also extends to the impacts and unmet support needs for carers of children with asthma.

What people said

- Understanding why some children with asthma stop having asthma symptoms or 'outgrow' their asthma.
- Understanding how the time before and after birth increases the rate of asthma in children. For example, a natural birth compared to a caesarean birth (surgery), or breastfeeding compared to bottle feeding.
- Understanding the impact of regular asthma symptoms on the growth, development, and wellbeing of children.
- New treatments for children with asthma
- Understanding the best treatment plan for children with asthma.
- Anxiety among parents/carers of children with asthma.
- Support and training programs for carers or school staff to manage asthma attacks.

What people asked

- What factors influence asthma recurrence in children, and what strategies allow for children to outgrow asthma?
- Does having a natural birth vs caesarean birth or breastfeeding vs bottle feeding reduce the incidence of asthma in children?
- How does frequent episodic asthma impact growth, development and well-being in children aged 2-5 years? What can be done to overcome any impacts?
- What is the best treatment plan for young children with asthma?
- What is effective in reducing family carers'/significant others' anxiety in caring for children with asthma
- What training is required to increase knowledge of parents/carers and staff (school and childcare) in managing acute asthma attacks?



PRIORITY 2

COVID-19 AND ASTHMA

This theme talks to the long- and short-term impacts of COVID-19 for people with asthma, if COVID-19 can cause asthma, and the effects of COVID-19 strategies (such as mask wearing), on people with asthma.

What people said

- The impact of asthma and COVID-19 on quality of life. For example, the impacts on wellbeing due to avoiding hospital because of fear of COVID-19.
- How mask wearing impacts people with asthma, especially during daily tasks such as shopping.
- Symptoms experienced by people with asthma who have COVID-19.
- Understanding if COVID-19 can cause asthma.
- Care and support for people with asthma who have to isolate due to COVID-19.

What people asked

- What are the short-term and long-term health impacts of COVID-19 in people with asthma?
- Why do people with asthma experience breathing difficulty while wearing a mask, and how can it be managed?
- What are the symptoms experienced by people with asthma who develop COVID-19 infection? Does COVID-19 trigger asthma symptoms?
- What are the overall needs of people with asthma during home isolation with COVID-19?
- Does a COVID-19 care support program improve quality of life with asthma who are isolating with COVID?



PRIORITY 3

ASTHMA CARE AND SELF-MANAGEMENT

This theme included issues around access to and delivery of health services, patient-clinician partnership, self-management strategies and patient empowerment.

What people said

- What stops and supports developing truly personalised home-based care plans.
- Improved education and communication tools (for patients and their families) about how to properly use asthma devices (inhalers and puffers).
- Ways to improve health literacy (understanding) in people with asthma. For example, how to use medication, and understanding asthma terms.
- Making sure everyone can access healthcare regardless of where they live.
- Better ways for doctors to collaborate with other health care professionals involved in asthma care.
- Ways to improve the relationship between people with asthma and health professionals.
- Most effective ways to improve knowledge of health professionals understanding of asthma.

What people asked

- What barriers to optimal asthma care exist in disadvantaged communities?
- What are the optimal ways for sharing information and collaboration between multidisciplinary clinicians involved in asthma management to ensure continuity of care?
- What can be done differently to ensure timely access to GPs and/or specialists for people with asthma living in metro and rural communities?
- In what ways can the patient-clinician partnership be improved?
- Does shared decision making improve clinical outcomes in people with asthma?
- What training and educational strategies are most effective in improving the knowledge of clinicians in understanding asthma variability in their care settings?
- What is the most feasible and acceptable approach of home-care plans for people with asthma?
- In what ways can home-administration of asthma medication (steroids, biological therapies) in adults, adolescents and paediatric populations be improved?
- How can we improve health literacy (understanding) in people with asthma?
- What strategies best allow people with asthma to communicate effectively to carers and clinicians?
- In what ways can people with asthma be better supported by carers to reduce asthma burden.



PRIORITY 4

DIAGNOSIS AND MEDICATION

This theme relates to new and improved diagnostic tools for asthma, as well as incorporating diagnosis of commonly co-existing conditions (such as allergies) as part of the standard assessment. This theme also highlights issues around medications including side-effects and more personalised medication options to suit different people with asthma.

