



Not-for-profit Sector Development Blueprint

Blueprint Expert Reference Group

Asthma Australia Submission, December 2023

ABOUT ASTHMA AUSTRALIA

Asthma is a respiratory condition that affects 2.7 million Australians, with children being the most impacted. Asthma is responsible for at least one Australian death every day, making it a serious health concern. More than 30,000 people are hospitalised each year due to asthma, yet 80% of these hospitalisations are considered potentially avoidable.

Despite the prevalence of asthma, it is often misunderstood, causing fear and anxiety for those living with the condition. Asthma Australia has been the leading charity for people with asthma and their communities for over 60 years.

The challenges of climate change, unhealthy air, and health inequity make it more important than ever for people with asthma to have a voice. We search for new and progressive approaches to challenge the status quo. Our work is grounded in evidence and centred on the experiences of people affected by asthma. We believe by listening to those living with asthma, designing solutions with them, and influencing change, people with asthma can live freely, unrestricted by their asthma.

OUR SUBMISSION

Asthma Australia welcomes the opportunity to provide our response to the Not-for-profit Development Blueprint (the Blueprint) and its 10-year vision and priorities for the sector. We strongly welcome the Blueprint's support for, and recognition of, the not-for-profit sector and the critical work we undertake with governments, communities and consumers to meet their needs and fill service gaps. We look forward to working with the Federal Government (Government) to achieve its stated aims of boosting the sector's capacity and of ensuring a strong future for the sector through the Blueprint. In the following submission, we respond to specific questions relevant to our work as set out in the [Issues Paper](#).

Q2.1.1. What is your vision or aspiration for the NFP sector over the next 10 years?

Asthma Australia's vision for the NFP includes:

- That the NFP sector is appropriately **supported to work collaboratively** with consumers, communities, other organisations and governments. This includes ensuring that the sector has sufficient and secure funding and that it continues to be valued and recognised by governments for the work we undertake.
- That the **importance of person-centred approaches** is recognised and encouraged in the sector, alongside the empowerment of consumers to have their say and engage on issues affecting them.
- That the NFP sector is **supported to set bold impact goals, try new approaches and seek to disrupt systems to address ongoing issues**. Innovation, testing and learning are valued and incentivised, as is continuous improvement.
- That NFP funding and **accountability mechanisms and related bureaucracy are proportionate** and enable the NFP to undertake its core business and be agile in response to new opportunities.
- That there is **greater emphasis within NFPs on 'social enterprise'** as a part of a diverse revenue stream i.e. organisations sell products and/or services to provide a recurrent, reliable source of independent revenue, which is tied in some way to the mission of the organisation and enables greater organisational independence and sustainability.

Q2.1.2. What core values and considerations should guide a 10 year vision for Australia's NFP sector?

A 10-year vision for Australia's NFP sector should be underpinned by the following core values:

- **Collaborative.** Collaboration within the sector and with government agencies should be incentivised and rewarded. There are too many stakeholders working in siloes and many opportunities to improve outcomes through working together, thereby reducing duplication and leveraging a range of strengths and capabilities.
- **Empowering.** The NFP sector should be empowered by governments to show leadership and make decisions to reflect their independence. In turn, the NFP sector should strive to empower consumers and build their independence.
- **Person-centred.** Organisations should focus on understanding the issues, experiences and needs of the people they seek to serve and use these insights to shape and influence responses across research, policy and practice.

- **Innovative.** The NFP sector should be supported to be innovative and bold in its work. Risk should be appropriately managed to support organisational creativity and entrepreneurship, and accountability should be proportionate and not overly resource-intensive.
- **Partnership.** The NFP sector should be valued as a key partner to governments achieving their aims and improving the lives and communities of people in Australia. Governments and charities should work together through a meaningful partnership, respectfully and as critical friends.

A 10-year vision for Australia’s NFP sector should consider:

1. Climate change

As the consultation document acknowledges, the impact of climate change will have significant detrimental and inequitable effects on the health, environment and social aspects of communities throughout Australia. The NFP sector will play a key role in helping communities and consumers to mitigate, manage and live with the effects of climate change and it should be empowered to act and resourced to that end.

