

Asthma Australia Submission to the Department of Health

National Medicines Policy Review

October 2021

ABOUT ASTHMA AUSTRALIA

Asthma Australia is a for-purpose, consumer organisation which has been improving the lives of people with asthma since 1962.

Asthma is an inflammatory condition of the airways, which restricts airflow and can be fatal. There is no cure, but most people with asthma can experience good control of their condition.

Asthma affects one in nine Australians, or 2.7 million people. It has various degrees of severity (mild to severe) and affects people of all ages, from childhood to adulthood. Asthma can appear at all ages and stages of life.

Asthma Australia's purpose is to help people breathe better so they can live freely. We deliver evidence-based prevention and health strategies to more than half a million people each year. To ensure people can access effective treatments and best practice healthcare for their asthma, we work directly with people with asthma, their family and friends, health professionals, researchers, schools and governments. This way, we can ensure people with asthma are supported with education and access to high-quality information and care where they live, work and play in all stages of life.



Asthma in Australia

Asthma is one of the most common chronic conditions in Australia, with high prevalence rates by international comparison. Around 2.7 million Australians (11% of the total population) have asthma.¹ Asthma affects people of all ages.

There is generally a higher prevalence of asthma for people living in inner regional areas (12.9%) or outer regional and remote Australia (12.7%) compared with those living in major cities (10.6%).² This is more pronounced in New South Wales (14.1% in inner regional areas, 13.7% in outer regional and remote areas and 9.7% in major cities), Victoria (13.6% in inner regional areas, 13% in outer regional and remote areas and 10.9% in major cities) and South Australia (15% in inner regional areas, 18.1% in outer regional and remote areas and 11.4% in major cities).³

People with asthma experience poorer health outcomes and quality of life.⁴ People with asthma may live for a long period of time with its associated disability, and experience reduced participation in the workforce, school, childcare, sports and social events. Asthma is the 9th leading contributor to the overall burden of disease in Australia.⁵ Asthma is the leading cause of burden of disease for people aged 5-14 years.⁶

In 2020, there were 417 deaths due to asthma in Australia. Approximately 400 people die each year due to asthma. Asthma mortality and hospitalisations in Australia are high by international standards. Hospitalisations due to asthma are costly: on average, each emergency department presentation for asthma costs \$443, an uncomplicated hospital admission costs \$2,591 (approximately 1.5 hospital days) and a complicated admission costs \$5,393 (approximately three hospital days). The total cost of asthma in Australia in 2018-2019 was \$801M.

Introduction

Asthma Australia welcomes the opportunity to respond to the Review of the National Medicines Policy (NMP) Discussion Paper. This review is important to people with asthma, who need to manage their chronic condition with regular use of medication.

Our submission responds to terms of reference 1 to 5, and has been drafted in consultation with our Professional Advisory Council and our Consumer Advisory Council.

Term of Reference 1: Evaluate the current NMP objectives and determine whether these should be modified or additional objectives included. This includes consideration of the proposed principles to be included within the NMP

Objectives

Asthma Australia supports review of the four current objectives of the NMP, which are:

 timely access to the medicines that Australians need, at a cost individuals and the community can afford



- medicines meeting appropriate standards of quality, safety and efficacy
- quality use of medicines; and
- maintaining a responsible and viable medicines industry.

As one of our Consumer Advisory Councillors observed, of the four objectives, only one is within the power of the consumer to control: the quality use of medicines. For people with asthma—both children and adults—the ideal management of their condition requires regular use of medication.

The other objective that is particularly significant for consumers, including people with asthma, is access to medicine.

This section shares the consumer experience with respect to these two objectives.

Timely access to the medicines that Australians need, at a cost individuals and the community can afford

"Asthma medication is expensive...It should be everyone's right to breathe freely, and this shouldn't be impacted by whether or not we can afford the medication. There are many additional costs beyond the cost of the drug." Person with asthma

Although access to affordable medicine is a stated objective of the NMP, people who engage with Asthma Australia—through our Asthma Champions program, our COACH program, 1800 ASTHMA and through responses to our social media posts—consistently advise us that asthma medication is too expensive. As a chronic condition, asthma requires constant self(/carer)-management, which means frequent use of medication.