What people said

- Diagnosing asthma earlier in children and adults.
- New ways to better diagnose and confirm asthma.
- Making allergy testing part of the standard process to assess and diagnose asthma.
- Understanding when to see a respiratory specialist for asthma diagnosis in children.
- Better and personalised medication options to suit different people and lifestyles.
- Clear information on medication side-effects and how to reduce medication side-effects (for example trembling).
- Ways to better manage the effects of long-term use of medications (for example steroids).
- Promoting effective patient-doctor relationships to reduce the chance of medications not working and maximise the benefit of prescribed treatments.

What people asked

- In what ways can asthma diagnosis be improved?
- What are the optimal ways to ensure allergy testing as part of the routine assessment and in asthma action plans?
- How can asthma diagnosis in children be improved?
- What is the best targeted and tailored treatment plan to optimise asthma management?
- What strategies are most effective for managing the short and long term impacts of asthma medications?
- In what ways can people with asthma impacted by long-term medication effects be better supported by clinicians?



PRIORITY 5

MANAGING ASTHMA ATTACKS

This theme talked about improving education and training to better recognise and respond during acute asthma attacks.

What people said

- Education and awareness on early warning signs that may lead to asthma attacks.
- Building confidence through education and training to better recognise and respond during asthma attacks (for example when to seek emergency medical services).

What people asked

- Does early symptoms recognition improve acute asthma management?
- Which knowledge and skills are needed for patients and family carers to achieve confidence in recognising and responding to acute asthma attacks?
- What are the problems and opportunities to better understand acute asthma attacks?
- What is the best emergency management for adult or children with asthma?
- What influences patient and family carers decision to call for emergency medical services?
- Which symptoms pose the highest risk in people with asthma calling for emergency medical services?



PRIORITY 6

CAUSES, PREVENTION AND FEATURES OF ASTHMA

This theme encompasses better understanding of the causes and prevention of asthma, including the role of genes and diet. It also extends to understanding the intergenerational impacts of asthma, development of severe asthma and prevention of irreversible lung damage.

What people said

- More understanding about what causes asthma and how to prevent it.
- More understanding about how asthma develops from mild/moderate asthma to severe asthma.
- More understanding about why people are more likely to have asthma if other people in their family have asthma. What role do genes play?
- Understanding the impacts on families and communities when many people in families/between generations have asthma.
- Understanding the role that diet or foods can play in preventing and improving asthma symptoms.
- Greater understanding of how to prevent irreversible lung damage.

What people asked

- What underlying causes influence the development of asthma? Why do some people get asthma and some don't? How can it be prevented?
- How can the causes of asthma be better explained?
- What is the relationship between asthma and family genetic factors? What gene is associated with asthma? Can genetic modification prevent asthma?
- What are the effects of generational asthma on families?
- Do lifestyle food choices impact asthma control?
- How can diet influence the onset and severity of asthma?
- What nutritional behaviour modifications improve asthma control?
- What factors are associated with irreversible lung damage in people with asthma? How can it be prevented?



PRIORITY 7

MENTAL HEALTH

This theme focuses on research to understand the relationship between asthma and psychological factors (anxiety and depression), how these impact self-management and wellbeing, and how to manage mental health conditions in people with asthma. The need for tailored psychological support following a life-threatening asthma attack was also identified.

What people said

- More understanding about the relationship between asthma and anxiety or depression. For example, how it triggers asthma.
- How to manage anxiety and depression in people with asthma.
- How anxiety and depression impact asthma self-management.
- Understanding if different types of asthma have a different impact on psychological well-being.
- Understanding the long-term mental health impacts for people who have multiple asthma attacks.
- Better and more personalised mental health support after a life-threatening asthma attack.

What people asked

- What is the relationship between asthma and anxiety and/or depression?
- How to better manage asthma and symptoms of anxiety and/or depression?
- What treatment options are available for people with asthma experiencing symptoms of anxiety and/or depression?
- What are the social and psychological impacts of asthma?
- What strategies are most effective in improving the well-being of people with asthma?
- How does mental health impact self-management?
- What is the long-term psychological impact of people surviving multiple severe life-threatening asthma attacks?
- What is the effective mental health management plan following acute asthma attacks?
- Does asthma impact on well-being vary in people with different types of asthma?



PRIORITY 8

ASTHMA AND AGEING

Central to this theme was the need for understanding what triggers the development of late onset asthma. Strategies to better manage asthma in older population, and how this differs to management in other population groups were also highlighted.

What people said

- Understanding what causes asthma to develop in older people and if it can be prevented.
- How to better manage asthma in older people.
- The differences in asthma management between older people and children.

