Asthma Australia

Strategic Research Framework

March 2016
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Foreword

I am delighted, on behalf of the Asthma Australia Research Trust, to present this Strategic Research Framework. This document provides a vision that will guide and inform Asthma Australia’s future research activity and investment between 2016 and 2020.

Asthma is not a problem that has been ‘solved’. More than 10% of Australians have asthma (1). The recent The Hidden Cost of Asthma report commissioned by Asthma Australia and the National Asthma Council estimated asthma costs Australia $27.9bn a year. (2)

People with asthma still commonly underestimate the severity of their condition. Adherence with best practice guidelines for treatment and management of asthma remains variable. In 2012–13, there were more than 37,000 hospitalisations due to asthma. (3)

Asthma Australia will continue to be a catalyst for high-quality research that makes a difference in the lives of people with Asthma. This Framework will guide Asthma Australia’s support for research into the future, to ensure continued research investment and innovation and improved outcomes for people affected by asthma.

Professor Judith Black AO
Chair, Asthma Australia Research Council
Overview

Asthma Australia’s Research Program

Asthma Australia is the national peak consumer asthma organisation. Research has been a priority for the Asthma Foundations since they were established in 1961, and since that time the Foundations have provided millions of dollars in research grants. This investment has supported world-class asthma research and helped to establish Australia as a leader in asthma research.

Asthma Australia’s Research Program has functioned well. The total funding available through the Asthma Australia Research Program is currently approximately $500,000 per annum. Research grants in recent years have been funded for one or two years and grants have ranged in value between $75,000 and $150,000 per annum. A range of scholarships, fellowships and travel grants are also funded through the Research Program.

This Framework will guide Asthma Australia’s Research Program from 2016 until 2020 to improve the lives of people affected by asthma.

Asthma Australia’s role

Asthma Australia:

- works collaboratively to improve quality of life for people affected by asthma
- seeks to increase asthma knowledge and awareness, and to improve self-management practices
- is a voice for people affected by asthma
- gives priority to meeting the needs of people and communities that are hard to reach, isolated or disadvantaged
- engages with the Commonwealth, state and territory governments, industry and other organisations to ensure that asthma remains a priority.

Research has been a key activity of the Asthma Foundations since their inception. Asthma Australia has already set the goal of providing $1.5 million per annum to support basic science and population health research by 2018 (4).
Vision

Improving the lives of people affected by asthma by funding and supporting research into prevention, treatment and cure.

Priorities

- Improving quality of life
- Innovation
- Targeted treatment

Activities

- Project grants
- Fellowships and scholarships
- Innovation grants
- Collaboration & Advocacy

Success

- Enhanced research impact
- Enhanced research investment
- Improved management of asthma
Why this Framework matters

More than 2.5 million Australians are affected by asthma (1). The only long-term health conditions that affect more people are mental illness, hypertension and arthritis (1).

Research has played, and will continue to play, a critical role in:

- developing better treatments, including cure, and better models of care
- making more effective use of existing treatments
- reducing asthma’s overall burden of disease, chronicity and impact across the life course
- preventing asthma (5).
Introduction

About

In July 2015, Asthma Australia began the development of a Strategic Research Framework (the Framework) to guide its future priorities and strategic investment in research.

The development of the Framework has been informed by:

- a national survey of asthma researchers and research stakeholder organisations
- consultation interviews with asthma researchers
- a national forum of research stakeholders
- a review of research activities that Asthma Australia has funded over the past three years
- a background paper
- a national online consultation on the draft Framework.

Through consultation with key stakeholders, Asthma Australia aimed to have a better understanding of:

- asthma research priorities
- Asthma Australia’s role in supporting and advancing asthma research
- the impact and value of Asthma Australia-funded research.

The resulting Framework is a significant step towards a strategic approach to funding and supporting research that will prevent, treat and cure asthma. It emphasises the importance of leveraging Asthma Australia’s involvement to ensure continued asthma research and innovation, and better outcomes for people affected by asthma.