The cost of preventer medication for people with asthma who do not have a concession card ranges from \$6 per person per month to \$40 per person per month.¹³ However, 80% of all preventers prescribed are expensive ICS/LABA combination preventers, which are the more expensive medications at approximately \$40 per person per month.¹⁴

The cost of asthma medication can therefore rapidly become a barrier to management of this condition and this may lead some people with asthma to underuse their medication. People who live in areas of lower socioeconomic status or remote areas are more at risk for cost-related underuse of their medication. A recent cross-sectional survey of adults and parents of children 5–17 years with asthma in Australia found that [c]ost-related underuse was reported by 52.9% adults and 34.3% parents, predominantly decreasing or skipping doses to make medicines last longer". This is particularly concerning, because underuse of cost-effective preventive treatments by people with asthma increases their morbidity and mortality. Other situation-dependent factors can influence patient adherence to asthma management, including convenience, efficacy and perception/knowledge of the severity of a person's condition.

Children and access to medicine

As is the case with adults, all children with asthma need medication to manage their condition. Prevalence of asthma among children is high:

• in 2017–18, an estimated 10% (around 460,000) of Australian children aged 0–14 were reported to have asthma as a long-term condition; and



• asthma prevalence was twice as high among children with disability (18%) compared with children with no reported disability (8.9%).¹⁹

In comparable jurisdictions to Australia, like the United Kingdom (UK) and New Zealand (NZ), some medicines are free for children. In the UK, people 16 and under or 16 to 18 and in full-time education, can get free National Health System prescriptions. In NZ, "[t]he prescription charge for each subsidised prescription medicine is usually \$5. This standard charge does not apply to children aged 13 and under". In the UK, people 16 and under the UK, people 16 and under the UK, people 16 and under or 16 to 18 and in full-time education, can get free National Health System prescriptions. In NZ, "[t]he prescription charge for each subsidised prescription medicine is usually \$5. This standard charge does not apply to children aged 13 and under".

Asthma Australia suggests that a similar scheme should be considered for children in Australia. This cost relief on medication for children would improve the affordability of medication for adults where their prescription is not subsidised to the same level. Further, setting good healthy behaviours in place during childhood is important because it can result in a highly likelihood of healthy behaviours into young adulthood.

RECOMMENDATION 1: Asthma Australia recommends medicine is made free for children.

Access to medicine during natural and health emergencies

Medication supply and timely access to medications has been an issue for people with asthma in recent emergencies, namely the December 2019–January 2020 bushfire period and during the COVID-19 pandemic.

Air pollution is a common asthma trigger and during periods of sustained air pollution, demand for asthma medication is likely to increase. For example, during the 2019–2020 bushfires, Asthma Australia undertook a survey of 12,152 people during this period which revealed 76% of people reported an increase in the use reliever inhaler, and 41% reported an increase in existing preventer dose/ frequency. The table below summarises the range of actions undertaken by people with asthma during this period to manage/ relieve symptoms caused by bushfire smoke.

Actions taken by people with asthma to manage/relieve symptoms due to bushfire smoke in Dec 2019/ Jan 2020

Actions taken by people with asthma to manage/relieve	Percentage
symptoms due to bushfire smoke in Dec 2019/Jan 2020	(%)
Increased reliever inhaler	76
Increased existing preventer dose/frequency	41
Visit a GP	23
Steroids (oral or injection)	16
Administered asthma first aid	8
Was prescribed a preventer	7
Attended ED	6
Hospital admission	2

During the 2019–20 bushfires, the Federal Government introduced policy changes that allowed people affected by the bushfires to access full quantities of prescription-only medicines without a prescription and with Pharmaceutical Benefits Scheme (PBS) subsidy.²² These arrangements were in place until 31 March 2020, and were welcomed by Asthma Australia.

The demand for asthma medication also increased in the early stages of the COVID-19 pandemic, such that some people with asthma reported to us that they experienced difficulties accessing



asthma reliever medication. In March 2020, Asthma Australia became aware of some temporary shortages of salbutamol in some local pharmacies due to higher-than-expected consumer demand. Advice received from the Therapeutic Goods Administration at the time was that there was plenty of medication in Australia and that stock was being replenished in affected pharmacies.

It is important that pharmacies are sufficiently stocked with or can quickly obtain medications to manage and treat asthma. In the case of future emergency events, preventer medication should again be sold over the counter during the crisis period to ensure people can access the medication they need, when they need it. Pharmacists should also be sufficiently stocked with this medication.

It is important that the NMP can address barriers to obtaining medication, such as that illustrated above, where there is increased demand owing to issues such as natural or public health disasters.

RECOMMENDATION 2: Asthma Australia recommends the NMP is prescriptive about how to address barriers to access to medication, particularly during natural and health emergencies.

Quality use of medicines

Another important current objective of the NMP is the quality use of medicines. Good health literacy and self(/carer)-management is particularly important for using asthma medication.