What people asked

- What is the effect of late onset asthma on the elderly?
- What triggers the development of late onset asthma in older people? Can this be prevented?
- What are the best management strategies used by older people with asthma?
- How does asthma management differ between population groups (childhood vs elderly)?
- What are the optimal ways to better manage exercise-induced asthma?



PRIORITY 9

SEVERE ASTHMA

This theme encompasses better understanding of the features, causes and impacts of severe asthma, as well as the relationship between severe asthma and anxiety/depression.

What people said

- Understanding how severe asthma can change throughout life. For example, from children to adults.
- Impact of severe asthma on brain function and memory.
- Coping with anxiety and depression in severe asthma.
- Understanding what causes severe asthma and whether it can be predicted.

What people asked

- How does severe asthma change throughout life, especially from childhood to adulthood?
- How do people with severe asthma cope with psychological symptoms (anxiety and/or depression)?
- How does severe asthma impact brain function (memory)?
- How does severe asthma develop? Can this be predicted?



PRIORITY 10

ASTHMA AND OTHER HEALTH CONDITIONS

Central to this theme was how to best manage asthma with multiple comorbidities, with a particular focus on vocal cord dysfunction.

What people said

- Effective ways to manage asthma and other health conditions.
- Challenges managing asthma due to other health conditions. For example, not being able to use an asthma puffer because of arthritis in hands.
- Understanding vocal cord dysfunction and how to manage it with asthma. [Vocal cord dysfunction is a condition where your vocal cords close when they are supposed to be open. This can cause asthma-like symptoms and is often misdiagnosed as asthma.]
- How to better access management plans for vocal cord dysfunction and asthma.

What people asked

- What are effective ways people with asthma can manage multiple co-existing conditions?
- In what ways do restrictions caused by co-existing conditions impact asthma control? (ex: Arthritis)
- What are the optimal ways to manage asthma and vocal cord dysfunction?

CONCLUSION AND NEXT STEPS

Asthma Australia successfully adapted the JLA approach to determine the top 10 research priorities. This has been a rigorous process with a consistent focus on the needs of end-users of asthma research throughout. We have engaged with almost 600 end-users across the project to deeply understand their priorities. We found that of the final top 10 themes, seven themes were consistently ranked in the top 10 across all consensus workshops, strengthening the validity of the final top list (noting two of these common themes were collapsed in to one theme for the final list).

Consumers have articulated a very extensive, detailed, and wide-reaching research agenda. This list also highlights that despite the advances in treatment options and approaches to the assessment of asthma, the impact of asthma on the people with the disease remains significant.

This approach has been a successful way to understand and establish the research priorities most important to end-users of asthma research.

Asthma Australia looks forward to sharing the outcomes of National Asthma Research Agenda widely with policy makers, government, research institutes and other relevant peak bodies investing in research to:

- Influence research funding and policy decisions in Australia,
- Support increased investment in and attention to priority issues identified by the end users of asthma research, and
- Facilitate conversations about the necessary research investment to address these priorities.

To hear more about the project, or discuss how you can use these priorities, please contact research@asthma.org.au

APPENDIX

APPENDIX A

SURVEY QUESTIONNAIRE

Page 1

1. Please select one option below which best describes you.

- a. I have been told I have asthma by a doctor
- b. I care for someone who has been told they have asthma by a doctor
- c. I have a personal connection to someone who has asthma
- d. I care for people with asthma in my profession
- e. I manage asthma services/develop asthma policy

2. Asked if answered (b) to question 1.

What is the age of the person you care for? If you care for more than one person with asthma, please answer this question thinking about the youngest person.

- 1-5
- 5-12
- 12-17
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75+

Page 2

We would like you to take a few minutes to think about the important areas for future asthma research. This can be about prevention, diagnosis, treatment and day-to-day concerns as a person living with or caring for someone with asthma. If you care for people with asthma in your profession or are involved in asthma services/policy, we would also value your perspective.

3. What would you like to see answered by research to improve living with asthma on a day-to-day basis?

This might include limitations (e.g. not being able to exercise regularly), restrictions (e.g. activities asthma stops people from doing), and impact of asthma (e.g. how asthma affects life in general).

4. Are there any other issues you would like to see answered by research?

These might be more details about the issues you raised in question 3 or new issues.

5. Asthma Australia is committed to reducing the burden of asthma caused by hospitalisation. Every year in Australia, almost 40,000 people go to hospital due to an asthma attack. Many of these hospitalisations are avoidable.