This Framework recognises Asthma Australia’s unique role:

- as the national peak consumer asthma organisation
- in increasing asthma knowledge and awareness
- through nation-wide contact with people affected by asthma
- in fostering and supporting research and collaboration
- in advocating on behalf of people affected by asthma.
Navigating the Framework

**Background**
A snapshot of asthma in Australia and Asthma Australia’s investment in research

**Vision**
The vision that will guide Asthma Australia’s Research Program between 2016 and 2020

**Principles**
The principles that will guide Asthma Australia’s Research Program between 2016 and 2020

**Research Program**
An overview of the activities within Asthma Australia’s Research Program between 2016 and 2020

**Program governance**
An overview of the different bodies involved in Asthma Australia’s research governance and their roles in contributing to the Research Program

**Research collaborators**
A description of Asthma Australia’s key research collaborators and partners

**Measures of success**
An overview of how Asthma Australia will determine its success in achieving the goals of its research program
Background

The impact of asthma in Australia

Asthma affects more than 1 in 10 Australians (1; 5), causing significant illness, disability and poor quality of life (6).

Because it is common and affects Australians of all ages, asthma accounts for a significant portion of the burden of disease. Asthma is the seventh leading contributor to the non-fatal burden of disease in Australia and New Zealand, and is the highest contributor among children aged between 5 and 14 (7). People who have asthma from early childhood can experience an asthma-related disability for much of their life.

People with asthma have higher levels of anxiety and depression than people without asthma (8). One in three people with asthma says it interferes with their daily living (9). It is one of the most common conditions requiring people to take time off work, school or study (9).

Asthma is often accompanied by comorbid medical conditions. More than 50% of people with asthma aged 44 years or over have another chronic disease and nearly 30% had two or more other chronic diseases (10). Deaths associated with asthma are often associated with comorbidities such as heart, stroke and vascular disease, acute respiratory infection, chronic respiratory conditions, and chronic obstructive pulmonary disease. Many comorbid conditions are also triggers for asthma, including allergic rhinitis and gastro-oesophageal reflux disease (2).

Prevalence

- 2.5 million Australians are affected by asthma (1).
- The prevalence of asthma has increased from 9.9% of the population in 2007-08 to 10.8% in 2014-15 (1).
- Asthma affects people of all ages. In children it is more common in males, but among people aged 15 and over it is more common in females (7).
- Asthma is twice as common in Aboriginal and Torres Strait Islander people. The prevalence of asthma is also higher among people living in socioeconomically disadvantaged areas (7).

Mortality

- Asthma caused 389 deaths in Australia in 2013 (11). While this number is low, Australia’s asthma death rate is high by international standards. The rate is particularly low for young people aged between 5 and 34 (5).
- Asthma-related deaths in Australia peaked in the 1980s. The number of deaths then declined by almost 70% in the period to 2003, and has been stable since. The current rate is less than 2 deaths per 100,000 people (12).
- Asthma mortality is higher for:
• people aged 65 and older
• Aboriginal and Torres Strait Islander Australians
• people living in more remote areas
• people living in lower socioeconomic status areas (12; 13)

• Mortality is also higher for women, who account for 64% of all asthma deaths (7).

**Figure 1. Deaths from asthma per 100,000 population**

![Deaths from asthma per 100,000 population](image)

*Source: AIHW (7)*

Most deaths due to asthma occur in people aged 65 and older. These people often have one or more other chronic conditions (co-morbidities) such as heart disease, stroke, chronic respiratory conditions, hypertension or diabetes. The Australian Health Survey 2011-12 found more than 50% of people aged 44 years or over with asthma have another chronic disease. Nearly 30% had two or more other chronic diseases (10). Comorbidity also complicates diagnosis of asthma in older people (14). This comorbidity is likely to compromise their quality of life and complicate the management of their asthma.

**The costs of asthma**

• Recent estimates put the total annual cost of asthma at $27.9 billion (2). This estimate includes more than $3 billion in annual direct healthcare costs, medication and lost productivity.

• The burden of disease was estimated to cost $24.7 billion each year, which includes disability, suffering and premature deaths.

• Much of this cost could be prevented by better symptom control and better use of existing treatments (15).
Asthma policy in Australia

A priority area

Asthma has been a National Health Priority Area since 1999 due to its impact on individuals and the community, and the effective interventions that can reduce the burden of disease.

Australia has been well-positioned to be an international leader in asthma policy development and implementation because of:

- longstanding government commitment and funding
- a history of collaborative efforts between asthma, respiratory and lung health organisations
- world-leading asthma research
- the commitment of health professionals to improving asthma outcomes.

