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Eureka Project 3246

EUREKA
strategic research

TABLE OF CONTENTS

Executive summary 1

Research context 7

2.1 Background 7
2.2 Research objectives 3

Research design 5

3.1 A qualitative approach 5
3.2 Sample structure for people with asthma or asthma-like symptoms 6
3.3 Sample structure for GPs and pharmacists 11
3.4 Conduct of the research 13

Research findings 15

4.1 People with asthma 15
4.2 People with asthma-like symptoms 30
4.3 GPs and pharmacists 38

Conclusions and recommendations 55

Appendix A 60

Discussion guide for people with asthma / their carers 60
Discussion guide for those with asthma-like symptoms 65
Discussion guide for GPs, pharmacists and AHWs 68

Appendix B 72

People with asthma 72
People with asthma-like symptoms 76
GPs and pharmacists 76

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1

EXECUTIVE SUMMARY

Research context

Good management of asthma has been shown to reduce the likelihood of severe episodes and improve quality of life for those with asthma. Consequently, the Australian Government Department of Health and Ageing has been funded to implement an Asthma Management Program, including recent funding for an asthma awareness-raising initiative. The Department commissioned this qualitative research to inform strategy development and help shape key messages of the communication initiative, so as to increase the incidence of best practice asthma management and reduce the impact of asthma on individuals and society.

Research design

In total, 22 group discussions, 5 mini-group discussions and 21 in-depth interviews were conducted in April and May, 2006. Given the relatively high incidence of asthma among Indigenous communities, a component of the research was dedicated to exploring the views and experiences of Indigenous Australians.

The primary target audience was people with asthma or whose children have asthma, ranging from teenagers through to those aged 55 years and over. In addition, people who exhibit asthma-like symptoms, but who have not been diagnosed with asthma, represented another key audience, with an emphasis on those over 40 years of age.

The research also included primary health care professionals, who formed the secondary target audience for the communication initiative. This audience included General Practitioners (GPs), pharmacists and Aboriginal Health Workers (AHWs).

People with asthma

Most people felt that their knowledge of asthma was sufficient to enable them to manage their condition adequately. Therefore, participants generally did not perceive a critical need to seek further information to improve their knowledge above its current level. Asthma was typically perceived as an episodic, rather than a continuous, condition - a perception that potentially

acts as a barrier to pro-active and ongoing asthma management. Some people with asthma were unaware of what they should do in an emergency situation, particularly at what stage they should go to hospital. Overall, medication was the most widely known form of treatment for asthma. However, some participants did not distinguish between preventer medication and reliever medication.

Participants generally realised that asthma could be serious and, in some cases, potentially life-threatening. Those with severe asthma typically experience a more significant impact on their daily life. However, most of those with mild to moderate asthma see it primarily as an inconvenience or hassle, rather than a serious health concern. Any limitations that were experienced were usually regarded as normal for people with asthma, or at least normal for the person concerned. Many tend to adjust their life to fit their asthma, rather than questioning whether their management is optimal and whether the impact of their asthma could be reduced.

Some people with asthma are clearly accepting high levels of symptoms and real restrictions on their lives, rather than taking appropriate action to treat their condition and improve their health. Certainly, the use of preventer medication appeared sub-optimal. Few participants appeared to monitor their asthma, other than by monitoring their symptoms in a general sense, and peak-flow measurements were rarely taken.

Most participants reported that they only raise the issue of asthma with a health professional if their symptoms deteriorate, or if they require a new script. Since having their diagnosis initially confirmed, relatively few with mild to moderate asthma have had lung function tests conducted by a health professional. Many participants said that they would welcome their health professional raising the issue of asthma, although for some this would be dependent on the tone that was adopted. Only some pharmacists appear to be playing a role in people's asthma management and this is largely confined to explanation of the medication that people are using and potential interactions or side effects.

Participants were able to identify the key benefits of managing their (or their child's) asthma better, in particular, having better overall health, and greater peace of mind. However, the research identified a range of factors which act as barriers to optimal asthma management. These are detailed in the report, but key barriers included a sense of complacency regarding how one deals with one's asthma, and believing that one's asthma is as good as can be expected. An over-reliance on reliever medication is also apparent, with some misperceptions and limited awareness of the role of preventer medication.

Only a few participants knew what a written asthma action plan was, and even fewer actually had one. Many perceived (or assumed) that an action plan contained instructions for a severe episode and this was appreciated. When the typical content of an action plan was explained by the facilitator, participants were able to recognise the benefits of a plan. These benefits were

(seen to be) most valued by parents, people with newly diagnosed asthma and those with severe asthma. People who had been dealing with asthma for any length of time generally felt more confident in the way that they were currently managing their asthma, and saw little benefit in a written asthma action plan. Similarly, people with relatively mild asthma typically felt that a complicated plan would be unnecessary given their basic treatment requirements.

People with asthma-like symptoms

Several participants who had not been diagnosed with asthma nonetheless reported experiencing symptoms which could potentially be asthma, some for most of their lives. Most felt that their symptoms were mild, intermittent and had little impact on their lives, and as such were considered to be more of an annoyance than a significant concern. Some had discussed their symptoms with others, but few had tried to address them specifically.

Knowledge of asthma varied widely among this 'undiagnosed' segment. Generally, asthma was perceived to be a severe and constant condition, typically affecting children, with family history seen as an important risk factor. However, not all participants saw it as serious, and some perceived adult asthma to be relatively mild in comparison with childhood asthma. Asthma was widely recognised as manageable through medication, yet awareness of other treatment options (such as exercise) was limited. In addition, there was evidence of a perceived stigma surrounding asthma, including connotations of weakness and not being able to lead a normal life.

Potential motivators to better management of their symptoms included having an explanation for their symptoms, understanding that their symptoms could be treated and, consequently, increased peace of mind and sense of health.

There were, however, a number of barriers to improved management of symptoms among this segment. One such barrier was the belief that shortness of breath and wheezing during exercise are fairly normal among older people. For many, the low perceived severity and impact of their symptoms made addressing them seem neither urgent nor important, particularly given that asthma was often seen as something diagnosed in childhood and something worse than what they were experiencing. Some showed a general reluctance to visit a doctor, often due to fear of the outcome, a 'soldier-on' mentality or the time and cost involved. Some already had an alternative explanation for their symptoms, and many did not want to be diagnosed with asthma. The belief that their symptoms could not be addressed was a barrier for a few. Further, some were reluctant to use (prescribed) medication on an ongoing basis, and many needed to be convinced that not treating asthma (or their unidentified symptoms) would in fact be detrimental and that treatment could maintain or improve their lung function for longer.

For these participants, the major source of information about asthma had been the experiences of family members with asthma, and (to a lesser extent) advertising and media. Yet most people with asthma-like symptoms had not actively sought information about asthma and, in the absence of a diagnosis, most showed little interest in finding out more. The main barriers included potential 'information overload' and low perceived relevance of asthma-related information (which could potentially be addressed by highlighting the range of symptoms associated with asthma). Many reported a preference for face-to-face communication, with pharmacists seen as accessible but potentially biased towards product sales. Most said that they would be open to advice from their doctor, although some would prefer to consult other sources of information before choosing a particular course of action (for example, naturopaths and the internet).

GPs and pharmacists

GPs and pharmacists considered the ongoing disease burden associated with asthma to be substantial. They often commented that, although they appreciate the severity of asthma, its gravity is often downplayed among those with asthma. In turn, it is believed that this then increases the seriousness of asthma, because people do not give it the attention that it warrants.

GPs and pharmacists felt that missed diagnosis is reasonably common, given the barriers that prevent patients from seeking treatment for asthma-like symptoms and that the diagnosis of asthma can be clinically difficult. Interestingly, late onset asthma appears not to be salient in the minds of health professionals.

GPs' and pharmacists' state of knowledge is not perceived by them to be a barrier to asthma management. However, there is some anecdotal evidence of missed diagnosis, and late onset of asthma appears to be less salient in their minds than other forms of the disease.

Poor management of asthma was considered to be a much larger problem than under-diagnosis. GPs and pharmacists see patients as being more reactive than proactive, not seeing their asthma as a chronic condition.

Many pharmacists feel their role in asthma management is important, yet limited. Pharmacists perceived their primary role as to advise patients on medicines, particularly overuse of Ventolin. AHWs are also seen to play an important educational role. Some feel it would be valuable to improve access to asthma educators, given the time constraints that GPs and pharmacists face.

GPs believe their role includes helping patients to be aware of any deterioration of asthma symptoms and identifying sub-optimal management. However, the extent to which doctors feel able to make a difference is seen to rely on client's level of motivation. Given patients are

perceived to have a low level of interest in their asthma, it was widely agreed that increasing awareness of asthma management in the community would be potentially very useful for GPs. Educational aids were seen as valuable in generating patients' interest in asthma management and providing basic information. It was felt that tailored resources are required for Indigenous people with asthma.

GPs generally appreciated the purpose and elements of written asthma action plans. Pharmacists were less familiar with these key elements, with some seeing plans as covering only emergency procedures.

GPs and pharmacists identified a number of potential advantages of written asthma action plans. Patient empowerment was seen as a key benefit of written plans. Despite these perceived benefits, the vast majority of GPs seldom write plans, if at all. Doctors said they expect most patients will not use written asthma action plans and will not return for a review.

GPs and pharmacists cited a range of sources from which they had learnt about asthma. When asked whether they would trust information from the Australian Government Department of Health and Ageing, there was concern that the Department's perspective would be impractical. The preferences stated by GPs and pharmacists in the research suggest that no single communication channel will suit everyone.

Conclusions and recommendations

Many people with asthma adjust their life to fit their asthma, rather than questioning their management regime. Therefore, there is a need to increase people's recognition of the indicators of poor asthma management, to help them to understand that these are largely avoidable, and to highlight the benefits of managing asthma better.

There is clear evidence of a number of significant knowledge deficits, persistent false beliefs, and suboptimal practices. Despite this, there is little appetite for information on asthma, except at and soon after initial diagnosis and after more severe episodes and/or hospitalisation. Others say that they will accept information, but not seek it out. Therefore, to communicate successfully with people with asthma, it is important to make better use of the limited opportunities for knowledge transfer, given most are unmotivated to learn more about asthma.

Most people with asthma need to be convinced that a plan would have more than minimal value in their circumstances. This is particularly the case for those with mild or intermittent asthma, or for those who see their current management regimes as stable and adequate. A key challenge for the asthma awareness initiative, especially the promotion of written asthma action plans, is to encourage asthma management to be seen as an ongoing issue, not something that only happens when one's symptoms deteriorate.

Many who are undiagnosed, but have asthma-like symptoms, do not appreciate that asthma can have mature onset and can be mild or variable. The perceived relevance of asthma to these people could be increased by highlighting the symptoms associated with asthma. The asthma awareness initiative needs to encourage people and their GPs to see symptoms such as wheezing, persistent coughing and shortness of breath as potentially being asthma and amenable to management.

There was limited interest among GPs and pharmacists in more information about asthma. The Department faces some skepticism about its role in directly facilitating asthma management, given it is not seen to be in touch with frontline practice.

Increasing awareness of the potential for better asthma management could assist GPs and pharmacists in generating interest among patients. This would help to overcome one of the most significant barriers to GPs' and pharmacists' taking a more active role in asthma management.

2

This section outlines the background to the project, and specifies the research objectives

RESEARCH CONTEXT

2.1 Background

What is asthma?

Asthma is a chronic inflammatory disorder which affects the airways and causes recurrent episodes of wheezing, chest tightness and shortness of breath. Although the causes of asthma are still poorly understood, the risk factors are better understood, both in terms of constitutional factors specific to the individual with asthma, and environmental factors such as pollen and other triggers.

There are more than 2.2 million Australians with asthma. According to the "Asthma in Australia 2005" report, asthma affects 14-16% of children and 10-12% of adults. Among pre-teens, asthma is more common in boys than girls. However, among adults, it is more prevalent in women than men. Further, asthma rates are higher among Indigenous Australians than non-Indigenous Australians, and asthma fatality rates are highest among older Australians (over 65 years). Evidence also suggests that there are differences in the management and impact of asthma between men and women, younger and older people, residents of major cities and regional or rural inhabitants, and Indigenous and non-Indigenous Australians .

Asthma management initiatives

Although, as yet, there is no known cure for asthma, good management of the condition can reduce the likelihood of severe episodes and improve quality of life for those with asthma. Clearly defined interventions can significantly reduce the burden of asthma on individuals and

the community. These include the conduct of medical reviews, self-management, asthma education and the development of written asthma plans.

These interventions have been incorporated into asthma policy in Australia over the past 20 years. The strategic background to asthma policy development in Australia is outlined below:

- In the late 1980's, a National Asthma Management Plan was developed as a result of the concerns of health professionals, consumers and governments over rising morbidity and mortality rates associated with asthma.
- At this time, the National Asthma Council (NAC) was established to raise community awareness of asthma, and to promote asthma management. NAC was responsible for the first national public education campaigns which were run in 1988.
- In 1999, asthma was identified as a National Priority by Australian Health Ministers.
- The National Asthma Reference Group (NARG) was established in 2000 to advise on the implementation of initiatives designed to improve asthma outcomes.

Within the strategic framework described above, a variety of initiatives and programs have been launched in order to improve asthma awareness and management. The sections below provide an overview of these initiatives

Past campaigns and education programs

The NAC has undertaken several communication campaigns since the late 1980s, including "Could it be asthma?", a large scale social marketing campaign which included television, radio and print advertisements. Communication activity around asthma has also been undertaken by pharmaceutical companies, and in some States by their respective Asthma Foundations. Recently, Government funded communication activities have been undertaken, which are discussed below in more detail.

Short Wind asthma sickness campaign (video and print materials): The short wind series was developed by the Asthma Foundation Northern Territory and was produced with the support of Aboriginal people to show how short wind/asthma sickness can be managed. The materials provided information regarding the symptoms, how to manage asthma through different medications and what to do when a person is in danger.

The **National Asthma 3+ Visit Plan Pharmacy Communication Strategy**: In 2004 the Pharmacy Guild of Australia and the Pharmaceutical Society of Australia were provided with funding from the Department to develop the National Asthma 3+ Visit Plan Pharmacy Communication Strategy. This strategy involved benchmark research, the development of promotional and advertising material targeting pharmacists, GPs and stakeholders. A campaign

was conducted from August to October 2004, which included promotional and advertising material targeting pharmacists and GPs, such as an information kit (consisting of posters, information cards, referral pad, pharmacy counter mat, and consumer information deskpad), and the Asthma 3+ visit plan flyer for health professionals.

Supporting communication materials: In March 2005, a set of eight information "papers" targeting health professionals and eight consumer brochures targeting the general public was launched. These papers covered the following topics:

- Asthma and allergies
- Asthma and air pollution
- Asthma and Complementary therapies
- Asthma and Infant Bedding
- Asthma and pain relievers
- Asthma and lung function
- Asthma and diet in early childhood
- Asthma and Wheezing in the First Years of Life

These resources were developed to support health professionals and people with asthma to understand and manage their asthma.

The Asthma Management Program

In the 2001-02 Federal Budget, the Asthma Management Program was announced. This was originally established as a four-year program, managed by the Department of Health and Ageing, with the aim of reducing the impact of asthma within Australia. Specifically, the Program's objectives were to facilitate best practice treatment and management for people with asthma; to encourage proactive asthma management through education initiatives; and to reduce the social and economic impact of asthma. The Asthma Management Program comprised a number of sub-programs, which are outlined below.