What would you like to see answered by research to prevent you from needing to go to the hospital for your asthma/the person you care for needing to go to hospital for their asthma/people with asthma needing to go to the hospital?

We just have a few final questions for you to help us analyse the survey.

6. What is your gender?

- Male
- Female
- Non-binary
- I use a different term/other
- Prefer not to answer

7. What is your age?

- 12-17
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75+

8. What state or territory do you mostly live in?

- Australian Capital Territory
- New South Wales
- Northern Territory
- Queensland
- South Australia
- Tasmania
- Victoria
- Western Australia

9. What is your postcode?

[Open text response]

10. Do you speak a language other than English at home?

- No
- Yes, please specify what language____

11. What cultural background or ethnicity do you identify with?

[Open text response]

12. Are you of Aboriginal or Torres Strait Islander origin?

- No
- Yes, Aboriginal
- Yes, Torres Strait Islander
- Yes, Aboriginal and Torres Strait Islander

APPENDIX B

WORKSHOP PRE-READING DOCUMENTS

Please spend some time before the workshop reading and thinking about the themes and questions listed below, they have come from a survey of people interested or concerned with asthma. We will be discussing these at the workshop, please make notes about any of the themes, especially if something isn't clear.

ID THEMES

A Asthma in children

- Understanding why some children with asthma stop having asthma symptoms or 'outgrow' their asthma.
- Understanding how the time before and after birth increases the rate of asthma in children. For example, a natural birth compared to a caesarean birth (surgery), or breastfeeding compared to bottle feeding.
- Understanding the impact of regular asthma symptoms on the growth, development, and wellbeing of children.
- New treatments for children with asthma.
- Understanding the best treatment plan for children with asthma.
- Anxiety among parents/carers of children with asthma.
- Support and training programs for carers or school staff to manage asthma attacks.

B Severe asthma

- Understanding how severe asthma can change throughout life. For example, from children to adults.
- Impact of severe asthma on brain function and memory.
- Coping with anxiety and depression in severe asthma.
- Understanding what causes severe asthma and whether it can be predicted.

C COVID-19 and asthma

- The impact of asthma and COVID-19 on quality of life. For example, the impacts on wellbeing due to avoiding hospital because of fear of COVID-19.
- How mask wearing impacts people with asthma, especially during daily tasks such as shopping.
- Symptoms experienced by people with asthma who have COVID-19.
- Understanding if COVID-19 can cause asthma.
- Care and support for people with asthma who have to isolate due to COVID-19.

D Asthma and other health conditions

- Effective ways to manage asthma and other health conditions.
- Challenges managing asthma due to other health conditions. For example, not being able to use an asthma puffer because of arthritis in hands.
- Understanding vocal cord dysfunction and how to manage it with asthma. [Vocal cord dysfunction is a condition where your vocal cords close when they are supposed to be open. This can cause asthma-like symptoms and is often misdiagnosed as asthma.]
- How to better access management plans for vocal cord dysfunction and asthma.

E Mental health

- More understanding about the relationship between asthma and anxiety or depression. For example, how it triggers asthma.
- How to manage anxiety and depression in people with asthma.
- How anxiety and depression impact asthma self-management.
- Understanding if different types of asthma have a different impact on well-being.
- Understanding the long-term mental health impacts for people who have multiple asthma attacks.
- Better and more personalised mental health support after a life-threatening asthma attack.

F Exercise and sleep

- Wanting to be active and engaged in exercise without fear of an asthma attack later.
- Personalised exercises to reduce or manage asthma symptoms for people with severe or uncontrolled asthma.
- Best exercises to stay fit and healthy despite being restricted by severe or uncontrolled asthma.
- Understanding how asthma affects sleep and how to better treat or manage it.
- Ways of getting better sleep without having asthma attacks.
- How to manage exercise induced asthma.

G Diagnosis and medications

- Diagnosing asthma earlier in children and adults.
- New ways to better diagnose and confirm asthma.
- Making allergy testing part of the standard process to assess and diagnose asthma.
- Understanding when to see a respiratory specialist for asthma diagnosis in children.
- Better and personalised medication options to suit different people and lifestyles.
- Clear information on medication side-effects and how to reduce medication side-effects (for example trembling).
- Ways to better manage the effects of long-term use of medications (for example steroids).
- Promoting effective patient-doctor relationships to reduce the chance of medications not working.