For people with asthma, the NFP role will be important in managing their condition as there are numerous climate change pathways that can cause and exacerbate asthma in Australia, including air pollution from bushfires, exposure to mould caused by heavy rainfall and flooding events, increased ground level ozone, increased pollen production, thunderstorm asthma epidemics, and extreme heat events.¹ This means people with asthma, those at risk of developing asthma and people with other respiratory conditions are particularly vulnerable to the risks associated with climate change. They look to organisations such as Asthma Australia for advice on how to better manage conditions as climate change progresses and to access services for support.

AirSmart: responding to the need for better public health information on air quality

Asthma Australia’s AirSmart public education campaign is an example of a successful collaboration between a NFP, government and philanthropists that responded to one of the largest air quality challenges Australia has faced: the 2019-20 bushfire smoke crisis. Asthma Australia took the lead on developing and piloting the public education campaign and air quality app after the need for improved community education and guidance around air quality was identified by the bushfire crisis. This need was recognised through our own survey, and by the Royal Commission into National Natural Disaster Arrangements, among other inquiries. The multi-channel campaign seeks to ‘make the invisible visible’ by revealing local pollutants using the AirSmart App, empowering people who are sensitive to low air quality with the information they need to make choices to protect their health.

¹ See e.g.: Salas R N, Solomon C G. 2019. The Climate Crisis – Health and Care Delivery. *N Engl J Med* 2019; 381:e13; Friel S. 2019. Climate change and the people’s health. Oxford University Press; Abdo M et al. 2019. Impact of Wildfire Smoke on Adverse Pregnancy Outcomes in Colorado, 2007–2015. *International Journal of Environmental Research and Public Health*. 16(19):3720; Holm S M, Miller M D & Balmes J R. 2021. Health effects of wildfire smoke in children and public health tools: a narrative review. *J Expo Sci Environ Epidemiol* 31, 1–20; National Asthma Council. Fact Sheet: Healthy in the heat. Available online: <https://www.nationalasthma.org.au/living-with-asthma/resources/patients-carers/factsheets/healthy-in-the-heat>; WHO. 2022. Ambient (outdoor) air pollution. Available online: [https://www.who.int/news-room/factsheets/detail/ambient-\(outdoor\)-air-quality-and-health](https://www.who.int/news-room/factsheets/detail/ambient-(outdoor)-air-quality-and-health); International Panel on Climate Change. 2022. Sixth Assessment Report Working Group II – Impacts, Adaptation and Vulnerability; Fact sheet – Australasia: Climate Change Impacts and Risks, available online: <https://www.ipcc.ch/report/ar6/wg2/about/factsheets/>; Thien F et al. 2018. The Melbourne epidemic thunderstorm asthma event 2016: an investigation of environmental triggers, effect on health services, and patient risk factors. *The Lancet Planetary Health*. Vol 2, Issue 6, E255–E263. Available online: [https://www.thelancet.com/journals/lanplh/article/PIIS2542-5196\(18\)30120-7/fulltext](https://www.thelancet.com/journals/lanplh/article/PIIS2542-5196(18)30120-7/fulltext)

To develop AirSmart, Asthma Australia formed an expert advisory committee with representatives with expertise in air quality standards, public health, environmental health and technology, and from organisations including the University of Sydney and the NSW Department of Planning and Environment. The Committee members contributed to the design of the AirSmart campaign and planning its implementation and evaluation.

AirSmart was piloted in communities across southern NSW, ACT, and regional Victoria over a six-week period in July-August 2022. The pilot was evaluated and strongly indicated that Australians want access to local, responsive air quality information and tools. The strong engagement in the campaign was demonstrated by over 16,000 app downloads and 23,000 website views in just six weeks.