The 3+ Visit Plan: The 3+ Visit Plan provides financial incentives for GPs to improve the care provided to people with moderate to severe asthma. Under this plan, patients make three visits to their GP in order to assess their condition, receive asthma education, and develop and then review a written asthma management plan. Since its introduction in 2001, additional initiatives have been launched to assist GPs to better manage their patients' asthma, including a Chronic Disease Management item which has been added to the Medicare Benefits Schedule.

Asthma Friendly Schools Program: The Asthma Friendly Schools Program is designed to give teachers, students and parents the information and practical skills needed to recognise an asthma emergency and to take appropriate action. The rationale for a focus on schools reflects the high prevalence of asthma among school-aged children and the fact that asthma has a significant impact on school attendance and participation.

Asthma Community Support and Community Grants Program: The Asthma Community Support Program provides community based support to people with moderate to severe asthma, and complements the role of GPs in facilitating the successful uptake of the written asthma action plans by consumers. The Asthma Community Grants Program is designed to increase knowledge of best practice asthma management and to promote active participation by local communities.

Physicians Asthma Communication and Education (PACE): This Program provides doctors with information on how to communicate more effectively with patients and how to educate patients about asthma. The aims of the PACE Program are to reduce asthma morbidity and to improve the quality of patient care by enhancing clinicians' therapeutic, patient education and counselling skills.

A-Teams: The A-Teams Project is conducted by the NAC and funded by DoHA. The aim of the project is to educate GP and allied health professionals in best practice management of asthma and use of the Asthma 3+ Visit Plan.

The Asthma Management Program 2005-06 to 2006-07

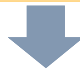
The 2005 Budget renewed funding for the Asthma Management Program. Following advice from NARG, Parliamentary Secretary Christopher Pyne approved a four-year framework to implement the program against six strategic objectives, being Asthma Awareness; Consumer Action and Self Management; Service Improvement; Care Models for Priority Groups; Workforce Development; and Monitoring & Evaluation. The program funds activities consistent with these objectives including support for best practice management of asthma through the MBS, the Asthma Friendly Schools Program, the Asthma Community Support Program, the Asthma Targeted Intervention Grants Program, and the Australian System for Monitoring Asthma. Funds of $3.9 million have been made available for the Asthma Awareness Communication Initiative until June 2009.

The objectives of the strategy are illustrated in the following diagram.

To inform the ‘undiagnosed’ of symptoms associated with asthma and problems resulting from poor asthma management.
(Emphasis on older Australians with undiagnosed asthma)

To increase the proportion of people with asthma or asthma symptoms who consult medical advice to review symptoms and develop a written asthma action plan.

To increase the proportion of people with asthma who use a written asthma action plan to manage their asthma effectively.



To increase awareness among GPs and other health professionals of available resources to facilitate best practice asthma management.

The primary target audience for the communication initiative will be people with asthma and their carers, including priority population groups such as parents/carers of young children, older Australians, Indigenous Australians and people from non-English Speaking Backgrounds.

The secondary target audience will be health care professionals, including general practitioners, asthma educators, pharmacists and other health professionals, including community nurses, Aboriginal Health Workers and state and local government health workers.

Need for research

The Department of Health and Ageing commissioned research to inform the development and key messages of the communication strategy. This helped ensure that the communication strategy would reach the appropriate target audiences, fill existing knowledge gaps, and correct misperceptions so as to increase the incidence of best practice of asthma management and reduce the impact on individuals and society.

2.2 Research objectives

The research explored the following key areas:

- Perceptions of asthma: diagnosis, symptoms, frequency and severity, causes, treatment, management, impact of asthma on a person’s life.

- Knowledge, attitudes and beliefs regarding asthma, including awareness of best practice asthma management and perceptions of the role of health professionals.
- Behaviour and intentions with respect to asthma management.
- Perceptions of risk regarding asthma.
- Communication issues relevant to asthma management.

The research program undertaken to meet the research objectives and explore these issues of interest is outlined in the following section.

3

This section provides details of the research methodology.

RESEARCH DESIGN

3.1 A qualitative approach

In order to achieve the objectives outlined in Section 2.2, a qualitative exploratory research program was undertaken. This allowed for a detailed and flexible examination of issues relating to people's behaviours and the awareness, perceptions and attitudes upon which these behaviours are based. This flexibility is advantageous, in that it allows participants to raise issues, enabling researchers to identify the issues of greatest significance to the target groups.

Two methods were employed in this research, incorporating both group discussions and in-depth interviews. Group discussions offered a number of advantages, including increased interaction and efficiency. However, where suitable participants were of low incidence, it was hard to gather a group in any one location, and thus it was more feasible to conduct one-on-one in-depth interviews. In addition, in-depth interviews allowed more detailed exploration of the individual's knowledge, attitudes and behaviours. Additional information about the advantages and suitability of these methodologies is given below.

In total, the qualitative research program involved **22 group discussions, 5 mini-group discussions and 21 in-depth interviews**.

Research participants

The research primarily involved people who have asthma or whose children have asthma. One of the most common and accepted definitions of current asthma is those who report themselves (or their child) having been diagnosed with asthma and having had symptoms of,

or taken treatment for, asthma in the preceding year. Research participants were separated into the following segments:

- parents and carers of children aged up to 12 years who have asthma;
- teenagers (high school students) with asthma;
- 20-34 year olds with asthma;
- 35-54 year olds with asthma;
- those over 55 years with asthma, and
- those who exhibit asthma-like symptoms, but who have not been diagnosed with asthma, with an emphasis on those over 40.

Details of the sample structure for the research with people with asthma and their carers, and people with asthma-like symptoms, is detailed under Section 3.2.

The research also included GPs, pharmacists and Aboriginal Health Workers (AHWs), who formed the secondary target audience for the communication initiative. Details of this component of the research are explained under Section 3.3.

3.2 Sample structure for people with asthma or asthma-like symptoms

Sample structure (mainstream population)

A stratified purposeful sampling strategy was employed. The sample structure for people with diagnosed asthma is shown in the following tables, involving 16 group discussions and 9 interviews. In addition, 2 group discussions were conducted with people who had not been diagnosed with asthma, but had experienced asthma-like symptoms in the last twelve months. [1] The number of participants in each group discussion is shown in brackets in the table.

[1] Given the poor turnout in two of the group discussions, an additional 2 in-depth interviews were conducted to supplement each of these groups, as shown in the following table.

	Asthma status / severity	
	Moderate, mild or very mild	Very severe, severe or moderate
Parents and carers	4 mixed gender group discussions Sydney (7) Adelaide (7) Coffs Harbour (6) Goulburn (5)	2 in-depth interviews (male Adelaide, female Coffs Harbour)
Yrs7-9 at school	2 group discussions Female, Toowoomba (3) Male, Adelaide (8) 2 in-depth interviews Female, Toowoomba (2)	1 in-depth interview (male Adelaide)
Yrs 10-12 at school	2 group discussions Female, Cammeray (8) Male, Wagga Wagga (7)	
18-34 years	2 group discussions Female, Adelaide (6) Male, Dubbo (8)	3 in-depth interviews (female Adelaide, male Goulburn & female Coffs Harbour)
35-54 years	2 group discussions Female, Coffs Harbour (6) Male, Brisbane (6)	
55+ years	4 mixed gender group discussions Sydney (8) Brisbane (7) Goulburn (5) Toowoomba (6)	3 in-depth interviews (male Sydney, male Goulburn & female Toowoomba)
'Undiagnosed'	2 mixed group discussions Brisbane (5) Dubbo (8) 2 in-depth interviews 1 male 1 female	

The key variables taken into account in structuring the sample are discussed below.

Geographic location. Research has found that important differences exist between metropolitan and non-metropolitan areas in terms of their access to information, resources and healthcare. Although the incidence of asthma does not differ between cities and outer areas, people living in outer regional or remote areas are slightly more likely to die from asthma and have a higher rate of hospitalisation due to asthma, than people in cities and large towns. Therefore, metropolitan and non-metropolitan areas were equally represented in this study. Specifically, research was conducted across three states and territories, in the following locations:

- Metropolitan areas: Sydney (north and west), Adelaide and Brisbane.
- Non-metropolitan areas: Dubbo, Goulburn, Toowoomba, Coffs Harbour and Wagga Wagga.

Asthma severity. The majority (83%) of asthma cases are very mild or mild, while only 6% are severe or very severe, and 11% are classed as moderate. The group discussions with people with asthma included those who had (or whose children had) very mild to moderate asthma only. Those individuals with severe asthma may have had greater awareness and knowledge of asthma, and also more pronounced attitudes in relation to their condition. As such, if included in the group discussions, people with severe asthma would have had the potential to impact greatly on the views expressed by the rest of the group.

Hence, individual interviews were conducted with those who had more severe asthma (including very severe, severe and moderate asthma). In addition to the reasons outlined above, the very low prevalence of moderate to very severe asthma meant that in-depth interviews were the most appropriate methodology for researching this target group.

For the purposes of recruitment, people were not simply asked "Do you currently have asthma?", because there were likely to be a number of difficulties with this approach. One of the most common and accepted definitions of current asthma is those who report themselves (or their child) having been diagnosed with asthma and having had symptoms of, or taken treatment for, asthma in the preceding year. Therefore, the following questions were used to determine whether someone had asthma:

- Have you (has your child) ever been diagnosed with asthma?
- Have you (has your child) used asthma medication in the last 12 months?
- Have you (has your child) experienced any symptoms of asthma in last 12 months?

If participants answered yes to the first, and yes to either or both of the second and third questions, then they were classified as having asthma.

To determine eligibility for an in-depth interview or group discussion, a description of severe/very severe asthma was read out, and potential respondents were asked whether they believed that they were a severe or very severe asthmatic. A similar approach was used to help differentiate very mild or mild asthma from moderate asthma. This approach was chosen to minimise the subjectivity of participants' responses.

The following is what was read out to potential participants: "Most asthma cases are classed as very mild, mild or moderate. A small proportion of people with asthma, 6%, are classified as severe or very severe asthmatics. Very severe asthma is an incapacitating illness, with disabling symptoms everyday. Severe asthma is characterised by frequent wheezing every day, chronic illness, limited lifestyle and serious sleep disturbance on most nights. Would you say that your (your child's) asthma is severe? (If participant is unsure, read out description of

moderate asthma to compare.) Moderate asthma involves daily symptoms, with sleep disturbance at least once a week, and avoidance of sports and exercise."

For recruiting people with asthma-like symptoms, but no diagnosis of asthma, the following questions were used:

"Have you experienced any of the following symptoms in the last 12 months? [READ OUT:]

- Persistent wheezing
- Persistent coughing
- Regularly feeling short of breath
- Feeling tightness in the chest"

If potential participants said that they experience tightness in the chest, but did not report experiencing any of the other symptoms, then they were also asked, "Have you been diagnosed with a heart condition?" Participants who said no qualified for the research. All of the other symptoms were sufficient on their own to qualify for the group discussions, and tightness in the chest was sufficient on its own in the absence of a diagnosed heart condition.

Socio-economic status. Research has shown that people with asthma from lower socio-economic groups tend to know less about asthma and, therefore, manage their asthma less successfully. Location was used as a rough proxy for SES across the sample, with specific locations being selected to ensure broad SES representation in the research.

NESB. The incidence of asthma in people from non-English speaking backgrounds is lower than that found in other Australians, although people with asthma from non-English speaking backgrounds (NESB) may be less likely to seek information and support than those from English speaking backgrounds. Given budgetary constraints, it was not possible to conduct separate group discussions with NESB participants. However, NESB participants were represented in the sample, reflecting their natural incidence among the population of asthmatics.

Life stage. Parents and carers of young children were identified as a target group for this research. The sample of parents and carers included those with at least one child with asthma who is aged 12 years or younger. This included children who had been recently diagnosed, as well as those who had been diagnosed some time ago. The group discussions with parents were mixed in gender. Given that there are more female primary care-givers, the sample reflected a slightly higher proportion of females than males.

The four group discussions with teenagers were stratified by age, as reflected in school year. This was important in determining whether people's views differed with increased maturity, and also allowed greater group cohesion and comfort. High school age respondents were recruited into two strata, as shown in the preceding table (p16). School year generally provides a better basis for creating group cohesion and is a better proxy for developmental maturity than chronological age. Young people tend to identify by school year much more than by age. High school age young people were further split into two year bands: years 7-9 and years 10-12, simply because the gulf between year 7 and year 12 was too vast to be compatible with a cohesive group discussion.

Among teenagers and younger adults (20-34 years), separate groups were conducted with males and females. During one's school years, anecdotal reports revealed that asthma may be associated with being 'weak'. Therefore, there were likely to be issues that carried through to young adulthood that may affect self-image, perhaps more so with young males. For instance, people with asthma might have felt self-conscious about their asthma and thus felt uncomfortable disclosing their true feelings in front of members of the opposite sex. With young males, there may have been a tendency to exhibit macho behaviour if groups were conducted with mixed gender.

Despite the fact that the incidence of asthma is higher among adult women than adult men, adults aged over 55 were considered less likely to feel self-conscious in front of members of the opposite sex. Therefore groups of mixed gender were deemed appropriate for older adults.

Indigenous research component

Given that the incidence of asthma is higher among Indigenous communities than the mainstream population, a separate component of research was dedicated to exploring the views and experiences of Indigenous Australians. In total, 5 mini-group discussions were conducted with Indigenous people with asthma or their carers. These group discussions were conducted across metropolitan and non-metropolitan areas, as illustrated in the following table.

Parents and carers	1 paired interview 1 in-depth interview Dubbo
High school	2 mini-group discussions Female Redfern (2) Male Dubbo(3)
20-54 years	1 mini-group discussion Mixed gender, Wollongong (4)
55+ years	1 mini-group discussion Mixed gender, Redfern (4)

Due to the project time and budget constraints, it was agreed that the group discussions with Indigenous participants would be held in NSW only, in metropolitan, regional and semi-rural

communities. (As noted in Section 3.3, to gain further insight into the experiences of Indigenous people with asthma, interviews with GPs, pharmacists and AHWs who work with Indigenous communities were conducted across three states, including remote locations).

The mini-group discussion conducted with Indigenous female teenagers had a poor turnout, with only two eligible participants. The recruiters made several attempts to reschedule this group discussion, working with three further communities to try to recruit appropriate participants. None of these proved successful avenues in the project timeframe.

Input was sought from the National Aboriginal Community Controlled Health Organisation (NACCHO) in developing the discussion guide for the Indigenous component of the research.

3.3 Sample structure for GPs and pharmacists

General population component

The sample structure for the non-Indigenous group discussions with GPs and pharmacists is shown in the following tables, involving four group discussions and six interviews. (A separate Indigenous component of six interviews is described further down.)

	Profession	
	GP (or other primary care giver)	Pharmacist
Metro area with older patients	1 group discussion Sydney(6)	1 group discussion Adelaide (6)
Metro area with younger patients	1 group discussion Brisbane(5)	1 group discussion Sydney(5)
Rural area	3 interviews (Toowoomba x 2, Coffs Harbour)	3 interviews (Dubbo, Coffs Harbour, & Goulburn)

Five or six health professionals were involved in each group discussion. Keeping the numbers in each discussion manageable was necessary to allow sufficient time to explore participants' knowledge, skills, attitudes, behaviours and communication issues relevant to asthma management.

The key variables taken into account in structuring the group discussions are discussed below.

Health professional. The first category of health professional sampled as of relevance to the proposed asthma awareness communication initiative were GPs, who are generally responsible for diagnosing asthma, and developing and delivering the tailored Asthma Management Plan.