H Asthma self-management**(Home-care management plan and patient education/empowerment)**

- What stops and supports developing truly personalised home based care plans.
- Improved education tools about how to properly use asthma devices (inhalers and puffers).
- Ways to improve health literacy in people with asthma. For example, how to use medication, and understanding asthma terms.
- Education and communication tools to educate family members about the importance of maintaining good asthma control.
- Support groups for people with asthma and their family/carers.

I Asthma and pregnancy

- Diet and lifestyle changes during pregnancy that lower the risk of asthma in the child.
- Ways of preventing childhood asthma during pregnancy (for example the impact of hormonal changes during pregnancy).
- Understanding how asthma develops during pregnancy (for the mother).

J Causes, prevention and features of asthma

- More understanding about what causes asthma and how to prevent it.
- More understanding about how asthma develops from mild/moderate asthma to severe asthma.
- More understanding about why people are more likely to have asthma if other people in their family have asthma. What role do genes play?
- Understanding the impacts on families and communities when many people in families/ between generations have asthma.
- Understanding what diet or food can prevent asthma.
- Greater understanding of how to prevent irreversible lung damage.

**K Complementary treatments
(Naturopathy, diet, breathing exercise)**

- Better education for people with asthma on non-medication treatment options.
- Understanding the role of natural medicines in asthma management.
- Understanding if breathing exercises at home or with a physiotherapist improve lung health.
- Understanding what diet or food can improve asthma symptoms.

L Asthma and ageing

- Understanding what causes asthma to develop in older people and if it can be prevented.
- How to better manage asthma in older people.
- The differences in asthma management between older people and children.

M Managing asthma attacks

- Education and awareness on early warning signs that may lead to asthma attacks.
- Building confidence through education and training to better recognise and respond during asthma attacks (for example when to seek emergency medical services).

**N Asthma care
(Delivery, access and partnership)**

- Making sure everyone can access healthcare regardless of where they live.
- Making sure the most important asthma care is available for people at greatest risk of poor outcomes.
- Better understanding of the challenges people in disadvantaged communities face accessing asthma care.
- Better ways for doctors to collaborate with other health care professionals involved in asthma care.
- Ways to improve the relationship between people with asthma and health professionals.
- Most effective ways to improve knowledge of health professionals understanding of asthma.

O Digital and mobile health

- Using telehealth to ensure access to good quality healthcare.
- Telehealth refers to appointments with health professionals over the phone or video.
- Effectiveness of telehealth to manage asthma symptoms compared to face-to-face.
- Smart phone apps which help people better manage their asthma. For example, apps which give early warning on triggers or predict symptoms.
- Using technology to prompt people with asthma to take action. For example, taking medications or protect themselves from weather conditions.

P Asthma awareness and stigma
(Social awareness and work places)

- Reducing the stigma of asthma.
 - Better community understanding of asthma.
 - More recognition from health professionals and community about the impact of asthma on people's lives.
 - Acknowledgement of the impact of asthma on workers quality of life.
 - Lack of understanding from employers/workforce about asthma.
 - Ways for people with asthma to be better supported at work.
-

Q Medication costs

- Reducing the medication cost for those who will most likely have lifetime use of daily medication.
 - Providing affordable/subsidised medications to vulnerable populations. For example to those with multiple members in the family, low income, students or children.
-

R Asthma triggers

(In particular climate change, food irritants, viral infections, stress-induced and chemical / perfume)

- Understanding the long-term impacts of air pollution (bushfires, wood fire heaters).
 - Ways to manage asthma in high-risk situations (e.g., bushfire smoke).
 - Improving awareness of different asthma triggers.
 - Better ways to manage different asthma triggers.
 - How to prepare for changing seasons and their impact on asthma.
 - Understanding the dangers of climate change for people with asthma. For example, is climate change directly affecting people with asthma.
-

APPENDIX C**WORKSHOP AGENDA**

Please spend some time before the workshop reading and thinking about the themes and questions listed below, they have come from a survey of people interested or concerned with asthma. We will be discussing these at the workshop, please make notes about any of the themes, especially if something isn't clear.