However, our progress in developing AirSmart was at times hampered by the Federal Government as no one department has responsibility for air quality. As result, it proved challenging to engage with different government portfolios (Health, Environment, Emergency Services) on its development, despite our upfront organisational commitment of \$700K.

Asthma Australia is now looking to roll-out AirSmart nationally, and to date, has secured funding for this purpose from the ACT Government.

2. Housing

The issue of affordable, healthy housing for all people in Australia is long-standing and being compounded by the cost-of-living crisis and the increasing, extreme weather events of climate change. These events can further deteriorate poor housing conditions through causing damp and mould, while poor ventilation and air tightness leave homes ill-equipped to keep people safe against bushfire smoke and extreme heat.

As a result, it is possible that younger generations could develop more health conditions, such as asthma, due to poor housing and climate change, while people with asthma who are more vulnerable to unhealthy homes are likely to need to access healthcare services more often if poor housing is not addressed. The NFP sector can help to provide policy and service solutions to easing this crisis and we set out examples of our work in this area below.

Asthma Australia's research, policy and support on healthy homes

In 2022, Asthma Australia undertook a nationally representative survey of 5,041 people to understand how healthy Australian homes are for people with asthma or allergies and those at risk of developing asthma.² In particular, we sought to uncover how common are key triggers, such as mould, emissions from cooking and heating and pests, in Australian homes and the actions people take and the barriers they face to reduce these triggers in their homes.

The survey found that three in ten respondents with asthma and allergies reported that their symptoms are worse after spending time in the home, that many people are exposed to asthma triggers in their home and that specific population groups (such as those living in social housing or

² Asthma Australia, 2022. Housing, Health and Asthma in Australia. Available online: [AA2022_Housing-Survey-Report_full_v4.pdf \(asthma.org.au\)](https://www.asthma.org.au/AA2022_Housing-Survey-Report_full_v4.pdf)

Aboriginal and Torres Strait Islander peoples) who are more vulnerable to these triggers were also more likely to be exposed to them in their homes. In addition, respondents reported the following barriers to reducing triggers within the home:

- **Lack of autonomy** to make necessary changes in their home as they do not own it.
- **Cost** of making changes or buying equipment to improve the health of their home.
- **Lack of concern and/or knowledge** about the health of their home and how poor housing can affect their health.

Based on these findings, we have developed a suite of policy recommendations for governments to improve housing health and have advocated in many different avenues for their adoption. In addition, we have developed our own resources for homeowners and renters on steps they can take to make their homes healthier, while healthy homes was the focus of [Asthma Week](#) consumer campaign in 2023.

3. Cost of living

The cost-of-living crisis is affecting the social determinants of health, leaving people on low incomes with difficult choices to make about their health given the high costs involved with accessing health care services and medicines. More measures like the much welcomed 60 day dispensing policy being phased in for people with stable, long-term conditions needs to be considered, while the Federal Government's needs to ensure that people disadvantaged by income or location are provided with accessible primary care in its Strengthening Medicare reforms.

The NFP sector provides cost-effective solutions to gaps in the health care system that, left unfilled would mean people would need to access more costly healthcare and emergency services. For example, Asthma Australia delivers an asthma education telephone service (1800 ASTHMA), which can help support people with their asthma control as well as care coordination and follow-up post hospitalisation.³ We also develop a range of free online resources to help people with asthma and their carers better manage their condition. For example, only 28% of people with asthma have a written asthma action plan.⁴ An asthma action plan is evidenced as one of the most effective interventions to support people with asthma by guiding their actions in response to a change in their asthma control and condition.⁵ All healthcare professionals need to be aware of the importance of asthma action plans so they can help support consumers to appropriately consult it when their symptoms escalate. With the aim of increasing uptake, knowledge and accessibility of these plans, we developed an easily accessible [Asthma Action Plan](#) for both adults and children.⁶

³ <https://asthma.org.au/what-we-do/how-we-can-help/1800-asthma-3/>

⁴ Australian Institute of Health and Welfare 2018. Australia's health 2018. Australia's health series no. 16. AUS 221. Canberra: AIHW.