The second category of health professional was pharmacists, who may assist people with asthma with some of the practicalities of using the Asthma Management Plan and about the effective use of their asthma medications.

Geographic location. As noted above, research has found that important differences exist between metropolitan and non-metropolitan areas in terms of their access to information, resources and healthcare. Therefore, research with GPs and pharmacists was conducted in both metropolitan and rural locations. Group discussions were held only in metropolitan locations. In rural locations, in-depth interviews were used as an alternative, given the difficulties that can be experienced bringing together GPs and pharmacists, and the small population of health professionals in small country towns.

Patient population. The vast majority of GPs and pharmacists service people across the age and life-stage spectrum. Clearly, however, practices do vary in the proportion of patients who may be classified as older and younger, often because the location is considered attractive to, say, retirees or young families. In the metropolitan areas, we conducted one discussion with GPs and pharmacists who had a relatively higher proportion of older patients, and one discussion with GPs and pharmacist who had a relatively higher proportion of younger patients. Across the three in-depth interviews with GPs in rural areas, and three in-depth interviews with pharmacists in rural areas, we again ensured that some interviews were with GPs and pharmacists whose practice services a higher proportion of older patients and some with GPs and pharmacists whose practice services a higher proportion of younger patients.

Size of practice. GPs were recruited from a mixture of both small and large medical practices.[2] We included a minimum of two people from small practices and two people from large practices per group discussion.

Pharmacists were recruited from both individually-operated stores and from stores operating within a chain. We included a minimum of two pharmacists from individually-operated stores and two from stores operating within a chain per discussion.

Experience. It was vitally important when conducting this research with GPs and pharmacists to take steps to ensure that not all participants were relatively recent graduates, who are often more likely to agree to attend a group discussion for a multitude of reasons including the attractiveness of the incentive. Therefore, we ensured an appropriate spread of both graduation years, and roles within the business (whether they are self-employed or employees).

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[2] To allocate participants, GPs were asked, "Would you say that your practice is relatively small or relatively large?" during recruitment.

Gender. All groups were mixed in gender.

Indigenous population component

The sample structure for the six interviews with health professionals who service a higher proportion of Indigenous people is shown in the following table.

	Profession		
	GP	Pharmacist	AHW
Metro area	1 interview	1 interview	1 interview
Regional/Remote area	1 interview (Remote)	1 interview (Remote)	1 interview (Regional)

The key variables taken into account in structuring the in-depth interviews are discussed below.

Health professionals. Two interviews were conducted with GPs who service significantly more Indigenous patients than average and two interviews with Aboriginal Health Workers (AHWs) who are (or would be) responsible for the development and delivery of management plans for chronic health conditions. Two pharmacists who service significantly more Indigenous patients than average were also included.

Geographic location. One GP interview and one AHW interview were conducted in metropolitan locations, with one AHW interview taking place in a regional location and one GP interview taking place in a remote location. One of the pharmacist interviews was carried out in a metropolitan location, and the other in a remote location.

Across the six interviews, we ensured a range of experience and an equal representation of genders.

3.4 Conduct of the research

Eureka's project team personally conducted most aspects of the project, except the recruitment of research participants and moderation of the Indigenous mini-groups. Streetwize was subcontracted to arrange the Indigenous research component, and to co-facilitate these mini group discussions (in conjunction with Eureka's consultants). The analysis of the Indigenous component was undertaken by Eureka, with the draft report reviewed by the Streetwize Indigenous moderator, to ensure the cultural accuracy of the interpretation of findings.

Recruitment of research participants

Professional recruiters were used to find participants for the group discussions. Eureka devised a screening questionnaire that obtained information necessary to allocate participants to the appropriate group discussion. The screening process also ensured that participants:

- do not work in advertising, media or marketing, and
- had not participated in a focus group for the last six months.

Group discussions with people with asthma and their carers comprised an average of 7 participants, and group discussions with GPs and pharmacists involved 5-6 participants.

Content of discussions

Comprehensive discussion guides were developed in conjunction with the Department, as the basis of both the group discussions and interviews.

In conducting research with people with asthma, a key challenge is to unearth the barriers to asthma management. In previous research, Eureka found that a common barrier to proper asthma management was the belief that one's asthma was not bad enough to warrant further action. Such research has shown that it is useful to challenge people's attitudes by asking them the following questions:

- Recently, how often have you typically used your reliever medication each week?
- Do you wheeze or cough frequently?
- Do you wake at night from your asthma?

Eureka believes that these questions form a useful diagnostic to determine whether someone is actually managing their asthma properly, and this approach was therefore adopted in the current research.

Duration and incentives

All group discussions were approximately 1½ hours in duration. In-depth interviews were approximately 1 hour in duration.

Participants with asthma or their carers, or people with asthma-like symptoms, received an incentive of $60 to encourage participation and compensate them for costs incurred. For group discussions, GPs and pharmacists received $200 and for in-depth interviews, they received $120.

4

In this section, findings from the group discussions and interviews are documented.

RESEARCH FINDINGS

This section reports the findings from the group discussions and in-depth interviews conducted with:

- people with asthma;
- people with asthma-like symptoms; and
- GPs, pharmacists and AHWs.

Where it would assist the reader to understand the research findings, verbatim quotations from research participants have been included. These illustrate the range of views typically expressed. Further such quotations have been included as Appendix B to this report.

4.1 People with asthma

Knowledge about asthma

Most people felt that their knowledge of asthma was sufficient to enable them to manage their condition adequately, as illustrated in the quotations below. Although many realised that there were some gaps in their knowledge, people did not expect to know everything. Therefore, participants generally did not perceive a critical need to seek further information to improve their knowledge above its current level.

"I think I have a good grasp and, because I am not really that bad, it doesn't really interfere with my life." [55+]

"At this stage, I know enough to keep my son healthy and keep myself healthy so, unless it changed, then I would further my knowledge." [35-54]

Most people had a good knowledge of the range of asthma symptoms. The most widely mentioned symptoms were tightness in the chest, difficulty breathing, and wheezing. Most adults knew that asthma could be fatal in some cases. However, a few younger participants did not realise that asthma could cause death.

Some people confused asthma with other illnesses, or believed that symptoms of other conditions and ailments were attributable to asthma, as indicated in the following quote.

"His symptoms in between attacks were, like, snotty nose and ear-aches and stuff." [Parent]

Most could not describe the physical mechanism of asthma, particularly younger people with asthma. That is, a number of participants displayed poor knowledge regarding the internal workings of the body during an asthma attack.

"It could be dust getting caught in your throat, giving you less breathing space to let less air into your lungs." [Teenager]

"I have an idea – when you're running you're wheezing from all the pollens coming in – it fills up your pipes. It's just an idea here." [Teenager]

There was high awareness of the common asthma triggers, particularly dust and pollen. Other frequently mentioned triggers included exercise and physical activity, weather (including humidity and extremes or changes in temperature), illness (particularly colds, flu or chest infections), chemicals and perfumes, certain foods (such as dairy products and non-organic foods), stress, and animal fur or hair. Generally, tobacco smoke was a less salient trigger and tended to be mentioned more frequently by non-smokers than smokers (and normally only after prompting).

There was significant discussion of asthma being an episodic, rather than a continuous, condition. This was largely due to asthma often being induced by specific factors. For example, many participants perceived their asthma as cold-induced, exercise-induced, or related to bronchial conditions or seasonal factors.

"It's different during different times of the year. Sometimes it flares up. Other times it seems to be OK." [55+]

"Things can trigger me, like dust. So I'm not really an asthmatic, but if I get caught in a situation like that it very quickly creates asthma, and very quickly it turns to bronchial asthma, into bronchitis." [35-54]

"It's just mainly seasonal, mainly in winter and in spring with the pollen in the air he gets affected a lot." [Indigenous parent]

Many people realised that there is no known cause of asthma, although this was an area of interest for most. Some participants mentioned causal theories that they had heard, which suggested asthma might be caused by increases in environmental pollutants or, conversely, children being raised in overly sterile environments (that is, lack of exposure to germs and pollutants). Hence, this was one particular area where knowledge was seen to be lacking or less certain. In addition, some found it hard to differentiate between triggers and causes. Family history was particularly salient as a key risk factor for asthma, with many participants having other family members with asthma, often across multiple generations.

KNOWLEDGE OF TREATMENT

Among this sample, medication was the most widely known form of treatment for asthma. However, some people did not distinguish between preventer medication and reliever medication. The role of preventer medication, and the fact that it needed to be used on an ongoing basis, was not always understood.

"He hasn't got any energy so he'll sleep, and that's how you know that he needs some [preventer]." [Indigenous parent]

In addition, exercise (particularly swimming) was commonly seen as an effective form of treatment. Yet others felt that exercise was to be avoided, as it was a trigger for their asthma.

Participants demonstrated some awareness of alternative treatments, including breathing techniques (such as the Buteyko Breathing Method), acupuncture and naturopathy. Overall, awareness of treatment options appeared lower among Indigenous people than non-Indigenous people.

Some people, especially Indigenous teenagers, were unaware of what they should do in an emergency situation. For others, best practice in an emergency was seen to involve the following key elements:

- use your reliever medication;

- try to calm down; and
- call an ambulance or doctor if the situation is dire.

On the last point, it should be noted that some find it quite difficult to judge when they have reached the stage at which they need to go to hospital, as indicated below.

> *"Then there's times when you should have gone [to hospital], but you didn't because you think you're alright, but you're not really." [55+]*

Attitudes towards asthma

Participants generally realised that asthma could be serious and, in some cases, potentially life-threatening. In fact, several had had acute episodes that they viewed as serious.

> *"You don't know what is going to happen. You wonder about yourself, 'Am I going to come out this time?'" [Indigenous, 55+]*

Mostly, however, people did not see their asthma as serious. Instead, asthma was seen as a minor irritant: something that comes and goes. Participants generally rejected the idea of asthma as a disabling condition.

Indeed, some teenagers see their asthma as transient, with some participants saying that they felt that they would outgrow their asthma. Yet people with severe asthma were more likely to perceive their ongoing condition as serious.

People's reactions to being diagnosed with asthma ranged from relief, that the source of their health problems had been identified and was able to be treated, to shock, particularly among those with mature onset asthma, as it was typically perceived as a condition affecting children. Other participants had a great deal of trouble accepting the diagnosis.

> *"I used to wake up at night and not be able to breathe, and when I found out what it was, I thought, 'thank God'." [35-54]*

> *"It depressed me because I was thinking, 'oh God, I now have something wrong with my lungs'. It depresses you when you wake up of a morning, and I cry." [Indigenous, 55+]*

It is evident that there is still some stigma associated with asthma, with some participants feeling embarrassed about friends or strangers finding out that they have asthma, or about taking medication in front of others.

"I don't tell my friends that I've got asthma." [55+]

"I used to get hassled in year three [for taking my puffer to school]. So I stopped." [Indigenous teenager]

On a day-to-day basis, most see asthma primarily as an inconvenience or hassle, rather than a serious health concern. For some, this relaxed attitude seemed to be a way of coping with having the condition (that is, staying positive and getting on with one's life, rather than being constantly worried).

Parents were more likely to be worried about their children's asthma than their own (among those who also had the condition), and parents were more likely to see asthma as serious compared with other groups involved in this research. In particular, parents often said that they were particularly concerned about their children's asthma when first diagnosed.

"If it was your kid, you'd probably go [to hospital] straight away. With yourself, you're saying 'I've got other things to do, I won't go now'." [55+]

"When [my son] first got it, I didn't know what it was … it frightens you more than anything, because they can't breathe." [Indigenous parent]

Some parents, who also had teenage children with asthma, expressed frustration that their children do not share their perception of asthma as being serious.

Participants were asked about the ways in which asthma impacted on their and their children's lives. The following types of impact were mentioned:

- needing to take time off from work and/or study;
- not exercising or exercising less frequently than previously;
- being short of breath in everyday situations;
- feeling tired and/or experiencing disruptions to one's sleeping patterns;
- being more susceptible to respiratory illness;
- emotional impact (such as increased frustration, irritability and stress);
- deciding to move to another location in order to avoid triggers that relate to one's current surroundings (such as climate, pollution levels, dust levels and so on);

- being an inconvenience for those around you; and
- other ways in which asthma can impact on one's lifestyle (such as reduced social activities).

Illustrations of the ways in which asthma was perceived to impact on one's life are provided in the following quotations.

> *"They will never get 100% at school because he does get a lot more colds than other kids." [Parent]*

> *"If you are on an outing or something and you can't climb the steps and can't keep up with the rest and you might have to wait behind…it doesn't stop me, it just slows me down." [55+]*

> *"Come, say 5pm, when it's cold and that, they have to come inside and they're upset… the fact that they can't go out and play like the other kids." [Parent]*

> *"Then I lay down again and it will start again. I was up all night the other night, up and down like a yo-yo." [Indigenous, 55+]*

> *"Winter we will just stay at home because I don't like to travel when he is sick. Well I can't, because he needs to be stable. So you can't really. It's frustrating." [Indigenous, parent]*

> *"I play soccer and before like for ten minutes the other week, I couldn't breathe. So I used to play 90 minutes a week, now I play ten minutes." [Indigenous, 20-54]*

> *"I used to like going for a walk and sitting in the park for a couple of hours. I can't do that no more. You are a prisoner in your own home." [Indigenous, 55+]*

> *"I'm pretty mild all year round but if I actually start to run – I just try to keep exercise to just walking or dancing." [18-34]*

Those with severe asthma typically experience a more significant impact on their daily life. For example, some people in this sub-segment had become unable to work full-time. In addition, some felt that they had a severely constrained social life, with fairly basic activities (such as going to a family picnic or going shopping) becoming a significant burden or being avoided altogether.

> *"My life runs around it. It limits your social life." [55+ severe]*

"It runs my life. I don't have a quality of life - I just exist." [55+ severe]

Among those with mild to moderate asthma, many, especially teenagers, downplayed the impact that their asthma has on their life. Any limitations that were experienced were usually regarded as normal for people with asthma. Many tend to adjust their life to fit their asthma, rather than questioning whether their management is optimal.

Asthma management

This sub-section reports on findings relating to asthma management, including current practices among the research sample, key motivators and barriers, and the role of written asthma action plans.

CURRENT PRACTICES

Some people with asthma are clearly accepting high levels of symptoms and real restrictions on their day-to-day lives, rather than taking appropriate action to improve their health. With regard to current treatment, most reported using some form of reliever medication. However, the use of preventer medication appeared sub-optimal. A number of participants who had been prescribed preventer medication were not taking it as often as recommended or, indeed, at all. Others had not had their asthma reviewed for extensive periods of time (e.g. for five years, or even since diagnosis) and had just increased their use of reliever medication without considering whether an alternative medication regime might be required. As a result, some people's asthma was having a significant impact on their life.

"She only uses a puffer. She doesn't need it that often, but the fact that she wheezes at times at night and doesn't get a good night's sleep like she should, that's why she gets tired during the day." [Parent]

Compliance with medications (including preventer medications) generally seemed to be higher among older people than among teenagers and young adults.

Few participants appeared to monitor their asthma, other than by monitoring their symptoms. Peak-flow measurements were rarely taken, with many having limited awareness of their peak flows. Such measurements were perceived by some as unreliable, and some found them to be unnecessary (particularly those with mild asthma, or those who had had asthma for a long time). Peak flows were rarely used to detect pre-symptomatic worsening of one's condition. The following quotations highlight these issues.