The context of chronic conditions

The overarching national policy direction for asthma control in Australia will be detailed in the National Strategic Framework for Chronic Conditions, which is being finalised.

A chronic conditions approach recognises that asthma often coexists with other chronic conditions. These have shared health determinants and risk factors, and actions that may improve outcomes for asthma can also have a positive impact on a broad range of conditions.

National Asthma Strategy

Australia has had National Asthma Strategies since 1999, with the previous formal Strategy for the years 2006-2008. The National Asthma Strategy 2016-2020 has been developed by the National Asthma Council Australia in partnership with Asthma Australia, with funding from the Australian Government Department of Health.

The National Asthma Strategy provides a national framework to optimise asthma diagnosis and management, with a focus on vulnerable groups and frequent users of health services. The Strategy aligns with other national strategies that address relevant health conditions, risk factors and population groups, including the National Allergy Strategy, the National Tobacco Strategy 2012–2018 and the National Aboriginal and Torres Strait Islander Health Plan 2013–2023.

The healthcare system and workforce reforms that are underway will influence the implementation of the National Asthma Strategy. These include the Healthier Medicare initiative, the review of the Pharmaceutical Benefits Scheme, and the National Medical Training Advisory Network (health workforce) review.

Asthma Australia’s Strategic Research Framework has been developed in this context. It aligns with the National Asthma Strategy, which includes support for research as an integral component.
Asthma Australia’s investment in asthma research

Funding context

In Australia, asthma research is primarily funded by:

- the Australian Government, through research grants awarded through the National Health and Medical Research Council
- pharmaceutical companies
- philanthropic and non-government agencies, including individual donors and trusts.

For over 50 years Asthma Australia and its member Asthma Foundations have provided funding for asthma research. This has involved working with researchers, consumers and health professionals to increase knowledge, and to translate knowledge into practice.

Since their establishment in 1961, state and territory Asthma Foundations have provided millions of dollars in research grants. Asthma Australia’s investment in vital basic science and population health research has supported world-class asthma research in Australia, contributing to national and global advances in the understanding of asthma and asthma management.

In 2012 the Asthma Foundations combined their resources and established a national Asthma Australia Research Program to research improvements in care for people affected by asthma and to identify better ways to treat asthma. This has involved pooling funds and consolidating activities.

The Asthma Australia Research Program has three funding streams:

<table>
<thead>
<tr>
<th>Project grants</th>
<th>Fellowships and scholarships</th>
<th>Innovation grants</th>
</tr>
</thead>
<tbody>
<tr>
<td>To fund specific research projects</td>
<td>To build the capacity of asthma researchers by funding students, career fellowships and travel grants.</td>
<td>Priority-driven and strategic funding for research and development activities</td>
</tr>
</tbody>
</table>

The total funding available through the Research Program is currently approximately $500,000 per year. In recent years, research grants have been funded for one or two years and ranged in value between $75,000 and $150,000 per annum. A range of scholarships, fellowships and travel grants have also been funded.
Vision

Improving the lives of people affected by asthma by funding and supporting research into prevention, treatment and cure.

Asthma Australia’s research activities will, where possible, focus on **meeting the needs of population groups who experience higher rates of asthma and worse outcomes**, including:

**People experiencing the impact of asthma**

- people with severe and poorly controlled asthma
- people with comorbid conditions
- people experiencing mental health impacts as a result of asthma

**Priority population groups**

- Aboriginal and Torres Strait Islander people
- culturally and linguistically diverse groups
- low socioeconomic status groups
- regional and rural communities

**Across the life course**

- children and young people
- adolescents
- older people.

Asthma Australia will work in partnership and leverage research opportunities. Research funding will be a catalyst for improving asthma outcomes for people and to reduce the burden of disease of asthma.
## Principles

Asthma Australia’s research activities will be informed by five principles. These principles will determine the focus and prioritisation of research funding.

<table>
<thead>
<tr>
<th>1. Researching innovative models of asthma care and treatment.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Informing clinical practice, education and policy.</td>
</tr>
<tr>
<td>3. Involving people affected by asthma in research.</td>
</tr>
<tr>
<td>4. Contributing to national and international understandings of asthma through collaboration.</td>
</tr>
<tr>
<td>5. Monitoring, evaluating and enhancing the impact, capacity and resourcing of asthma research.</td>
</tr>
</tbody>
</table>
Research Program

Research priorities

Asthma Australia will fund research in the following priority areas.