Asthma is a long-term chronic condition which requires a tailored medical treatment plan as the mainstay of management, which is self-administered by the person with asthma (or their carer) in the context of their everyday life. However, we note persistent gaps between the availability of effective medicines to treat asthma in Australia and their use, including adherence to Australia's world-leading asthma guidelines, the level of asthma control experienced by people with asthma, and the uptake of asthma action plans for adults and children.

In 2019, Asthma Australia conducted a number of workshops to examine how best to develop innovative ideas and strategies to increase the uptake of clinically effective asthma medicines by addressing perceptions of cost compared to utility/ value, as a means by which to improve asthma management and quality of life. The results of these co-design workshops demonstrated the importance of education and information to support people with asthma better manage their condition including non-adherence to preventative medication.²³

Through these workshops, it was found that consumer education, training and support are critical to the quality use of medicines, especially in regard to improving health literacy and asthma self-management skills. It is particularly important that consumer education, training and support be accessible to people at greater risk of poor health outcomes. Consumer resources must therefore be:

- provided in Plain English, and Easy English
- provided in different languages for people from culturally and linguistically diverse backgrounds
- culturally safe and appropriate; and
- available in different formats (such as in person, telephone, paper, web, digital).

Asthma Australia is encouraged by the focus on the quality use of medicines in the existing NMP. However, the fact that consumers are not adhering to their preventer prescription as recommended, suggests that this objective is not operating effectively. Effective operation of this objective could be achieved with improvements to health literacy, discussed further below in response to term of



reference 3.

The proposed NMP principles

The Discussion Paper outlines five Proposed Principles for the new NMP, and notes that:

It is expected that these principles should be evident in the planning, design and implementation of programs, systems and initiatives created to deliver positive health outcomes for all Australians through their access to, and appropriate use of, medicines.

The proposed principles are:

- Equity
- Consumer centred approach
- Partnership based
- Accountability and transparency
- Stewardship

Asthma Australia considers that these principles are appropriate. Of those proposed, equity and consumer centred approach are the most significant for people with asthma.

The Discussion Paper defines 'equity' as meaning that "all Australians receive effective, safe, high-quality, and affordable access to medicines when needed irrespective of background or personal circumstance". At present and by this definition, access to medicine is not equitable. For example, and as discussed above, out-of-pocket costs for patients can be a barrier to accessing health care and can affect the ability of patients to get the care and medication they need, when they need it. Out-of-pocket health care costs comprise a considerable portion of health spending in Australia, compared with other OECD countries, accounting for 20% of expenditure on health care in Australia, slightly higher than the OECD average of 19%. ²⁴ By contrast, out-of-pocket costs account for only 10% of health spending in the UK, 13% in NZ and 14% in Canada, all of which have similar government funded health systems.

Patients' out-of-pocket spending on Medicare services in 2016–17 illustrates that the costs to consumers are substantial and for some consumers are a barrier to accessing care. Significantly, of the two thirds of people (68%) who had received a prescription for medication from a General Practitioner in the last 12 months, 7% delayed or decided against filling a prescription due to cost.²⁵

Asthma Australia supports an NMP that enables universal access to medicine, which is designed to be equitable in access and outcomes and helps to improve health and reduce health inequities. The principle of equity cannot be achieved if the cost of medicine is a barrier to this access.

The NMP Discussion Paper defines 'consumer centred approach' as meaning that "consumers should be informed, engaged, and empowered to participate in medicines policy, recognising their key role in supporting the achievement of the policy's objectives." Asthma Australia welcomes the Australian Government's Strategic Agreement with Medicines Australia, *Strategic Agreement 2022–2027:*Building a Future for Earlier Access to New Medicines and considers this to be a good example of how to inform, engage and empower consumers. Asthma Australia looks forward to observing how this agreement will lead to substantial change in medicines policy.



Term of Reference 2: Consider the definition of medicines and whether the NMP needs to be expanded to include health technologies

The Discussion Paper notes:

The NMP currently considers the term "medicine" to include prescription and non-prescription medicines, including complementary healthcare products. The Therapeutic Goods Act 1989 defines "medicine" as therapeutic goods (other than biologicals) that are represented to achieve, or are likely to achieve, their principal intended action by pharmacological, chemical, immunological or metabolic means in or on the body of a human. It also considers that medicines are those that do not fit the definition of therapeutic devices.

The emergence of new drugs and novel medical technologies have the potential to alter the boundary between the term 'medicine' and 'medical devices'.