"But you can feel it yourself, if you are tight. You don't need a peak-flow meter." [55+]

"[Peak-flow meters] are for when you're little. Your parents do that." [18-34]

"I used it in the early days but I found it didn't make any difference at all. It went out in the last garage sale." [55+]

"She doesn't use it all the time but if she feels a bit wheezy then she'll blow into it and check it out." [Parent]

Most participants reported that they only raise the issue of asthma with a health professional if their symptoms deteriorate, or if they require a new script. Some people with moderate to severe asthma and parents of children with asthma have regular appointments with a health professional to monitor their condition, but this was fairly uncommon. For some, hearing about new treatment options (for example, through word of mouth or media articles and programs) may prompt discussion with a health professional. Some Indigenous teenagers were generally reluctant to ask the doctor questions, including their asthma, as noted below.

"I am a bit afraid of the doctor. I don't feel comfortable to talk about anything else." [Indigenous teenager]

"I just want to deal with my kind of asthma but then, if it gets worse, I'll probably go get check-ups, and then I guess, if I get older and it doesn't really improve or it gets worse then, in the next couple of years, I'll go to the doctor's." [Teenager]

Since having their diagnosis initially confirmed, relatively few with mild to moderate asthma have had lung function tests conducted by a health professional. Some reported that their GP would ask about their asthma during a consultation on an unrelated matter. More importantly, many said that they would welcome their GP raising the issue of asthma, providing the subject was raised in a non-confrontational manner, as suggested below.

"If the doctor was like 'so, have you been giving him his preventer morning and night?', like in a kind of accusing way, then I might take affront. But if he was to say 'so, how's the asthma going?', I think that's great. I'd feel very positive about the doctor being proactive like that." [Parent]

A few people were less open to this idea of the GP asking about their asthma, particularly smokers, who felt they would be berated for continuing to smoke.

Based on discussions with people with asthma, only some pharmacists appear to be playing a role in people's asthma management. This is largely confined to explanation of the medication that people are using, including potential side effects and interaction effects between different types of medication.

Some teenagers appear to be taking (at least) partial responsibility for their own medication. However, parents seem to take significant responsibility for managing the asthma of their teenage children. For example, engaging in a dialogue with the doctor and the purchase of medication are usually left to the parent. Many parents also act as a reminder for their children to take their asthma medicine.

> *"I never used to take it and I used to get it really bad, but now I take it because I don't want to miss out on any game of footy, so I want to be more responsible with it." [Teenager]*

> *"My mum always, always has a puffer in the car and one in her handbags, and really useful places, and just sort of reminding." [Teenager]*

Generally, knowing and avoiding one's asthma triggers are seen as important aspects of asthma management. In particular, a number of participants have taken steps to minimise dust in the household (for example, the removal of carpets, installing air filters and using special vacuum cleaners). In addition, many people with asthma try to avoid extreme temperatures or humid environments, and several report avoiding certain foods (such as dairy products and non-organic foods). Parents appear to be particularly cautious about potential triggers for their child's asthma. However, participants showed limited understanding of the nature of passive smoking, often believing that it was sufficient to avoid smoking inside when their children were in the same room. In this way, the importance of smokefree homes was not always recognised.

Some reported using exercise (particularly swimming) to manage their asthma, and a few had used some form of alternative therapies (such as naturopathy, acupuncture and breathing techniques).

MOTIVATORS

To identify potential motivators for improved asthma management, participants were asked what they felt would be the benefits of managing their (or their child's) asthma better. Key perceived benefits were as follows:

- better overall health and increased energy levels;
- the ability to lead a normal life;
- easier to exercise, so one could maintain greater fitness;
- less need for medication;

- not needing to carry reliever medication at all times, (which appeared to be particularly important for teenagers), which is likely to be an unrealistic goal for most;
- experiencing fewer symptoms or reduced intensity and severity of symptoms;
- less worry of a severe asthma attack;
- less likely to become ill;
- less long-term lung damage;
- reduced impact on one's family and friends;
- greater independence;
- better sleep; and
- for those with severe asthma, the most critical benefit was seen as staying alive!

BARRIERS

Participants were also asked what, if anything, makes it difficult to manage their (or their child's) asthma better. Key perceived barriers to improved asthma management were as follows:

- complacency, particularly among those who had been dealing with asthma for a significant number of years;

    "Having had it all my life, I get a bit blasé about it." [35-54]

    "I don't manage mine, I just respond to it. That's not management." [35-54]

    "I've had it for 40 years, so I wouldn't mention it [to my doctor] every time. I might mention it if I had it really bad." [35-54]

- seeing their own (or their child's) asthma as mild, or as good as could be expected;
- self-confessed laziness and competing priorities;
- only perceiving the importance of managing asthma when their (or their child's) symptoms flare up;

- not recognising the importance of preventer medication, as indicated below:

> *"It's like taking an aspirin every day in case you get hurt. You wouldn't take an aspirin every day." [35-54]*

> *"I don't take preventative every day. If I feel that something is not quite right, then I will take it." [55+]*

- fear or distrust of steroids and other medications, particularly any side-effects or long-term health effects, as the following quotations suggest:

> *"I really worry about the steroids and, in my mind, I'm determined not to take it every day. I've heard that people can develop other health problems, like my friend, who told me her husband died because of steroid use for a heart condition." [35-54]*

> *"I try to put off using the puffer as long as I can, because I don't want to form a dependency on it." [35-54]*

- experiencing no evidence of the effectiveness of preventer medications;
- difficulties remembering to take their medication (or difficulties ensuring that their child remembered their medication every time);
- poor understanding of medications;
- not returning to see a doctor, and therefore being unaware of the range of appropriate treatment options;

> *"I just felt that the Ventolin was the only sort of treatment there was, and that if I went to the doctor, they'd just give me Ventolin." [35-54]*

- self-medicating (that is, obtaining Ventolin over-the-counter instead of through a GP);
- needing further information to be convinced that medication will prevent long-term health damage;

> *What I need to know in order for me to take preventative stuff is, first of all, what damage asthma is doing (like it scars your lungs) and I would need to know what it's doing long-term." [35-54]*

the cost of medication, asthma devices and health consultations being seen as high, particularly among Indigenous participants;

- concerns regarding access to medical services, particularly in rural and remote areas;
- perceiving doctors to lack time, and difficulties making an appointment;

> *"The doctors have got that many patients and they're in and out, same with the hospitals. That's why they don't tell you anything. They just treat you, get you out." [Parent]*

> *"It's really hard, when I get sick, to be told that I can't see the doctor for three weeks." [18-34]*

- lack of faith in the health profession's knowledge about asthma;

> *"Say, with heart disease, there's surgery, there's bypasses, they know what it is and they can fix it. Whereas with asthma, I don't think my doctor has a friggin' clue what it is." [35-54]*

- perceiving that they had limited ability to modify their environment;
- the desire to continue smoking or the inability to quit smoking;

> *"I don't drink...I don't take drugs, only what the doctor gives me, so what do you do? You smoke." [Indigenous, 55+]*

- certain school policies regarding medication, such as the need for teachers to keep medication in a locked cabinet and an unwillingness to assist in administering inhalers;
- poor understanding of asthma within the community, including the perception that asthma is not particularly serious, as suggested below;

> *"The teachers used to think I was putting it on. I was a bit of a rat bag, so they thought I was putting it on, and you would be there slowly dying, and they weren't interested, 'get back into P.E.'. That became life threatening a couple of times, because they didn't take me seriously." [18-34]*

> *"They had the cross country at school and before it he talked to a teacher and she said, 'Stop being lazy and get out there'. He is a big boy. He ended up keeling over and the school rang me and I had to take him home because he had a bad asthma attack. I was ropeable." [Parent]*

- among Indigenous people, difficulties communicating with the doctor;
- a 'set-and-forget' mentality, where people fail to review the effectiveness of their existing asthma management practices; and
- among teenagers, believing that they will grow out of their asthma, which can reduce the incentive to take their asthma management more seriously.

WRITTEN ASTHMA ACTION PLANS

Only a few participants knew what a written asthma action plan was, and even fewer actually had one. There were a few notable exceptions.

> *"I have to change the number of puffs I have according to how high I blow on the peak-flow so that's easier, and because my doctor writes out a procedure, so instead of going in there [to the doctor], I just have to read that." [Teenager]*

Many perceived (or assumed) that an action plan contained instructions for a severe episode. When the typical content of an action plan was explained by the facilitator, a number of benefits were perceived by participants. For example, an action plan was seen as giving a person with asthma the ability to monitor their progress or health status objectively, with the additional benefit of increased confidence regarding what to do if their asthma worsens (because the instructions would have the health professional's imprimatur). Further, having a doctor create a personal action plan was seen as creating a sense of partnership with the doctor. These findings are illustrated in the following quotations:

> *"Certainty of knowing that it is getting better or worse, rather than just the vagueness of memories." [Parent]*

> *"You feel like he's taking a genuine interest in you... that you are actually a patient and not another number." [55+]*

> *"I would think, 'oh, this is a good doctor, he's actually asking me about something I haven't mentioned that he knows about me'. That would make me feel like my doctor pays attention to me." [35-54]*

The benefits of a written asthma action plan were (and were seen to be) most valued by parents, people with newly diagnosed asthma and those with severe asthma, as the comments below suggest. People who had been dealing with asthma for a longer period of time generally felt more confident in the way that they were managing their asthma, and people with mild

asthma typically felt that a complicated plan would be unnecessary given their treatment requirements.

> *"I think the only people that would be good for is people that have just been diagnosed, because it is a really steep, fast learning curve. I don't think people like us would really take that much from it." [Parent]*

> *"That sort of information is what you give to a brand new person who never had asthma before. [We] know what to expect." [35-54]*

> *"I don't think in my case I need an action plan because it is moderate. I simply deal with the certain situation as it arises. I can understand if you have it fairly seriously, that's a different story." [55+]*

Nevertheless, some participants were receptive to the notion of a simple action plan that was tailored to their treatment needs and preferences. Many, however, saw minimal value in having a written plan for themselves or their child. For example, many felt that they were managing their asthma (or their child's) adequately and that they generally know what to do. Some were satisfied with verbal instructions from a health professional and felt there was no need for these instructions to be written down. Some participants did not want to view their (or their child's) asthma as an ongoing condition, and were concerned that an action plan would emphasise that they were sick. These points are illustrated below.

> *"Well, it is probably too late. Once you have dealt with it for about five years it become obsolete; you know the warning signs, you know what medication they are. I would just think it was silly now." [Parent]*

> *"I don't need a piece of paper in front of me telling me what to do. Anyway, it's up to me if I do it." [Indigenous, 20-54]*

> *"But that reinforces the idea that you are sick. I don't want to do that. The whole point of me exercising is that I don't want to feel like I'm some sort of sufferer. I don't want a plan." [35-54]*

In addition, some doubted the potential for written asthma action plans to reduce the incidence of hospitalisations and the mortality rate from asthma.

Information and education

Many adults rely on their doctor as a primary source of information about asthma. Some would clearly like doctors to play a greater educative role, as the following quotations suggest:

"[Your GP] should say 'log onto this website and read about it' or 'here, I'm giving you a referral to this group and they'll explain to you what it is you've got'. Instead, they just send you away with the Ventolin." [35-54]

"My local doctor had an asthma afternoon. He got a group of people together and we went in and did peak flows, and they made us run up and down the hallway and they'd take our peak flows again… It was good, and it was free." [18-34]

Some people had consulted their pharmacist in relation to asthma medication and potential interactions with other forms of medication. However, pharmacists were often perceived to lack time to discuss asthma and medications with customers.

Family members and friends appear to be important sources of information, particularly for teenagers and among Indigenous people. Several participants had sought asthma-related information from the internet, although this was less common among older people and participants from the Indigenous community. Few who had used the internet for this purpose could articulate specific searching criteria used or websites they had visited, although the National Asthma Council was sometimes mentioned. A few people had obtained material from the Asthma Foundation, typically after the initial diagnosis rather than during later stages. Others reported having received information from hospitals. Personal experience was also seen as a significant source of learning, particularly for helping people understand their own condition.

Interest in information about asthma was highest at, or soon after, diagnosis, as well as after the person had experience more severe episodes. Some suggested that an asthma information pack would be a useful reference upon initial diagnosis. Most others were not motivated to actively seek information about asthma, but several were willing to receive it. The following quotations illustrate these findings.

"None of us suffer that bad to want to go and look at it. If you had it really bad, you might want to find out more. Most of us don't have it that bad, so it doesn't bother me that much." [Teenager]

"I think I'm too far gone to know more about it. I know what I want to know." [Indigenous, 55+]

In terms of content, the greatest level of interest was shown for information about new developments, particularly developments in asthma treatment options.

With regard to other communication channels, brochures in medical waiting rooms were seen as likely to be read by patients. Face-to-face communication was especially preferred among the Indigenous community. Video material was also considered to be attractive for use with

Indigenous people with asthma. Overall, there was evidence of demand for tailored visual materials that are easily recognisable as relevant for Indigenous people.

4.2 People with asthma-like symptoms

Experience and reactions

Although they had not been diagnosed with asthma, several participants within this segment exhibited symptoms which may potentially be asthma, as illustrated in the following quotes. For some, these symptoms were relatively new, only appearing within the last two to five years. Others, however, reported having these symptoms for most of their lives.

> *"Tightness in the chest, constant coughing and shortness of breath. I've had it all my life. It comes and goes, and it depends on the weather a lot. The humidity I find as well will bring that tightness in."*

> *"I had difficulties with breathing, especially when I go to sleep at night time. It might persist for a few weeks, sometimes a bit harsher than others, and it comes back. I've always had it."*

> *"Mine is related to exercise, particularly if I've been unwell. I get shortness of breath. When we were in Bathurst it was a lot worse – the cold air seemed to affect it."*

> *"I was doing a cycle class yesterday and I nearly died, because I've never really experienced a lot of wheezing unless I'm sick, but I couldn't get a good breath in."*

> *"It is associated with the feeling as if I can't feel my lungs, so that's tightness of the chest. There's a band around it."*

> *"I find the dust at times makes it worse around the house."*

A few participants were concerned about their symptoms, but most described their symptoms primarily as an annoyance. Many claimed that their symptoms were mild, intermittent, and did not impact significantly on their lifestyle, as suggested below.

> *"It's not every day you get shortness of breath or everyday you get the wheeze. It's spasmodic. So, you say, 'I'm alright'."*

"When I have those times when I'm coughing constantly at night time I can't sleep, you get frustrated, but for a short time only anyway. It's not really affecting me that much and I don't have it 24/7."

Most of the participants had discussed their symptoms at some stage with family members and/or their partner. In addition, symptoms were sometimes discussed with a pharmacist. In some cases, people reported that the pharmacist failed to recommend that they see a doctor. Some people with asthma-like symptoms had tried to self-medicate with cough or bronchitis medication. Only some had actually consulted a doctor about their symptoms, although, as shown in the following quotes, this was generally seen to have been of little benefit.

"Yes, generally I would say 'I've got a bit of a wheeze' or 'I'm a bit short of breath from exercise', and they would generally recommend an over-the-counter product."

"My mum took me to the doctor when I was about eight years old. They prescribed [some medication and] I had an allergic reaction to it. I just learned to live with it, I suppose."

"I have been to a doctor and the typical is 'you've just got a cold' and I could be coughing while I'm there and they'll just say, 'put more clothes on, be warm and go home'."

"Everyone says 'go see a doctor or get a cough medicine'. I normally do that. They don't help that much."