<table>
<thead>
<tr>
<th>Improving quality of life</th>
<th>Innovation</th>
<th>Targeted treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research to improve the quality of life of people living with asthma.</td>
<td>Research that will lead to innovations in treating, managing or curing asthma.</td>
<td>Research that will lead to the development and use the right treatments for the right people at the right time.</td>
</tr>
</tbody>
</table>

Funding streams

Asthma Australia will allocate funds through the following mechanisms.

<table>
<thead>
<tr>
<th>Project Grants</th>
<th>Fellowships and scholarships</th>
<th>Innovation grants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding for research projects, with a focus on seed grants that will enable future opportunities.</td>
<td>Funding for researchers with a focus on early career and mid-career researchers</td>
<td>Funding for research projects, with a focus on new, robust and promising models of care and treatments.</td>
</tr>
</tbody>
</table>
Collaboration priorities

Asthma Australia plays a unique role as the national peak consumer asthma organisation. It has strong links with people affected by asthma, health professionals, researchers, government, other respiratory organisations in every state and territory. It will work in partnership with these groups to support asthma research at a national level.

In addition to funding research, Asthma Australia will collaborate and advocate to support research and the translation of research evidence in the following priority areas.

- Asthma research coordination and leadership.
- Research on interventions to promote best practices in asthma treatment and management.
- Research on interventions to support people with asthma to self-manage.
- Research on collaboration between primary health care and other health care providers.
- Promoting the development and use of targeted interventions to deliver new medications and treatments at the right time, to the right people.
- Research on interventions to increase awareness and understanding of asthma in the community.

Asthma Australia will achieve this through:

- promoting consumer engagement and involvement in research
- aligning the Research Program with Asthma Australia’s Corporate Donors Strategy
- targeted collaboration and partnerships with research and lung health stakeholder organisations
- supporting and catalysing research collaborations, including convening biannual research symposia.
Promoting consumer involvement in research

Asthma Australia will promote consumer involvement in its Research Program to ensure:

- research involves people affected by asthma to improve their outcomes and experiences
- consumers inform and make a difference in asthma research
- asthma care and services meet consumer needs, are high quality and reflect the best available evidence.

Clarity about consumers’ roles is important to ensure effective and meaningful consumer involvement (16), as outlined in Figure 2. The involvement if consumers will vary depending on the research, collaboration or advocacy activities being undertaken.

**Figure 2. Consumers’ roles in Asthma Australia’s Research Program**

<table>
<thead>
<tr>
<th>Partner</th>
<th>Valued for significant knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expert</td>
<td>Being recognised for expertise</td>
</tr>
<tr>
<td>Advisor</td>
<td>Giving experiential advice to influence decisions</td>
</tr>
<tr>
<td>Advocate</td>
<td>Representing the broad views and experiences of people affected by asthma</td>
</tr>
<tr>
<td>Personal engagement</td>
<td>Providing a personal perspective though story-telling, surveys, focus groups and discussions</td>
</tr>
</tbody>
</table>

Adapted from: *National Framework for Consumer Involvement in Cancer Control* (17)
Research governance

Asthma Australia will continue to build and draw upon Australia’s strength in asthma research to guide and develop its Research Program. Figure 2 outlines the different bodies involved in Asthma Australia’s research governance and their roles in contributing to the Research Program.

Figure 3. Asthma Australia’s research governance

Asthma Australia Board
- Overall governance and oversight
- Alignment of the Research Program to Asthma Australia’s Strategic Plan
- Attract research investment
- Research collaboration and advocacy
- Set Asthma Australia’s priorities

Research Council
- Led by researchers with consumer involvement
- Assess research needs
- Assess high quality research
- Assess and monitor research impact
- Set research priorities

Technical and expert research working groups
- Groups made up of researchers
- Review funding proposals
- Provide technical research expertise and advice
- Support the development of asthma research capacity
- Foster international links

Future research priorities working group
- Made up of researchers, consumers and asthma stakeholders
- Identify collaboration and advocacy needs
- Identify research collaboration and advocacy priorities
- Foster collaboration
- Advocate
Measures of success

Asthma Australia will demonstrate the value of its strategic research investment through monitoring the following measures, reporting on them annually and evaluating progress against them at the end of the 2016-2020 period.