⁵ [Asthma Action Plan - Asthma Australia](#)

⁶ <https://asthma.org.au/treatment-diagnosis/asthma-action-plan/>

3.1.3. What would an outcomes focused approach look like in your area(s) of work? What would be needed to move towards this and what unanticipated consequences should government and the sector consider?

An outcomes-focused approach should consider that:

- Outcomes often need **significant time** to be achieved and hence the approach should provide sufficient time to evidence intended outcomes, including long-term outcomes.
- Organisations should be **free to adjust the activities** they undertake as needed to optimise agreed outcomes and build on lessons learned.
- Outcomes should reflect the project/service's evidence-based **theory of change** and **outcomes framework**.
- Depending on the project and policy area, **outcomes can look very different** and reflect a range of different goals, including for example the steps taken in a path to behaviour change.
- Charities need **sufficient time to undertake their core work**, e.g. trying to improve outcomes, and hence the approach must be streamlined and not overly time-consuming to evidence.
- Rigorous evaluations are resource-intensive and **appropriate funding** should be allocated for this purpose in Government contracts.
- **Government has access to significant datasets** that can assist in measuring outcomes e.g. reduction in urgent healthcare utilisation or potentially preventable hospitalisations, and these should be shared with charities in real-time to enable us to see what is working.

4.1.2. What mechanisms are needed so that the expertise of the NFP sector is better used in designing policy and services?

The following mechanisms should be in place to support the better use of NFP sector expertise in the design of policy and services:

- **Codesigned consultation** that meaningfully draws on the expertise, experience and insights of the NFP sector from the very outset of the project/policy review process.
- **Funding for research and community engagement** to ensure the NFP sector can effectively uncover the views and experiences of the community, including seldom heard population groups, to inform policy and service design.
- **Funding to remunerate consumers and NFPs** for their participation in consultation events.

4.1.3. What could NFP organisations and networks be doing better to ensure their systematic advocacy directly involves the people and communities they serve?

Asthma Australia is very well positioned to engage with consumers to understand their experiences and needs and we use this insight to guide our advocacy. We have a Consumer Engagement Strategy, Consumer Advisory Council (CAC), Asthma Champion program, consumer research surveys, social media engagement and Voice of Customer program, which is comprised of solicited and unsolicited feedback channels. Evidence-based advocacy is critical to our work and hence we often undertake research to inform our work. Below, we set out how we used these channels in practice to inform our advocacy and service delivery during the COVID-19 pandemic.

Informing Australia's response to COVID-19

As an infectious respiratory disease, Asthma Australia immediately recognised that COVID-19 would have a significant impact on the lives of people with asthma. As the pandemic unfolded, we received a significant increase in calls to our Asthma Educators and engagements through our social media channels with people with asthma concerned that they were more at risk of contracting COVID-19, more vulnerable to its symptoms and to becoming very ill or dying. They were also concerned about ongoing access to asthma medications and healthcare services.

To ensure that we fully captured the concerns and experiences of people with asthma, we developed an extensive consultation approach with consumers with our CAC. This included undertaking three standalone surveys, the first of which was with nearly 2,000 people with asthma or their carers in April 2020. The aim of these surveys was to understand the experiences of people with asthma to inform our response and support to consumers, as well as advocacy and information-sharing to government. We then carried out a pulse survey with 200-500 respondents on a fortnightly basis for six months. This helped us to track real-time changing experiences and feelings to the pandemic and government actions, and to identify any new emerging challenges.