A few used exercise as a means of addressing their symptoms, believing that this would improve their lung function. Yet others perceived exercise as something to be avoided, as it tended to trigger their symptoms. Further, those who felt that their symptoms were related to the weather conditions had in some cases moved to a new location to try to reduce their symptoms.

"I could possibly be walking more and really stretching my lungs a bit, but whether that would bring it on I don't know, so there could be a little bit of fear on that aspect."

"I tried all up and down the coast, just to try and get a good climate that's suitable."

Knowledge of asthma

Overall, among those with asthma-like symptoms, knowledge of asthma varied widely. Some gave a basic definition of asthma as being 'difficulties breathing', whereas others had a more sophisticated understanding.

> *"It can be exercise, allergens, it can be emotional, and the sacs just don't fill up properly with air, and you start to experience tightness and lack of ability to breath properly, and your breathing becomes really, really shallow."*

> *"Asthma is a tightening of the airways due to exercise or hereditary factors, caused by either emotion, exercise, fluid and constriction of the lower airways, causing shortness of breath and stopping people from doing things in their life."*

Many did not appreciate that asthma has degrees of severity, and asthma was often perceived to be a severe and constant condition.

The risk factors for asthma were seen to include family history, being overweight and general lifestyle (for example, smoking, lack of fitness, living in a dusty environment). In addition, many felt that children were more at risk of developing asthma than adults (that is, themselves). On the other hand, some felt that asthma was reasonably indiscriminate in terms of who was at risk of developing the condition. A few noted that, in the past, asthma cases were sometimes overlooked as bronchitis.

Almost all recognised that asthma could be managed with medication, most notably 'puffers'. Exercise was not widely appreciated as a potential treatment for asthma, given that it was seen as a common trigger for asthma. This is reflected in the quotation below.

> *"I have read somewhere that one of the causative agents of asthma is exercise, that exercise can actually induce asthma, not cure it."*

Motivators for management

When asked about the likely benefits of managing their symptoms better, a key motivator for improved management was simply having an explanation for their symptoms and learning that one's symptoms could be addressed. Proper management was also expected to result in peace of mind, increased confidence, feeling healthier and not annoying other people, as indicated in the following quotations.

> *"I'd be resting more at night. I'd be able to hold proper conversations and I wouldn't be thinking I'm irritating someone else by coughing."*

"I'd feel a lot more secure and confident about traversing the places I normally do where I can usually bet that there would be some sort of reaction. I would feel a lot better, and it would certainly free me up to go and help my friend again, and it would relieve me of worry."

Barriers to management

The research also identified a number of potential barriers among this sample to managing asthma-like symptoms more appropriately (that is, monitoring their symptoms better, consulting a health professional, following a health professional's recommendations and so on). One key barrier to taking their symptoms seriously was the belief that shortness of breath and wheezing during exercise are fairly common and normal for older people, as the following comments highlight.

"I don't know whether it's age, but I get shortness of breath just by doing what you should normally be able to do standing on your head."

"I think it's fairly common that people who exercise will get that shortness of breath and a bit of a wheeze."

"I'm 68, and I think old age has got something to do with it too."

Most perceived the severity of their symptoms to be low and, in some cases, that their symptoms were largely under control. Therefore, addressing their symptoms was not seen as particularly urgent, important, or (for many) necessary, particularly given the time that would be required to visit a health professional.

"Of course, there's the time frame involved to try and go and search these things out and to have them tested and to go to a specialist, and this can take weeks or months and a lot of people just won't bother."

"For me, it's just shortness of breath and really you just live with it. It's never been bad enough to be afraid that I'm going to be hospitalised or that I won't be able to keep breathing. It's controllable."

"You know your own body and you know when there's something wrong, really wrong."

Another barrier was the fact that asthma was typically seen as something worse than their own symptoms. Several had witnessed people with asthma during an attack, and did not see their own symptoms as being comparable. Further, asthma was perceived as a condition usually

diagnosed during childhood, so many did not suspect that their symptoms might reflect this condition.

> *"No – I've heard and seen people with asthma and it's worse than what I've got. I've seen people nearly black and blue in the face, on their hands and knees."*

> *"I always thought asthma was something that kids had."*

Some were able to find an alternative explanation for their symptoms, such as not taking good enough care of one's health, poor fitness, or environmental factors. Therefore, they saw little reason to consider other explanations.

> *"If I haven't been looking after myself very well, or going out too much, that's usually when I start to see problems… and so if I started being more healthy, then perhaps I wouldn't experience these problems."*

> *"I grew up in Mt Isa, so that's what I attribute it to, from the fumes coming over the city."*

> *"I don't think for me it's anything medical; it's just simply that I'm unfit."*

> *"One night I'm coughing my lungs out, the next day it's not that bad, and I'm thinking 'Ok, I'm getting better'; and then it happens again and I just blame myself - maybe I didn't cover up properly, maybe I didn't drink enough of this…"*

Another important barrier to better management of their symptoms was a general reluctance to see a doctor. This reluctance was driven by various factors, including the fear of finding out that one's symptoms were a sign of something sinister, resistance to change or even obstinacy, the belief that one's symptoms are not sufficiently serious to warrant seeing a doctor, and the perceived cost and time involved in seeking medical advice.

> *"I think I'd have to be coughing up blood before I actually went, because of the fear of it, of actually finding out if it is something worse, or just that there's nothing at all."*

> *"I don't talk to them because I know that they'd say, 'Give up smoking'. I'm just not ready to go to a doctor yet."*

Many of these participants saw little benefit in addressing their symptoms medically, given that the impact on their day-to-day activities and lifestyle was fairly limited. If their symptoms

restricted their activities more, or were harder to control, then some felt they would be more likely to consult a health professional.

"I don't think it's that much of an inconvenience to me. I just sit down, have a drink of water and wait for it to go."

"It's not stopping me from doing things. If I was in a situation where I played tennis, and I had to stop in the middle and couldn't play any more because of shortness of breath, I would say 'this is an exercise–induced asthma attack. I should seek medical treatment'."

Furthermore, many did not want to be diagnosed with asthma or to see themselves as an asthmatic. For some, this was related to a fear of what they perceived as a potentially severe condition, and for a few others it seemed more to do with a perceived stigma associated with asthma.

"It's just that willpower saying 'I'm not going to be diagnosed as asthmatic, and take asthma medication for the rest of my life, when it doesn't actually affect me'."

"I've seen people with asthma and I've seen how they speak, they can't play sports very well, if they don't have their asthma puffer there they're in a bit of trouble. I don't like the idea. I'd be quite worried, quite scared."

"At this point, I feel maybe I'm too old. I think I know my own body enough to think that I don't need a diagnosis about something else. This is my problem – just deal with it."

"I don't have asthma. I hope I don't."

The belief that nothing (or nothing more) could be done to prevent or address their symptoms was a barrier for some participants. Some of these had actually consulted a GP, but found that they were unable to assist.

"I find when you go to the doctor they say you've got a cold or flu, go home and rest, so there doesn't seem to be much point."

"The doctors will probably just say take this cough medicine, that's about it. I don't think there's anything I can do to prevent it."

"I don't think it's preventable for me. The only way that I can prevent it is to stop doing the stuff that I love doing. It's not going to happen."

A number of participants expressed a reluctance to use medication (particularly prescribed medication) on an ongoing basis. This was especially pertinent for those who perceived their symptoms to be mild and infrequent.

> *"He recommended one of the asthma medications, but I never pursued that because I really don't want to start taking any of that sort of stuff, the cortisone based things, unless I am really, really, really in acute respiratory distress."*

A final barrier to better management among those with asthma-like symptoms was that some were unconvinced that not treating asthma is detrimental to one's health. Similarly, some wanted to see evidence that asthma treatment could maintain (or even improve) lung function for longer.

> *"There's no evidence I can see that not treating asthma is actually damaging your lungs … I wouldn't take medication until I saw the evidence or that the medication will actually increase your lung function and help you live five years longer, or ten years longer."*

Attitudes towards asthma

Some people in this 'undiagnosed' segment perceived adult asthma as relatively mild compared to childhood asthma, as suggested below:

> *"I think that, for children with asthma, it's quite serious, because they can get stunted growth and it can affect their lifestyle… but, for adult asthma, [it's] not that serious, because people learn to live with it."*

Generally speaking, asthma was seen as a potentially serious, but manageable, condition. However, not all participants saw it as serious. Some cited examples of athletes with asthma which tended to reduce people's perceptions of the seriousness of the condition.

> *"It's probably like a lot of things - if you don't look after yourself, it could knock you off."*

> *"I know people who have asthma and smoke as well, so when I look at people like that, it makes me think it's nothing serious."*

> *"Here's all these swimmers, swimming hundreds of laps and performing in the Olympics, and they're asthmatic."*

There was also evidence of a perceived stigma or negative connotations surrounding asthma, and having to take medication to control one's asthma. Some participants described people with asthma as typically weak, not able to perform a normal life, not able to exercise, and having a "puny" build.

Sources of information

Participants who had experienced asthma-like symptoms were also asked about the primary sources of their knowledge about asthma, and preferences regarding further information on this topic, in terms of both content needs and channel preferences.

CURRENT INFORMATION SOURCES

With regard to key sources of information about asthma, many reported having learned what they know through the experiences of family members with asthma. Other important sources of information included television advertising, newspaper or magazine articles, and the internet. Yet most within this segment had not actively sought information about asthma.

FURTHER INFORMATION

Overall, in the absence of a diagnosis, participants showed limited interest in finding out more about asthma. Some want to avoid 'information overload' and thus prefer to focus on what is most relevant to themselves or people they know. The perceived relevance of additional information would potentially be increased by highlighting the range of symptoms associated with asthma, as it seems that people would more easily relate to information about the symptoms they are currently experiencing than a condition they assume that they do not have.

> *"I can tell you 100 things about what my parents, Parkinson's Disease, breast cancer, etc., but asthma is not something I care about at this stage. I don't want to know about every disease there is."*

> *"I think, unless I was told I actually had it, it just wouldn't concern me too much."*

> *"Reminding people – so that they can say, 'well hang on, I've got that'."*

Many expressed a preference for receiving information face-to-face rather than in written form. Pharmacists were perceived as relatively accessible, as the following quotation suggests.

> *"The pharmacist is good because you can get in there and quickly say what's wrong and what to take – you don't have to wait like at the doctor."*

However, pharmacists were not always seen as reliable sources of information, given their vested interest in sales of medication.

Most people said that they would be open to advice from their doctor, but some said that they would refer to other sources of information before deciding on a course of action (such as learning what they could via the internet). A few said that they would prefer to consult a naturopath than a GP. The internet is also a potential source of information about asthma, although few have heuristics for evaluating the reliability of medical content online.

4.3 GPs and pharmacists

Perceived severity of asthma

When asked about the severity of asthma, GPs and pharmacists often commented that the incidence of life-threatening asthma has decreased. This was generally attributed to advances in medications used to treat asthma.

> *"There is much less morbidity than I used to see in the old days, with the new medications." [GP]*

> *"In terms of nebulisers and that sort of thing, we don't really do that anymore. I guess it's because of better drugs nowadays, they don't need to use it." [Pharmacist]*

Even so, the ongoing disease burden associated with asthma is considered to be substantial. Some GPs expressed concern regarding the potential loss of lung capacity associated with poor asthma management.

> *"There's a lot of disease burden going on and there is an association with lung change over time that's really been under-estimated and under-treated." [GP]*

The seriousness of asthma is sometimes seen to be compounded by co-morbidities, including diabetes, heart disease, and drug and alcohol problems. Social problems, including housing, education, and access to medical services, were also seen to exacerbate the severity of asthma. These health and social problems were considered to be a significant issue among Indigenous patients, as illustrated in the following quotes.

> *"... particularly among the men. So any use of regular medication simply doesn't happen when they're binge drinking." [GP, Remote Indigenous]*

"So the education system is completely failing these people, and also their housing is completely failing with seventeen people per house on average, the current figures. So the obstacles are simply huge – just basic literacy, learning conditions – where do you start?" [GP, Remote Indigenous]

"And also in mainstream general practice you might say to people, 'Just keep your preventer puffer in your bathroom cabinet, and every time you brush your teeth, morning and night, use your preventer.' Well, in an Aboriginal community, twenty per cent of homes don't have a functional bathroom, and people aren't necessarily in a routine, organised life where they brush their teeth every morning and evening, and they might not have a cupboard to put their medication in. So ordinary middle-class values that we just think of as being normal when we're thinking of medicine use, don't necessarily apply at all to people living in remote communities." [GP, Remote Indigenous]

"Things like cleaning out the house and a new mattress, and getting rid of carpets and all that – it's totally beyond the scope of life in the remote communities. On average, there are seventeen people per house in the top end in the communities, so people just don't have that control element over their homes... People can't just say, 'I'm going to have a clean house now'. There are a lot of challenges and obstacles." [GP, Remote Indigenous]

A few of the health professionals who were working with Indigenous communities were not cognisant of the relatively higher prevalence of asthma among Indigenous people. They realised that asthma was a significant issue within these communities, but did not appear to have given consideration to the relative incidence of asthma compared to the mainstream population.

Some GPs and pharmacists commented that, although they appreciate the severity of asthma, its gravity is often downplayed among those with asthma. In turn, it is believed that this then increases the seriousness of asthma, because people do not give it the attention that it warrants.

"Because people are often seeing it as a minor issue with intermittent flare-ups, they tend to not think of it as serious and that actually makes it more serious." [GP]

Diagnosing asthma

Many doctors ask new patients whether they have ever been diagnosed with asthma as a standard question, meaning that they are generally aware of the asthma status of their patients. This information was reported to be stored with patients' medical records.

GPs reported that persistent respiratory problems would prompt them to consider asthma as a possible diagnosis, particularly shortness of breath.

GPs, pharmacists and AHWs were asked to estimate approximately the proportion of undiagnosed cases of asthma. It was felt that missed diagnosis is reasonably common, given the barriers that prevent patients from seeking treatment for asthma-like symptoms and that the diagnosis of asthma can be clinically difficult.. However, missed diagnosis was also seen to be less prevalent than it was a few decades ago, when asthma symptoms were often attributed to bronchitis.

Some GPs feel that asthma can be easily overlooked. Some believed that other practitioners often treat acute respiratory conditions, but ignore the underlying asthma.

> *"I think they treat the acute respiratory conditions that might trigger asthma off. They're getting flogged with antibiotics but, if they just bothered to treat the underlying asthma, you'd be laughing." [GP]*

At the same time, over-diagnosis was also seen as an issue within the mainstream population, with GPs and pharmacists believing that society can be quick to label particular symptoms as asthma. Over-diagnosis does not seem to be perceived as an issue in Indigenous communities.

Among pharmacists, there was a general reluctance to identify undiagnosed asthma. Asthma diagnosis was considered to be challenging and outside their area of expertise. It was also felt that some patients were resistant to see their symptoms as potentially being asthma. These issues are illustrated in the following quotes.

> *"As pharmacists, we are not trained to diagnose conditions. So, for us, it's not an area that we can be more active in." [Pharmacist]*

> *"It's sort of hard to know when to clarify it as asthma. Someone might get a cold and suddenly they'll be short of breath for a while, but it's just related to that episode. Are they truly asthmatic? Putting the label of asthma onto someone is quite difficult." [Pharmacist]*

> *"Sometimes you might suggest somebody might have some asthma-like symptoms and they'll quickly defend themselves and say 'oh no, it's not asthma'. Normally you tell them that they may have a chest condition which you think really needs to have a doctor look at it." [Pharmacist]*

When directly questioned, GPs acknowledged that asthma can develop among older adults. However, when discussing diagnosis, they tended to focus on diagnosis among children. Late onset asthma appears not to be salient in the minds of GPs in considering their diagnosis of elderly patients.