Asthma devices

Unlike other diseases, chronic respiratory diseases like asthma and COPD are treated by the use of inhaler devices. This treatment presents consumers who have these diseases with a range of challenges and obstacles relating to the quality use of medicine and achievement of health goals.

For people with asthma, medicines are delivered via handheld inhaler devices of varying complexity and technical specification. Where correct treatment is well understood by prescribers and consumers, it can lead to the tailoring of treatment specific to the consumer's needs. When misunderstood, it can lead to challenges which could render the consumer's medicine unusable, unaffordable and/ or unsafe.

Other asthma medical devices include those which augment delivery of medicine, namely spacers and nebulisers. These devices have a very specific role, and when prescribed and used according to specific individual needs, can support good asthma health. These devices are not included in the definition of 'medicine' and are not subsidised.

Spacers are used to make it easier for people with asthma to inhale their medicine, and to a degree also protect against side effects like oral thrush. A spacer is a plastic container with a mouthpiece at one end and a hole for the inhaler at the other. Spacers can only be used with puffer style inhalers. The medicine is 'fired' from the puffer into the spacer and is then inhaled. Adults and adolescents are recommended to always use a spacer with their puffer inhaler. For most children, especially in the younger age group, a spacer is strongly recommended to support the delivery of their inhaled asthma medicines.

Asthma Australia's Consumer Advisory Council and Professional Advisory Council have considered whether medical devices should be captured by the definition of 'medicine' in the NMP. While there is general agreement that there are benefits to this, such as the opportunity to subsidise cost of devices under the PBS, there is a risk that if medical devices were more regulated there would be two barriers to PBS listings: medications and device approval. It is important that any expansion of the definition of medicines includes safeguards against such risks.

RECOMMENDATION 3: Asthma Australia recommends medical devices are included in the definition of medicines, and that any potential barriers arising from this change be addressed.



Term of Reference 3: Assess the NMP's utility in the context of rapidly evolving treatment options, population changes, interconnected relationships, and system-wide capacities

The Discussion Paper notes that the health policy landscape is constantly evolving, and identifies health literacy as one of the 'critical' aspects of this landscape. However, the Discussion Paper also recognises the low levels of health literacy in the population, and acknowledges that this corresponds with poor health outcomes. Concerningly, only about 40% of adults have the level of individual health literacy needed to meet the complex demands of everyday life, such as understanding and following health advice and making good health care choices.²⁶

We consider that a focus on health literacy is central to the success of the NMP. We also note that this is consistent with other plans and strategies. For example, health literacy is integral to the Australian Government's success in implementing its *Long Term National Health Plan*, including the 10 year *Primary Health Care Plan* and the *National Preventive Health Strategy*. Health literacy is also integral to the effective implementation of the 2017 *National Strategic Framework for Chronic Conditions* and the *National Asthma Strategy 2018*.

As noted above in response to the quality use of medicines objective under term of reference 1, Asthma Australia supports greater investment in consumer education, training and support to improve health literacy, health knowledge and self-management skills. In the asthma context, this means giving people the information, education, resources and tools they need to prevent, control and effectively manage asthma.

RECOMMENDATION 4: Asthma Australia recommends the NMP include emphasis on greater investment in consumer education, training and support.

Term of Reference 4: Consider the centricity of the consumer within the NMP and whether it captures the diversity of consumers' needs and expectations

The Discussion Paper states:

Discussions at the Stakeholder Forum emphasised the need for a patient-centric focus within the NMP to empower consumers to make informed choices about the [quality use of medicines]. This sentiment was widely held. The strengthening of the consumer voice and input in the policy was raised as an important principle.

An updated policy will need to recognise that consumers are becoming more active and informed participants in their care and broader health policy.

In Australia, the most disadvantaged and vulnerable suffer the most health-related harm. For example, the burden of disease far is greater for certain population groups, including those living in remote locations or experiencing socio-economic disadvantage.²⁷ A number of groups are also disproportionately affected by asthma, including Aboriginal and Torres Strait Islander people, people living in areas of lower socioeconomic status and people living in rural and remote areas.²⁸

The Discussion Paper acknowledges that "Australia is a culturally and geographically diverse nation, yet there is no acknowledgement in the [existing] NMP of the diversity of consumers and their



specific needs". The Discussion Paper focuses principally on health literacy with respect to this term of reference, and also sets out a number of actions that could be implemented to achieve consumer engagement. Our position on health literacy is discussed above in relation to term of reference 3. While we recognise the importance of health literacy, we consider that the measures discussed under term of reference 4 do not adequately capture the significance of the diversity of consumers' needs and expectations.