This comprehensive approach to consumer engagement enabled us to:

- Ensure people with asthma **felt listened to** during this period of uncertainty.
- **Raise awareness and advocate for the needs and concerns** of people with asthma to governments and other stakeholders. This included the difficulties people with asthma were having in accessing healthcare services and attending their regular check-ups with GPs since the symptoms of asthma overlap with COVID-19. We also advised governments about messaging on mandatory facemasks since some people with asthma were unable to wear them as masks trigger their symptoms, and so felt isolated and misunderstood as a result.
- **Develop resources to support people with asthma in direct response to their concerns and needs.** We provided support through our website COVID-19 hub (there have been 164,524 pageviews of COVID-19 pages since 2020), newsletters, blogs and social media posts as well as access to experts through Facebook live sessions. In view of consumer concerns, we also commissioned a systematic review of the evidence to determine the risk of COVID to people with asthma. Thanks to this research, we were able to alleviate concerns in the community and advise governments and healthcare and services professionals accordingly, at the same time as reinforcing key messages around reducing risk and remaining vigilant.
- **Use our established communication channels** to share information from government about medicines availability and public health messages.

4.1.4. How could the assets of the sector for example, the research expertise of larger organisations, including public universities be better used to build the evidence base for systemic advocacy and reform?

We have found that critical to optimising resources and building the evidence base for systemic advocacy and reform is collaboration with other organisations and stakeholders. In addition, we have embedded collaboration into research relating to asthma in the following ways:

1. We play an important role in fostering collaboration by **maintaining oversight of all asthma-related research** being undertaken in a range of different contexts and by a range of different bodies. In this role, we seek to build relationships and identify opportunities for collaboration.
2. We created a **Research Advisory Committee (RAC)** that consists of a range of **experts from research, clinical, scientific and lived experience backgrounds**. The aim of the RAC is to support Asthma Australia to deliver a high-quality research program, identify further research opportunities, and ensure that our research is relevant and achieves maximum impact.
3. We led the development of a new **National Asthma Research Agenda (NARA)**, which aims **to focus and coordinate the research community and limited resources on an overarching, strategic direction**. Based on the priorities of end-users, NARA responds to the 2018 National Asthma Strategy's recommendation for the development of a national asthma research agenda to help 'focus, coordinate and translate quality health research into policy and practice'. It was developed through a rigorous process adapted from the James Lind Alliance Priority Setting Partnership process, which focuses on bringing patients, carers and clinicians together to identify and prioritise longstanding and urgent issues. As recently published in the [Journal of Respiriology](#), NARA's 10 research priorities reflect people's lived experiences to ensure research can be translated into meaningful change in everyday settings. Asthma Australia has refocused our research program around NARA, and are promoting it widely with our stakeholders. We manage the National Asthma Research Program grant rounds, with support from our RAC.

8.1.1. How should government improve the way it funds and contracts charities?

To improve the way it funds and contracts charities, Government should provide:

- **Longer contracts** (e.g. 5 years plus with appropriate mechanisms to ensure accountability and performance) to:
 - provide security for the organisation and the consumers it supports,
 - support the achievement of long-term and sustainable outcomes, and
 - engender trust and good working relationships between all stakeholders.
- **Opportunities for organisations to modify indicators during the contract** as we learn what is and is not working in a project or service, which would encourage innovation, risk-taking and new approaches and enable an iterative or even bolder approach that can build on experience and lessons learned. Some contracts can be very fixed, which perpetuates a conservative approach to ensure indicators are met.
- **Provide contracts with funding that reflects the real cost of delivering services.** Grants do not cover operational costs of delivering services and as a result charities like Asthma Australia effectively subsidise these activities for government. The for profit organisations that Government contracts with would never be expected to deliver contracts with the expectation that they will subsidise the services they deliver. Government should treat the NFP sector similarly.
- **Develop better indexation arrangements for grants.** Grants effectively depreciate year on year so that charities are expected to deliver the same service with less funding and thereby put further pressure on charities to further subsidise the public contract. Grants should be indexed so that they appropriately reflect the rising costs of service delivery.
- **Improve contractual arrangements and practice.** Providing services is challenging when government funders give limited notice of contract renewal, granting or cessation. Government funding departments should work closely with the NFP sector during contracts awards and provide sufficient notice so we can plan our services and budgets accordingly.
- **Properly fund community peak bodies and advocacy organisations.** The work we undertake with Government has been recognised in this consultation and is welcome but appropriate and consistent funding must now follow.