> *"Certainly people in their 20s and 30s can develop asthma. But the majority is in children." [GP]*

Diagnosing asthma was seen as an inexact science. Some areas are considered to be particularly challenging, including paediatric diagnosis, diagnosis of mild cases and diagnosis among older patients, given the similarity of asthma symptoms with those of Chronic Obstructive Pulmonary Disorder.

Diagnosing asthma where patients see multiple GPs was also seen as difficult, because there is less opportunity to develop rapport with the patient and understand their medical history. Health professionals in some (more stable) remote communities commented that complete histories are often available for patients.

Even so, it was seen as more challenging to confirm diagnosis in more remote locations, due to testing equipment seldom being available and patients sometimes being unwilling to travel to have a diagnosis confirmed.

Spirometry is seen as a tool to assist asthma diagnosis. However, GPs indicated that spirometry is not always available. Furthermore, it was seen to be time-consuming, and to deliver variable results. Some reported that therapeutic trial is often used as a diagnostic for asthma. That is, they would put a patient on medication for a period of time and then assess whether the patient's symptoms have improved. In many cases, GPs said that they are often reliant on history.

> *"Sometimes I feel as if I'm left a bit in the dark, though, because there is no real great definitive test for asthma. It's largely a clinical diagnosis." [GP]*

> *"There are not great tools to assess it and manage it. Spirometry is not overly accurate." [GP]*

In some cases, it was felt that a certain stigma was associated with asthma. This was seen to sometimes act as a barrier to diagnosis.

> *"I know when I was a kid … the asthmatic kid was the last one picked for every sporting event. So no one wants to have their kid labelled as the fat, wheezy kid sitting in the corner, do they?" [GP]*

Risk factors for asthma were seen to include family history, being a child, occupation, smoking in the home, pets, and excessive hygiene in infancy.

Knowledge

Most GPs felt that they have a good working knowledge of asthma, perceiving themselves to have sufficient knowledge of the disease process, the testing criteria for diagnosis, medication and management, and patient education. While GPs are able to recognise some gaps in their knowledge of asthma (e.g. mechanism, physiology), they see these as only relevant to respiratory specialists. Similarly, pharmacists feel that their knowledge is adequate for the pharmacy setting.

> *"We have patients coming in with questions and I can normally answer them all and, if I can't, I know where to find the answers." [Pharmacist]*

In sum, GPs and pharmacists' state of knowledge is not perceived by them to be a barrier to asthma management. However, there is some anecdotal evidence of missed diagnosis, and mature onset of asthma appears to be less salient in their minds than other forms of the disease.

Asthma management

Poor management of asthma was considered to be a much larger problem than under-diagnosis. GPs and pharmacists see patients as being more reactive than proactive, not seeing their asthma as a chronic condition.

> *"Most people are reactive with their treatment of asthma. They treat it once it's started rather than stopping it before it lights up in the first place." [GP]*

> *"I'd say, 'Please come in when you're well, so that we can get a reasonable plan going and talk about your treatment so you don't get really sick,' but no, those people would present only when they were really sick. So it's Band-Aid medicine, if you like." [GP, Remote Indigenous]*

> *"There are a lot of people who only think about it when they're wheezing away and can't breathe. They don't necessarily look at it as a chronic problem." [GP]*

There were considered to be a number of indicators of poor asthma management. These include hospital admissions, the extent to which someone uses their reliever, waking at night, waking up tired, coughing, or one's asthma impacting on one's lifestyle. Of these, using one's reliever more than three times a week appeared to be widely used as an indicator of sub-optimal management. This was felt to represent an objective criterion, and GPs commented that it could be used to convince their patients of poor asthma management.

The perceived benefits of better asthma management included better health, improved quality of life, and financial benefits (i.e. less time off work and less spent on medications). In Indigenous communities, better asthma management was also thought to allow people to participate more fully in cultural activities.

> *"Particularly out bush … able to partake in some of the cultural activities like hunting, digging up their foodstuff, walking longer distances, increased mobility… they're the obvious day-to-day benefits." [Pharmacist, Remote Indigenous]*

> *"Sleep better, energetic, less sedentary, they don't have to take antibiotics so often." [GP]*

Many pharmacists feel their role in asthma management is important, yet limited. They tended to see their role as potentially providing information that can support advice given by GPs.

> *"I find the doctors give them a bit of brief information but as soon as you start making enquiries and asking them some questions, you realise that they haven't been told much, so we can provide them with more information." [Pharmacist]*

Pharmacists perceived their primary role is to advise patients on medicines, particularly overuse of Ventolin. Some reported that they sometimes identify patients who should be investigated further, and advise them to see a doctor.

The availability of Ventolin over-the-counter was considered to contribute to poor asthma management. This view was not confined to GPs.

> *"There are masses out there self medicating that never come to us, that just go and buy them." [GP]*

> *"The only issue I have is with Ventolin being available over the counter, we are probably not seeing all the asthmatics we should be seeing and there is probably overuse of Ventolin that we are not seeing." [GP]*

There was some discussion about Ventolin cards, which are carried by the patient and designed to represent documentation of each time someone purchases salbutamol. When used, it was agreed that Ventolin cards can allow a pharmacist to notice poor asthma management.

However, most pharmacists will supply Ventolin without a card in certain circumstances, and this is seen as appropriate practice. Pharmacists feel that patients have become very savvy in terms of their ability to access Ventolin with minimal scrutiny.

> *"I think asthmatics get sick of copping some scrutiny every time they want to buy something. They think, if they're going around, they'll be less noticed." [Pharmacist]*

> *"Invariably, if somebody is getting something made up fairly often they know that they'll get quizzed on it, so they have the answer for you before you even ask the question. 'Oh, you probably noticed I got one last week but I've left it behind, or lost it' – they've always got the answer." [Pharmacist]*

Some pharmacists suggested that GPs should be encouraged to look at their patients' Ventolin cards to ensure that they are aware of the extent to which people are using their reliever medication.

> *"I think it would be a great idea for GPs to insist on having a look at them. I think a lot of GPs would get a bit of a shock if they could actually see how much Ventolin their patients are using." [Pharmacist]*

AHWs are seen to play an important educational role. Some feel it would be valuable to improve access to asthma educators, given the time constraints that GPs and pharmacists face.

GPs believe their role includes helping patients to be aware of any deterioration of asthma symptoms and identifying and addressing sub-optimal management. However, the extent to which doctors feel able to make a difference is seen to rely on client's level of motivation.

> *"It's down to motivation … if I can motivate them or convince them that this is worth a go and they can do it and actually see that it's better." [GP]*

Some GPs reported that they have limited success in identifying poorly managed asthma, because patients are said to be rarely forthcoming about their asthma. Patients, particularly smokers, often realise that they are not managing their asthma as well as their GP would like. Other patients are believed to not raise the subject because they are satisfied that they are managing their asthma adequately.

Given patients are perceived to have a low level of interest in their asthma, it was widely agreed that increasing awareness of asthma management in the community would be potentially very useful for GPs. In particular, GPs reported that they struggle to help patients realise the importance of having their asthma reviewed when their symptoms are seen to be unproblematic.

> *"What would really help me is someone walking in and saying, 'I want to speak about my asthma, doc' when they're well." [GP]*

There was generally low awareness of the 3+ visits plan among pharmacists and some evidence of misunderstandings.

> *"I thought it encouraged them to go to three different health professionals." [Pharmacist]*

The 3+ visits plan was seen, particularly among GPs, to have failed because it relied on the patient to return for a follow-up.

Some perceived it to be slightly easier to encourage patients to return for an asthma review in rural areas. This was seen to be because populations are less transient and people typically attend only one practice. In addition, there are thought to be fewer competing priorities.

> *"When I was working in the country, it was very easy to get kids back because they didn't have anything else to do... in the city, certainly where I am practising, it is very hard to get people back, especially the young working adults. You can just forget it." [GP]*

Parents are seen to be more diligent in managing their children's asthma, compared to adults' self-management.

> *"It's almost where you see as close as possible the ideal management, parents to kids." [GP]*

> *"In my case it's a lot of mothers or fathers with children and they're always very keen to find out a bit more about asthma, whereas adult asthmatics have it pretty well organised." [Pharmacist]*

Similarly, those who have had a life-threatening event are viewed as more compliant.

Educational aids were seen as valuable in generating patients' interest in asthma management and providing basic information.

> *"There's a little plastic puff dragon and you stick the tongue depressor in and the light comes on and his nose glows. Kids love it, they just giggle away." [GP]*

> *"I'm the queen of brochures, I love handing them out because they're something concrete; 80% of them probably go in the bin or handbag but, for some people, they will actually mean something." [GP]*

It was felt that tailored resources are required for Indigenous people with asthma. To maximise the effectiveness of these resources, it was seen to be important that they represent

concepts visually, use simple language that is free of jargon, and include culturally relevant imagery. These views and their rationale are presented in the following quotes.

> *"There are ways of making materials culturally appropriate, and in the kind of Indigenous artwork that people can relate to. Sort of using Indigenous role models, instead of sort of anaemic-looking non-Indigenous people." [GP, Metro Indigenous]*

> *"Indigenous clients who I deal with relate much better to materials that have pictures or diagrams rather than words in them. So that's critical. Many of our Indigenous clients can't read. So that's another reason why pictures and diagrams are much more important." [GP, Metro Indigenous]*

> *"I think a lot of people like visual things, especially if you are trying to explain, it's best to have visual. And you might think it's gruesome, but it would be nice to have pictures of, you know, the lungs and all that sort of thing, and the tubes… how things happen, how they get thick and tighten up. I'd use … an education device. This is what your arteries should look like, and because you smoke or are overweight, this is what they are possibly like now, all clogged up. More visual education would be lovely." [Indigenous Health Worker, Metro]*

> *"Some of the brochures are a bit 'jargonified', I call it 'jargonified'. You can get the information out of it, and even sort of explain it to the client, then sort of break down the big jargon words." [Indigenous Health Worker, Metro]*

Some positive comments were made with respect to the Short Wind campaign materials, particularly the flip chart.

Time constraints (for both GPs and pharmacists, and for patients) represent a significant barrier to asthma management.

> *"It's very hard to pin people down. They might come in and say, 'what medication?' but when you say 'do you want to come in and get some spirometry done and look at an asthma plan?' it's always, 'another time'. Then 'another time' never happens." [GP]*

> *"It's very time limited, too, because generally you might not get them back and so to do all that in one session, make that assessment of a patient and figure out a plan, it's really challenging." [GP]*

> *"In our setting, where it's pretty busy, particularly in the lunch hour, there's no way we could sit down and talk to patients for 10 or 15 minutes." [Pharmacist]*

Not only do GPs and pharmacists cite insufficient time to provide best practice asthma management, there was not thought to be sufficient financial incentive to invest the necessary time and effort required.

> *"Not having enough time for spirometry or not having the financial incentives, I guess." [GP]*

> *"I think pharmacists would be very good at doing that role but I think you'd find them reluctant to do it unless there was some remuneration for it because, to make the time available, the pharmacist is going to incur some expenses." [Pharmacist]*

Some GPs felt that other practitioners have been lax with respect to managing asthma among their patients, and this was often seen to be a result of time constraints and insufficient incentives to do otherwise.

> *"It's also an issue that can be skimmed over quite easily as well. 'Have some Ventolin, see you later', or just ignore it altogether and you tend to get by. When you see patients who have been treated by other practitioners, you do see it where it's been clearly overlooked." [GP]*

The research also identified barriers to asthma management that were related to the proper use of medicines. Patients' negative perceptions of steroids were raised as an impediment to optimal use of preventer medication.

Some indicated that patients' not rinsing their mouth after using a steroid puffer was a common problem. In addition, poor puffer technique was considered to be widespread. One of the key issues that GPs and pharmacists reported was that patients do not coordinate their inhalation with the depression of the puffer. Addressing this issue was seen by many GPs to be the role of the pharmacist.

> *"With an acuvator, it's a very fine powder. Some of them don't feel it going in and might use it again and, rather than having one dose twice a day, they might be using three doses." [Pharmacist]*

> *"A good suggestion on how to treat asthma better is to get pharmacists to give a demo on how to use a puffer." [GP]*

However, some pharmacists indicate that they do not always have time or the opportunity to impart these skills.

Spacers were also reported to not be widely used, or in some cases, available. GPs and pharmacists feel that patients see little value in using a spacer and tend to regard them as only being for children.

Similarly, patients were believed to not see value in using peak-flow meters to monitor their asthma. This was seen to be partly because of their expense, but it was also seen to be because patients believe that they are able to judge whether their asthma is under control based on symptoms alone. In addition, peak-flow meters are seen as somewhat complicated to use. Therefore, attempts to make peak-flows easier to understand were seen as valuable. As illustrated in the following quotes, peak-flows were seen as meaningless within the context of the language of some remote Indigenous communities.

> *"The peak-flow measurements tend to be meaningless when their language only has words for 1, 2 and many … what's the value of 640?" [Pharmacist, Remote Indigenous]*

> *"With Seretide they were giving us peak-flow meters that actually had click in markers, so it had a red, orange and green mark. A green mark would be 80-100%. So you could say, 'When you get below orange I want you to double your dose'… That was making it a bit more user friendly." [GP]*

GPs and pharmacists also reported that patients have a poor understanding of some things that can trigger asthma, including exposure to environmental tobacco smoke, and ibuprofen.

There was also a view that not seeing one's regular doctor hindered asthma management.

> *"There isn't the same continuity of practice in this country. The freedom to move can be the freedom to do themselves harm." [GP]*

Some expressed reluctance to actively manage asthma among those who smoke. Indeed, some GPs commented that any asthma awareness initiative was futile without encouraging people with asthma who smoke to quit.

The research identified a number of specific challenges to asthma management for Indigenous communities. These included:

- The challenges of daily life, and the matrix of disadvantage experienced by some Indigenous people. Some GPs acknowledged that treatment often focuses on medication because addressing lifestyle factors is seen as challenging;

- Cost and access to services, medications and devices. One GP commented that he improvises with spacers, using a plastic cup instead;

- Lack of spacers, nebulisers, peak-flow, spirometers, and specialist support;
- Lower levels of literacy, making written asthma action plans less appropriate, and communication of medical information difficult;
- Cultural barriers:
    - Men are reported to be less likely to manage asthma adequately;

> *"But men as a rule will not front up when there's women nurses, and they're certainly less compliant with all their medication, regardless of what disease state. Part of it is status. Part of it is cultural." [Remote Pharmacist]*

    - Follow-up is challenging with transient populations, or where people have no telephone;

> *"People have moved from their housing place that they were in. They've gone back interstate or they've moved to another suburb, and they haven't come to your organisation to let you know things like that. That'd be one of the problems, keeping track of the people." [Indigenous health worker, Metro]*

    - The style of communication is less direct;

> *"Because of cultural reasons, it's quite easy to get people to tell you what they think you want to hear, rather than what is actually going on. I think it's quite different to the way in which you would talk with your typical non-Indigenous client." [GP, Remote Indigenous]*

    - Need to build greater trust with patients.

GPs and pharmacists were asked what things facilitate asthma management. Apart from the flip-side of the barriers identified above, a few suggestions were made. One such suggestion was automated letters from emergency departments to GPs. This would allow GPs to ensure that they were aware of any hospitalisations of their patients due to asthma.