TIME		TOPIC	BY
4.00pm	20 mins	Opening <ul style="list-style-type: none"> ▪ Welcome, Acknowledgment of Country, introductions of facilitators and co-hosts ▪ About the Priority Setting Project ▪ The workshop processes ▪ Any questions 	Peter Gibson Anthony Flynn Anne McKenzie
4.20pm	40 mins	Small group discussion #1: Review and discussion of themes <ul style="list-style-type: none"> ▪ Introductions ▪ General discussion about importance of themes ▪ Consider the following: <ul style="list-style-type: none"> – Are there other important themes missing? – Are there themes that can be combined? – Is the wording easy to understand? 	Small groups
5.00pm	5 mins	Break	
5.05pm	30 mins	Whole group discussion #1: Feedback from small groups <ul style="list-style-type: none"> ▪ Group facilitators to report: <ul style="list-style-type: none"> – General impressions of themes (positive & negative) – Suggestions for additional or collapsed theme(s) – Wording changes 	Whole group
5.35pm	5 mins	Break	
5.40pm	35 mins	Small group discussion #2: Priority setting <ul style="list-style-type: none"> ▪ Ranking the themes 	Small groups
6.15pm	10 mins	Break	
6.25pm	30 mins	Whole group discussion #2: The final 'Top 10' list <ul style="list-style-type: none"> ▪ Reaching consensus on the final 'Top 10' themes 	Whole group
6.55pm	5 mins	Next steps and thanks	Anthony Flynn
7.00pm		Close	

APPENDIX D

WORKSHOP FEEDBACK

After the workshops, all participants were asked to complete an online feedback questionnaire to check the quality of the process. Of the 29 attendees, 16 completed the feedback survey. Most participants reported they felt satisfied with the workshop (75%) and that their priorities for asthma research were listened to (94%).

In open text feedback, participants reported they felt positively about having their voice listened to, meeting other people with asthma, and the structure, organisation, and facilitation of the workshop. Some participants fed back they would have liked to interact with more or different people in the small groups, and that the process and importance of pre-reading could have been reinforced more.

Figure 1: Overall satisfaction with the workshop

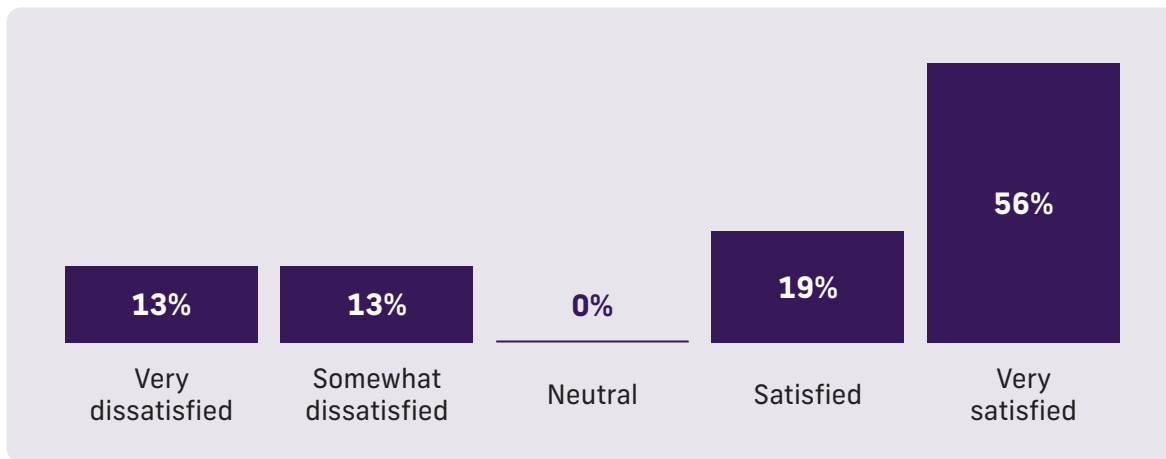


Figure 2: Agreement with statements about the workshop, % (n)

Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
The prereading information was useful	0%	0%	6% (1)	31% (5)	63% (10)
My priorities for asthma research were listened to	0%	0%	6% (1)	50% (8)	44% (7)
I could follow what was happening during the workshop	0%	6% (1)	0%	38% (6)	56% (9)
I was able to interact with the facilitators	0%	0%	6% (1)	25% (4)	69% (11)
I was able to interact with other participants	0%	0%	13% (2)	44% (7)	44% (7)
The length of the workshop was appropriate	0%	0%	6% (1)	44% (7)	50% (8)
There were enough breaks	0%	0%	6% (1)	38% (6)	56% (9)
I had no problems connecting and participating via Zoom	0%	0%	6% (1)	19% (3)	75% (12)



**ASTHMA
AUSTRALIA**

HEAD OFFICE

Level 13, Tower B
799 Pacific Highway
Chatswood, NSW 2067

P: 02 9906 3233

F: 02 9906 4493

ABN: 91 609 156 630

research@asthma.org.au

1800 ASTHMA
(1800 278 462)

asthma.org.au