We consider that the NMP should enable national medicines programs to engage with consumers on:

- cost pressures and the quality use of medicine
- access to medicines for vulnerable communities; and
- the quality use of medicine in public health emergencies.

Social determinants of health

One way in which to capture the significance of the diversity of consumers' needs and expectations is to acknowledge and incorporate into the NMP a social determinants of health perspective. While briefly discussed under term of reference 3, we consider that the NMP Discussion Paper does not sufficiently recognise the significance of the social determinants of health.

Research shows that broader determinants of health and social factors are more important than health care in ensuring a healthy population.²⁹ Research shows that health behaviours contribute to only 30% of our overall health, while socio-economic factors like income, job status and education comprise 40%. Our physical environment, including the built environment, contributes 10% to our health, and only 20% of our health is attributable to health care.³⁰ Other evidence suggests that the impact of health care is estimated at approximately 15–43%, while social and other factors is 45–57%.³¹

Although accessible, high-quality health care—including medication—is crucial, a healthy population cannot be achieved solely through reforms to the health care system and changes in an individual's behaviour. It is important to look beyond health care and individual choices to other factors that can improve the health of people living in Australia.

RECOMMENDATION 5: Asthma Australia recommends the NMP incorporates a social determinants of health perspective.

Co-design

The Discussion Paper sets out a number of ways in which to incorporate the consumer voice, most of which relate to consumer representation on committees. While involvement of a consumer representative on committees is welcome, this involvement is narrow insofar as it is limited only to those committees. Further, it is unlikely that a single consumer representative can reflect the diversity of consumers' needs and expectations.

There is a more effective way to capture the significance of the diversity of consumers' needs and expectations: co-design.



Co-design has the potential to equalise power imbalances between professionals, systems stakeholders and people with lived experience. It brings people with lived experience together with their health professionals, each contributing their own knowledge and expertise to design problem-solving activities.

Addressing co-design in the NMP would be consistent with the Government's position in the *Draft National Preventive Health Strategy* and the *Discussion Paper to inform the development of the Primary Health Reform Steering Group recommendations on the Australian Government's Primary Health Care 10 Year Plan.*

Asthma Australia believes that, in order to reflect the diversity of consumers, the NMP should be co-designed with consumers and guided by an Expert Steering Committee that includes an expert in chronic conditions such as asthma, airways disease and/or respiratory and lung health.

RECOMMENDATION 6: Asthma Australia recommends the NMP is co-designed with consumers.

Terms of Reference 5: Identify options to improve the NMP's governance; communications, implementation (including enablers) and evaluation

Asthma Australia notes that this is the first review of the NMP since its development in 1999. While we welcome this review, it is regrettable that a policy that has such a significant impact on the daily life of consumers has, to date, been out of the power of consumers to influence.

In respect of communication directly with consumers, while we welcome the focus on the need to incorporate the consumer voice in the Discussion Paper, there could be more detail provided on how this may be achieved. As noted above in response to term of reference 4, one way in which to further engage consumers and equalise power imbalance between stakeholders is to incorporate co-design practices.

We also consider that for the revised NMP to remain effective and relevant, it must be reviewed regularly, with necessary changes made to enhance its effectiveness. We therefore suggest the incorporation into the NMP of a regular review process. In order to maintain confidence in the policy, it is important that this process and the outcomes of the review are transparent and accessible.

RECOMMENDATION 7: Asthma Australia recommends regular reviews of the NMP, with reports of these made transparent and accessible to the public.

Terms of Reference 6: Review the NMP partners and provide options for building greater accountability including addressing conflicts of interest

No comment.



Summary of recommendations

RECOMMENDATION 1: Asthma Australia recommends medicine is made free for children.

RECOMMENDATION 2: Asthma Australia recommends the NMP is prescriptive about how to address barriers to access to medication, particularly during natural and health emergencies.

RECOMMENDATION 3: Asthma Australia recommends medical devices are included in the definition of medicines, and that any potential barriers arising from this change be addressed.

RECOMMENDATION 4: Asthma Australia recommends the NMP include emphasis on greater investment in consumer education, training and support.

RECOMMENDATION 5: Asthma Australia recommends the NMP incorporates a social determinants of health perspective.

RECOMMENDATION 6: Asthma Australia recommends the NMP is co-designed with consumers.

RECOMMENDATION 7: Asthma Australia recommends regular reviews of the NMP, with reports of these made transparent and accessible to the public.



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