Having a sense of pride in one's work was also said to be an important motivator for GPs to manage their patients' asthma.

Written asthma action plans

Doctors generally appreciated the purpose and elements of written asthma action plans. Key elements of a plan were seen to be helping the patient to:

- understand when their asthma is deteriorating;
- know the purpose of each of their medications;
- know which medications to modify under given circumstances; and
- know when to see the doctor or to go to hospital.

There was some awareness of programs on medical software that include a pro forma of written asthma action plans, although some admitted to being computer-illiterate.

Pharmacists were less familiar with these key elements, with some seeing plans as covering only emergency procedures. GPs appreciated that written asthma action plans were broader than this, including information for patients to help them recognise if their symptoms are deteriorating.

GPs, pharmacists and AHWs recognised a number of potential advantages of written asthma action plans. Patient empowerment was seen as a key benefit of written plans. This is because patients are able to take an appropriate course of action that has been endorsed by their health professional.

> *"If you're sick or unwell, you sometimes look for guidance, what do I do? You don't want to call an ambulance unnecessarily. If they feel like there's an emergency, they're sure about seeking help." [GP]*

Other perceived benefits include:

- better resource allocation (including reduced reliance on GPs);
- avoiding hospital admissions; and
- greater clarification of medicines.

Despite these perceived benefits, the vast majority of GPs seldom write plans, if at all. Most say that they give verbal instructions instead. In particular, written plans were considered a lower priority in the Indigenous community. This was due to competing priorities, low levels of literacy, and difficulties interpreting peak-flows. A typical perspective is illustrated in the following quote:

> *"You're best off getting them on a fairly good treatment and then working to keep them on that. [Plans are like] putting the cart before the horse." [Pharmacist, Remote Indigenous]*

Written asthma action plans were seen to be more relevant for parents than for adults with asthma. They are also considered to be more appropriate for those who are going to understand the plan and be motivated to use it.

> *"It depends on that person with asthma, what responsibility they're taking, whether they're going to understand it, and their motivation. So sometimes it's a waste of time writing it out. Sometimes people won't pay any attention to it or they know it already anyway." [GP]*

In those few cases that they were reported to have been written, this was often initiated by the patient. For example, some said patients had requested a plan in preparation for their child going to school camp. Doctors welcome these requests, as illustrated in the following quote:

> *Wants to take on some responsibility for themselves, I'd be very excited. [GP]*

However, doctors said they expect most patients will not use written asthma action plans and will not return for a review.

> *"I imagine it just sitting in the bottom of the handbag or the back drawer in the kitchen. That's probably why I'm not running around doing them all the time, I think." [GP]*

> *"I think, in an ideal world, it's fantastic and wonderful. In my ideal world, it will be somewhere they see it every day and they will be compliant. I just think in the real world it just gets lost." [GP]*

Several GPs were also reluctant to adjust their current practices.

> *"Doesn't fit into my way of practising medicine, I think perhaps you can't teach an old doctor new tricks … I've got into the habit of practising the way I do, so all these plans that have come along I'm afraid just are passing me by." [GP]*

As mentioned earlier, there was thought to be limited use of peak-flow meters among people with asthma. This meant several GPs saw written plans as largely redundant.

Some reported that patients had not understood plans that they have been given in hospital. Therefore, there was an expectation among some that patients may find a plan too complex.

The perceived difficulties associated with writing plans included:

- the time and effort involved;

- motivating patients;
- having to estimate an ideal peak-flow. This was reported to be overcome by using the predicted flow for the patient's age;
- using symptoms as a less reliable substitute for peak-flow measurements;

> *"They can use it on other symptoms alone, but peak-flow is the ideal. But some people just refuse to do it, so you've got to go on symptoms. But you can drop by 20-30% without your realising it, and a lot of people don't seem to take that to heart." [GP]*

- knowing what medication is appropriate when peak-flow is ideal; and
- low literacy, in some cases.

If GPs do instigate a plan, they reported that they normally omit peak-flow measurements from it, because use of peak-flows was seen to be very limited.

Information about asthma

GPs and pharmacists cited a range of sources from which they had learnt about asthma. These included university studies, hospitals, clinical experience, lectures, the Pharmaceutical Society of Australia, professional magazines, National Asthma Council publications, NPS bulletins (in particular, one pharmacist commented that the Prescribing Practice Review was seen as an excellent update), eMIMS and (to a lesser extent) representatives from pharmaceutical companies. For some, personal experience of asthma had also contributed to their knowledge.

The Asthma Foundation was seen as more of a support group for patients than an authoritative information source for GPs and pharmacists.

Some had not heard of the Department of Health and Ageing. When asked whether they would trust information from this Australian Government Department, there was concern that the Department's perspective would be impractical.

> *"It's a bureaucracy and it's a long way from what actually happens." [GP]*

As mentioned earlier, most GPs and pharmacists felt they had a good working knowledge of asthma. Accordingly, their interest in learning more about asthma was fairly limited.

> *"It's opportunity costs. Learning more about asthma comes at the cost of an opportunity to learn about something else. I think we're doing a lot, we could probably do a bit more, but I think we're doing a lot at the moment." [GP]*

Most said they would be open to learning more about asthma if there was something new, and a few commented that some patients are very savvy and one needs to be abreast of new research. However, it was generally believed that relevant developments in the area have been limited.

> *"You need to be up to date. We have a lot of asthma sufferers who are very aware of the latest research and developments in the treatment of asthma. I don't like being pulled up by customers for not knowing something!" [Pharmacist]*

> *"The symptoms and the signs are still the same. The treatments are pretty much, well, there's been nothing new for a while, has there?" [GP]*

Some expressed caution about adopting cutting-edge approaches, stating that they prefer to stick to well established methods, rather than taking risks with newly established medicines and so on.

There was some interest in receiving objective information, with a few GPs and pharmacists mentioning that most of the information that they receive is from pharmaceutical companies, which is seen to be potentially biased.

GPs and pharmacists acknowledged that printed material often goes unread, because it is rarely prioritised. Many expressed a preference for face-to-face learning, which is seen to be more interactive and interesting. It is also often seen as a way of socialising with one's professional peers.

> *"Usually no matter what you get to read, you put it on a pile on the desk to be read and move it down, then it's in the bin." [GP]*

> *"When you get home, if I'm going to log onto the internet I'll log onto something a bit more interesting than asthma. Whereas, if there's a training night on which is face to face, I'll make the effort and go along to that." [Pharmacist]*

The opportunity costs associated with attending professional development events were seen as significant, and there was therefore support for paid educational activities.

"I'm more thinking of time, because quite often to go to these courses you have to replace yourself and that's a cost. The actual cost of the courses I don't think is all that high." [Pharmacist]

"I think getting paid to learn things is a really good thing. Really, it's an hour and a half out of our day, out of our lives." [GP]

A centralised electronic database, covering multiple health issues (not just asthma), was also suggested by some.

The preferences stated by GPs and pharmacists in the research suggest that no single communication channel will suit everyone.

5

This section provides conclusions and recommendations with respect to each of the research objectives.

CONCLUSIONS AND RECOMMENDATIONS

To assist readers, this section has been structured around the research objectives, as they relate to the key target audiences for the communication initiative.

Perceptions of asthma

The first research objective was to explore perceptions of asthma diagnosis, symptoms, frequency and severity, causes, treatment, management and the impact of asthma on a person's life.

People with asthma reported that their reactions to a diagnosis of asthma varied from relief that their condition had been recognised and explained, to disbelief and disappointment at being labelled as having a chronic condition. There is a view among some members of the public as well as some GPs that over-diagnosis of asthma is as or more common than under-diagnosis.

Among people with asthma, there is a tendency to downplay the impact of the condition and accept its restrictions, seeing these as a normal part of having asthma. While recognising that asthma can be serious, many see their own asthma as relatively mild and primarily an inconvenience. Some are clearly accepting high levels of symptoms and real restrictions, yet this often does not prompt improved asthma management. Instead, many adjust their life to fit their asthma, rather than seeking treatment or questioning their management regime.

There is a need to increase people's recognition of the indicators of poor asthma management, to help them to understand that these are largely avoidable, and to highlight the benefits of managing asthma better.

EUREKA
strategic research

Knowledge, attitudes and beliefs

The second research objective was to explore knowledge, attitudes and beliefs regarding asthma, including awareness of best practice asthma management and perceptions of the role of health professionals.

The research has identified a number of significant knowledge deficits and persistent false beliefs among those with asthma and their parents. These relate both to knowledge about the condition itself and about how it can be managed, including:

- poor awareness of the potential value of written asthma action plans;
- limited understanding of the difference between reliever and preventer medication and their purposes;
- a view of asthma as episodic, rather than chronic, leading to low levels of motivation to act between episodes;
- believing that their asthma is as good as can be expected and that minor symptoms are therefore normal and not concerning; and
- insufficient clarity about what to do, and when, in an emergency.

Despite these knowledge deficits, there is little appetite for information on asthma, except at and soon after initial diagnosis and after more severe episodes and/or hospitalisation. Others say that they will accept information, but not seek it out.

To communicate successfully with people with asthma, it is important to make good use of the limited opportunities for knowledge transfer, given most are usually unmotivated to learn more about asthma.

Among people with asthma, few have an accurate understanding of written asthma action plans. When explained, many are able to recognise the benefits of a simple, tailored plan. Most, however, need to be convinced that a plan would have more than minimal value in their circumstances. This is particularly the case for those with mild or intermittent asthma, or for those who see their current management regimes as stable and adequate.

A key challenge for the asthma awareness initiative, especially the promotion of written asthma action plans, is to encourage asthma management to be seen as an ongoing issue, not something that only happens when one's symptoms deteriorate.

Many who are undiagnosed, but have asthma-like symptoms, do not appreciate that asthma can have mature onset and can be mild or variable. They find alternative explanations for their

current symptoms; in their mind, they are just unfit, or getting old, they see their symptoms as a response to occupational or environmental irritants, or as a result of smoking. Moreover, they see asthma as being more severe than their own symptoms and can rule it out as a possibility on this basis. Accordingly, interest in finding out more about asthma was limited, because these people do not, and are often unwilling to, see their own symptoms as potentially being asthma.

The perceived relevance of asthma to people with asthma-like symptoms could be increased by highlighting the symptoms associated with asthma. The asthma awareness initiative needs to encourage people and their GPs to see symptoms such as wheezing, persistent coughing and shortness of breath as potentially being asthma and amenable to management.

Although GPs and pharmacists recognise the ongoing disease burden of undiagnosed or suboptimally-managed asthma, mature onset of the condition is often not salient in their minds. This appears to be leading to under-diagnosis. Diagnosis is seen as challenging, with the methods and tools available for diagnosis being inexact and not always reliable. So, many rely on symptom history, and/or therapeutic trial to assist with diagnosis. Spirometry is used in some cases, and a few report using spirometry, pre and post Ventolin, for diagnosis.

There is some scope to increase GPs' awareness that asthma can affect significant numbers of people in later life and to make this more salient when older patients present with asthma-like symptoms. There may also be scope to assist GPs with standard means of reliably diagnosing asthma.

Behaviour and intentions

The third research objective was to explore behaviour and intentions with respect to asthma management.

The research identified a number of suboptimal practices and behavioural intentions, including:

- over-reliance on relievers and sub-optimal use of preventer medication;
- limited use of peak flow measurement as a way of monitoring one's asthma;
- limited consultation with health professionals except in relation to severe episodes or severe asthma;
- a lack of willingness to adopt major behaviour changes such as increasing exercise, losing weight or ceasing smoking, believing that any improvements in their asthma would not warrant the effort involved; and
- very limited use of written asthma action plans.

There is clear scope to improve the management of asthma, particularly in the correct and appropriate use of preventer and reliever medication. As mentioned above, the more widespread use of written asthma action plans is important in addressing this challenge, providing people can be shown the benefits to them from this approach.

Despite recognising a number of benefits of written asthma action plans, the vast majority of GPs seldom write them, unless their patients request one, for instance prior to a school excursion. Key barriers for GPs and pharmacists to prepare written plans are:

- limited patient-initiated demand;
- lack of time and appropriate incentives; and
- doubts about likely compliance, especially peak-flow measurement.

Plans were considered a lower priority in the Indigenous community, given numerous competing health imperatives, and practical constraints.

Perceptions of risk

The fourth research objective was to explore perceptions of risk regarding asthma.

Participants generally realised that asthma could be serious and, in some cases, potentially life-threatening. In fact, several had had acute episodes that they viewed as serious. Mostly, however, people did not see their own asthma as serious and did not perceive that managing their asthma suboptimally involved taking any significant risk. Instead, their asthma was seen as a minor irritant: something that comes and goes. Participants generally rejected the idea of asthma as a disabling condition and were largely unaware of any long-term harm (e.g. reduced lung function) resulting from poorly managed asthma.

Indeed, some teenagers see their asthma as transient, with some participants saying that they felt that they would outgrow their asthma. People with severe asthma were, however, more likely to perceive their ongoing condition as serious.

There is scope to remind people with asthma that the condition is a potentially serious one that needs to be well managed in order to reduce the risk of immediate and long-term harm and to gain lifestyle benefits.

Communication issues

The final research objective was to address any communication issues relevant to asthma management.

The research has identified a number of messages that could be disseminated to reduce the burden of asthma in the community. A key challenge for any communication initiative is to increase people's appetite for new information and messages, given the prevailing view among many people with asthma that their symptoms are normal and that their asthma management is adequate.

Given that many people with asthma appear to be over-reliant on reliever medication and may have only limited contact with health professionals, an opportunity exists to consider using medicine itself as a communication channel, perhaps including key messages and details of any web or telephone based resources, on flyers with asthma medication.

In general practice, there may be further potential for medical software to aid regular management, providing ongoing reminders for GPs to discuss asthma with their patients as well as providing the template for a written asthma action plan.

GPs and pharmacists would welcome educational aids for patients. Information packs, brochures, video material, and tailored Indigenous materials were suggested. It is worth remembering that GPs tend to read and learn from patient materials too, particularly about the key messages to communicate to people with asthma. In fact, a number of GPs say they are more likely to read something directed at patients than they are to read something targeting themselves, because of their professional desire to understand what messages they are sending to their patients. Of course, the existence of general public materials also signals to health professionals that asthma is an important issue and is on the public health agenda.

There was limited interest among GPs and pharmacists in more information about asthma. The Department faces some skepticism about its role in directly facilitating asthma management, given it is not seen to be in touch with frontline practice. Multiple communication channels were suggested. Print directed at GPs is likely to be least successful, given most say that they normally never read printed material, although they may read patient-oriented material, as noted above. Brief email, internet, or face-to-face communication methods were said to be preferred.

Asthma educators, practice nurses, and AHWs are seen as cost- and time-efficient providers of some asthma management. On the other hand, most pharmacists see their role in management as limited.

Finally, increasing awareness of the potential for better asthma management could assist GPs and pharmacists in generating interest among patients. This would help to overcome one of the most significant barriers to their taking a more active role in asthma management.

A

APPENDIX A

Discussion guide for people with asthma / their carers

Introduction

- Thank for coming along
- Topic: Asthma
- Facilitator's role: to raise topics and issues and then for you to tell me what you think. Moderator is not an expert on asthma issues
- No right or wrong answers, your opinion that counts. Please be honest
- Group rules: one person speaks at a time / feel free to disagree
- Audio / video taping, mirror. Reassure confidentiality, anonymity
- Session will take an hour and a half / Interviews will take around 45 minutes
- Hand out incentives (sign and check contents of envelope)
- Refreshments, toilet facilities, please turn off mobile phones
- Participants introduce themselves

Asthma experience and perceptions

- How long have you / your children had asthma?