<table>
<thead>
<tr>
<th>Success</th>
<th>Description</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enhanced research impact</td>
<td>Publication and dissemination of research</td>
<td>• Number of peer reviewed publications, conference presentations and reports/grey literature outputs linked to funded research</td>
</tr>
<tr>
<td></td>
<td>Demonstrating new research collaborations and partnerships</td>
<td>• Number of reported collaborative research projects</td>
</tr>
<tr>
<td></td>
<td>Subsequent research success</td>
<td>• Number of new research partnerships reported</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Proportion of funding recipients submitting subsequent research applications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Proportion of funding recipients receiving subsequent related research funding</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Value of total reported subsequent related research funding</td>
</tr>
<tr>
<td>Success</td>
<td>Description</td>
<td>Measures</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
<td>----------</td>
</tr>
<tr>
<td><strong>Enhanced research investment</strong></td>
<td>Increasing the number of project grants, fellowships and scholarships, and innovation grants&lt;br&gt;Increasing the amount of funding available&lt;br&gt;Securing new sources of funding&lt;br&gt;Demonstrating return on investment</td>
<td>• Total number of project grants, fellowships and scholarships, and innovation grants&lt;br&gt;• Value of total investment in project grants, fellowships and scholarships, and innovation grants&lt;br&gt;• Number of sources of Research Program funding&lt;br&gt;• Proportional contribution of sources of Research Program funding&lt;br&gt;• Number of <em>new</em> sources of Research Program funding&lt;br&gt;• Ratio of the amount of related research funding secured during the funding period and within three years of completion to the amount of Asthma Australia funding (benchmark set at 5:1)</td>
</tr>
<tr>
<td><strong>Improved management of asthma</strong></td>
<td>Funding research that leads to:&lt;br&gt;- prevention of asthma&lt;br&gt;- better management of asthma&lt;br&gt;- better use of treatments&lt;br&gt;- new treatments</td>
<td>• Case studies of research informing asthma prevention, management, use of treatments and the development of new treatments&lt;br&gt;• Qualitative data reported by grant recipients (survey short responses)</td>
</tr>
<tr>
<td>Success</td>
<td>Description</td>
<td>Measures</td>
</tr>
<tr>
<td>---------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| **Enhanced asthma awareness** | Enhancing the involvement of people affected by asthma research, including Asthma Australia's Research Program | • Reporting on the involvement of people affected by asthma in the Research Program’s governance and review processes<sup>1</sup>  
• Number of research projects reporting the involvement of people affected by asthma in:  
  o developing research questions  
  o the research process<sup>1</sup>  
• Case studies of the involvement of people affected by asthma in research  
• Number of media items about Asthma Australia funded research |
|                     | Enhanced media coverage of funded research                                   |                                                                                                                                                                                                          |
| **Enhanced collaboration** | Promoting new collaborations and partnerships to:  
  • enhance research translation  
  • enhance the impact of research on practice and policy | • Number of reported collaborative research projects  
• Number of new research partnerships reported  
• Measures of collaborations and partnerships<sup>2</sup>  
• Case studies of successful collaborations |

These measures of success will require coordinated work with a range of:  
• people affected by asthma  
• communities  
• researchers  
• health professionals  
• organisations  
• government.  
Together, this coordinated work will contribute to improving the quality of life for people affected by asthma.

<sup>1</sup> These measures reflect best practices in patient centred outcomes research (18).  
<sup>2</sup> Using methods for appraising partnerships such as the VicHealth *Partnerships Analysis Tool* (19)
Contributors

Asthma Australia would like to acknowledge the contribution of these people to the development of this Framework.

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<thead>
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<th>Name</th>
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<td>Asthma Australia Board</td>
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<td>University of New South Wales</td>
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</tbody>
</table>

Asthma Australia would also like to acknowledge the contribution of the 56 asthma people who completed the online survey on research activities, and the stakeholders who provided comment on the draft Framework through the online consultation process.
References


5. **Research Translation Faculty Asthma Steering Group.** *Case for Action - Proposal to NHMRC: Targeted therapy for asthma.* Canberra: Research Translation Faculty, National Health and Medical Research Council, 2015.