- How do you feel about having asthma / about your children's asthma? How did you feel when you/they were first diagnosed?

- How serious is asthma? Why do you say that? How serious is your / your children's asthma? How serious is it compared to other health issues? Is asthma serious at some times and not at others? When do you consider symptoms to be serious?

- What impact has asthma / your children's asthma had on your life? How does it affect you / your children on a day-to-day basis? In what ways? Are there things that you / they

avoid or miss out on doing because of your /their asthma? (e.g. exercise, impact on work or study) How typical do you think your experience of asthma is?

- Have you / your children ever been in an emergency situation because of your / their asthma? If so, how long ago was this? Have you / your children ever been to hospital because of your / their asthma? How did this change the way you view your / their asthma?

- Do you see yourself / your children as being at risk of a severe asthma attack? Why / why not?

Knowledge of asthma

- Without telling me what you know, how much do you feel you know about asthma?

- How would you explain to someone what asthma is?

    - What are the symptoms of asthma?

    - As far as you are aware, what causes asthma?

    - What things can trigger asthma, or make asthma worse, in different people? [Probe on respiratory infections, cold weather, pollens/allergens in air, smoking/exposure to passive smoke.]

    - What should people do in the event of a severe asthma attack / emergency situation?

    - Can asthma be treated? How? [If not mentioned prompt: medication, exercise, lifestyle, self-awareness, alternative treatments?] What is the best way to manage asthma? Why?

    - Can asthma be prevented? How?

Asthma management

NOTEPAD EXERCISE

- What would be the benefits of managing your / your children's asthma better?

- What, if anything, stops you from managing your / your children's asthma better?

- What do you do to try to keep your / your children's asthma under control?

- Is exposure to cigarette smoke an issue in your household? / Do people smoke in the house? What, if anything, makes it hard for you to limit the children's exposure to cigarette smoke in the home?
- How well do you feel you keep your / your children's asthma under control or manage your / your children's asthma?
    - Do you think you could you manage your / your children's asthma better? Why / why not? In what ways?
    - How would you know if you weren't managing your / your children's asthma properly?
- Some more specific questions about your / your children's asthma symptoms: Do you / they:
    - Use your / their reliever more than 3 times a week?
    - Wake up during the night because of your / their asthma?
    - Cough excessively?
    - How does this make you feel? Does it concern you? Why/why not?
    - Do you think you could do anything to prevent these symptoms? What?
- What would be the benefits of managing your / your children's asthma more effectively?
- What makes it easier or harder to manage your / your children's asthma? What stops you from managing your / your children's asthma better?
- What would assist you to manage your / your children's asthma better? (e.g. information, support, medication, exercise advice, etc) Why would this help? Who would be the best people or organisations to provide these to you?
- Has the way you manage your / your children's asthma changed over time? In what ways? Why?
- Do you think your friends, your peers or the broader community influence how you manage your / your children's asthma at all? In what ways?
- [Among young adults and teenagers] How much influence do your parents have on how you manage your asthma? Did they have more influence when you were a teenager?

- Who (if anyone) have you consulted about how to manage your / your children's asthma? [If not mentioned, prompt: GPs, pharmacists, hospital staff on discharge, family members, other asthma sufferers, alternative therapies, etc]

- In what ways could a doctor or health worker help to manage asthma? Do you think a doctor or health worker would be of benefit to you personally in managing your / your children's asthma? Why/why not?

- Do you ever go to see a doctor or health worker about asthma? When? What for? (e.g. To get prescriptions? When symptoms flare up, or only when they are there for something else? Would they go purely for management?)

- Do you ever monitor your / your children's asthma? What do you do? How often do you do it?

    - Do you know what peak expiratory flow measurements are? Do you keep track of these?

- Do you know what a written asthma action plan is? Can you describe what it is and what sort of information it contains?

- [If necessary, explain what an asthma plan is: "Written asthma action plans are written instructions on how to recognise when asthma is getting worse and what action to take when it does. For example, if you noticed changes in your symptoms or in your peak flow measurements, the plan would tell you what to do. This might include starting a new medication or changing your current medication in some way, or consulting medical advice."] What do you think might be the benefits of having a written asthma action plan? How valuable would a written asthma plan be to you?

- Do you have a written asthma action plan (for your children), or have you ever had one in the past? [If yes] I'd like you to tell me a bit about when you got one. Explore:

    - How did it come about?

    - Who was involved?

    - Was it your idea or did a doctor or health worker encourage you to have one?

    - [If doctor or health worker suggested] How did you feel when your doctor or health worker suggested a written asthma action plan?

    - Did you use your written asthma action plan? [If yes] In what ways? Did you find it helpful? [If no] What stopped/prevented you from using your plan?

- How would you feel if your doctor or health worker talked to you about how you manage your / your children's asthma? How would you feel if they approached the issue without your having raised it with them?

- What would prompt you to discuss how you manage your / your children's asthma with your doctor or health worker?

- If your doctor or health worker put together a written asthma action plan for you, do you think you would use it? Why / why not?

- Do you use any form of preventative medication? Have you been advised to? [If yes but doesn't use] Why don't you use your preventative medication?

Information and education

- Where have you learned what you know about asthma?
    - When did you learn it?
    - Has the information you've come across / found been sufficient? Are you interested in finding out more about asthma?
    - What else would it be helpful to know?

- What sources of information would/do you trust? Why?

- What would be the best ways for you to receive information about managing your / your children's asthma? [Probe information channels, such as GP, pharmacist, hospital staff, support groups, asthma organisations.]

- What (if anything) would make you more interested in information about asthma management?

Closing

- This research is being conducted on behalf of The Australian Government Department of Health and Ageing. The findings will be used to help the Department increase awareness about asthma and encourage people to manage their asthma better.

Discussion guide for those with asthma-like symptoms

Introduction

- Thank for coming along
- Topic: Health
- Facilitator's role: to raise topics and issues and then for you to tell me what you think. Moderator is not an expert on health issues
- No right or wrong answers, your opinion that counts. Please be honest
- Group rules: one person speaks at a time / feel free to disagree
- Audio / video taping, mirror. Reassure confidentiality, anonymity
- Session will take an hour and a half / Interviews will take around 45 minutes
- Hand out incentives (sign and check contents of envelope)
- Refreshments, toilet facilities, please turn off mobile phones
- Participants introduce themselves

Experience of and reaction to asthma symptoms

- Do you ever experience tightness in the chest, wheezing, persistent coughing, or shortness of breath?
  - How often?
  - Do you wake up during the night because of these things?
  - How long have you had these symptoms?
  - What impact have these symptoms had on your life? How do they affect you on a day-to-day basis?
  - How typical do you think your experience of these symptoms is?
  - How do these symptoms make you feel? Do they concern you? Why/why not?
  - Do you think you could do anything to relieve or prevent these symptoms? What could you do?
  - What would be the benefits of addressing these symptoms? How much of a difference would it make to your life?
  - Have you tried to address these symptoms? What have you done? Did it work?

- Who (if anyone) have you consulted about them? [If not mentioned, prompt: GPs, pharmacists, hospital staff on discharge, family members, alternative therapies, etc]
- What else, if anything, do you think you could do to address these symptoms?
- [If not already mentioned] Do you think a doctor or health worker would be able to help in any way? Why/why not? In what ways?
- What would prompt you to mention or discuss these symptoms with your doctor or health care worker? How bad would your symptoms need to be before you sought advice?
- Have you ever thought that these symptoms might be asthma? What made you think it might be asthma? What made you think it wasn't asthma?

- How would you feel if your doctor or health worker talked to you about your experience of tightness in the chest, wheezing, persistent coughing or shortness of breath? How would you feel if they approached the issue without your having raised it with them?
- What would be the best ways for you to receive information about understanding and managing the symptoms of tightness in the chest, coughing, wheezing, or shortness of breath? [Probe information channels, such as GP, pharmacist, hospital staff, support groups, asthma organisations.]

Knowledge of asthma

I'd now like to talk to you about asthma.

- Without telling me what you know, how much do you feel you know about asthma?
- How would you explain to someone what asthma is?
  - What are the symptoms of asthma?
  - As far as you are aware, what causes asthma?
  - What things can trigger asthma, or make asthma worse, in different people? [Probe on respiratory infections, cold weather, pollens/allergens in air, smoking/exposure to passive smoke.]
  - What should people do in the event of a severe asthma attack / emergency situation?

- Can asthma be treated? How? [If not mentioned prompt: medication, exercise, lifestyle, self-awareness, alternative treatments?] What is the best way to manage asthma? Why?
- Can asthma be prevented? How?

Perceptions of asthma

- How serious is asthma? Why do you say that? How serious is it compared to other health issues? Is asthma serious at some times and not at others? When do you consider symptoms to be serious?

Beliefs and attitudes

- Is asthma more likely to affect some people than others? Who do you think is most likely to be affected by asthma?
- Are some people better able to treat their asthma? Why do you say this?

Information and education

- Where have you learned what you know about asthma?
  - When did you learn it?
  - Has the information you've come across / found been sufficient? Are you interested in finding out more about asthma?
  - What else would it be helpful to know?
- What sources of information would/do you trust? Why?
- What (if anything) would make you more interested in information about asthma management?

Closing

- This research is being conducted on behalf of The Australian Government Department of Health and Ageing. The findings will be used to help the Department to improve asthma care in the community. If you would like more information about asthma, here are the contact details of the Asthma Foundation. The symptoms we have been discussing may or may not be indicators of asthma. If you wanted to discuss your individual symptoms, we would encourage you to see your doctor.

Discussion guide for GPs, pharmacists and AHWs

Introduction

- Thank for coming along
- Topic: Asthma
- Facilitator's role: to raise topics and issues and then for you to tell me what you think. Moderator is not an expert on asthma issues
- No right or wrong answers, your opinion that counts. Please be honest
- Group rules: one person speaks at a time / feel free to disagree
- Audio / video taping, mirror. Reassure confidentiality, anonymity
- Session will take an hour and a half / Interviews will take around 45 minutes
- Hand out incentives (sign and check contents of envelope)
- Refreshments, toilet facilities, please turn off mobile phones
- Participants introduce themselves

Perceptions of asthma

- How serious is asthma? Why do you say that? How serious is it compared to other health issues?

Knowledge of asthma

- How much do you feel you know about asthma?
- Are there any things you are unsure of, or can you identify any "gaps" in your knowledge of asthma?
- As far as you are aware, what causes asthma?
- What things can trigger asthma, or make asthma worse, in different people? [Probe on respiratory infections, cold weather, pollens/allergens in air, smoking/exposure to passive smoke.]

Diagnosing asthma

- Do you know the asthma status of all your patients?
- What would prompt you to find out whether the person has been diagnosed with asthma?
- In your opinion, how common is undiagnosed asthma? Are there any types of people who are likely to have undiagnosed asthma?

- In what sort of circumstances would you do tests or assessments to determine whether someone has asthma?
- What tests/steps would you do/take to confirm a diagnosis of asthma
- Is asthma diagnosis difficult? Why?

Beliefs and attitudes

- Is asthma more likely to affect some people than others? Who do you think is most likely to be affected by asthma?
- Are some people better able to treat their asthma? Why do you say this?
- Do you think asthma in our community could be better managed? In what ways? By whom?

Asthma management

- What are the signs that someone may not be managing their asthma properly? (Check for mention of: using reliever more than 3 times a week; waking during the night because of asthma; coughing excessively).
- How successful do you feel you are in determining whether someone is managing their asthma as well as they could?
- How might someone benefit from managing their asthma better? What sort of impact could it have on their day-to-day life?
- In what ways can you help someone to manage their asthma? What sort of a difference do you think you can make to how someone manages their asthma?
- Do you think you could manage your patients' asthma better? Why / why not? In what ways?
- What makes it easier or harder to manage your patients' asthma? Is there anything that stops you from managing your patients' asthma better?
- What would motivate you to be more active in managing asthma with your patients?
- What would assist you to manage your patient's asthma better? Why would this help? Who would be the best people or organisations to provide these to you?

- Has the way you manage your patient's asthma changed over time? In what ways? Why?

- Do you know what a written asthma action plan is? Can you describe what it is and what sort of information it contains?

- [If necessary, explain what an asthma plan is: "Written asthma action plans are written instructions on how to recognise when asthma is getting worse and what action to take when it does. For example, if a patient noticed changes in their symptoms or in their peak flow measurements, the plan would tell them what to do. This might include starting a new medication or changing their current medication in some way, or consulting medical advice."] What do you think might be the benefits of having a written asthma action plan? How valuable would a written asthma plan be to your patients?

- Have you ever written an asthma action plan for a patient? [If yes] I'd like you to tell me a bit about your experience in writing asthma action plans. Explore:

    - What prompted you to do this?

    - [If patient suggested] How did you feel when your patient suggested a written asthma action plan?

    - For roughly what proportion of patients with asthma would you have developed a written asthma action plan?

    - Did you have any difficulties in writing a plan for your patient? What do you consider is the most difficult component of writing a plan? How did you overcome these?

    - What do you consider to be the essential components of a written action plan?

    - As far as you know, did your patient use their written asthma action plan? [If yes] In what ways? Did they find it helpful? [If no] What stopped/prevented them from using their plan?

    - Do your patients tend to return for a review of their asthma? What things might help to ensure that your patients returned for an asthma review?

- If haven't written a plan:

    - What would prompt you to develop a written asthma action plan?

    - Do you think it would be difficult at all? In what ways? How could these difficulties be overcome?

- How likely would it be that your patients would return for a review of their asthma? What things might help to ensure that your patients returned for an asthma review?

Information and education

- Where have you learned what you know about asthma?
  - Has the information you've come across / found been sufficient? Are you interested in finding out more about asthma management? Why? / Why not?
  - What else would it be helpful to know?
- How easy is it to keep up-to-date with knowledge that is relevant to asthma? How do you do this?
- What sources of information would/do you trust? Why?
- Do you know of any resources that can be used to support the delivery of best practice asthma management? What? Have you found these to be useful? How?
- What would be the best ways for you to receive information about best practice asthma management?

Closing

- This research is being conducted on behalf of The Australian Government Department of Health and Ageing. The findings will be used to help the Department increase awareness about asthma and encourage people to manage their asthma better.

B

APPENDIX B

This appendix contains quotations from participants that had been included in an earlier draft of the findings but were transferred here at the request of the Department, to reduce the interruption to the flow of the discussion of the results.

People with asthma

Knowledge of asthma

"I didn't think it could kill you." [Teenager]

"If the asthma is not really bad then I forget about it until next time really, because it is usually mild." [55+]

"[Exercise] is something we have shied away from... by not letting him go and run on the football field." [Parent]

Attitudes towards asthma

"It's just an everyday thing. You've just got to cope with it." [55+]

"It's not a major disability; I can manage it quite easily. It comes and goes." [35-54]

"Mine is fairly moderate, so it's more of an irritant." [55+]

"I actually went into denial [when I was diagnosed]. I refused to believe it. I was in the RAF... and I kept it secret for 22 years." [55+]

"I was very surprised… because when you're an adult, you don't expect to be diagnosed with asthma." [35-54]

"I couldn't believe that, at my age, I got it… and from a virus!" [55+]

"It's a bit weird. People look at you when you take your puffer." [Teenager]

"I remember when I used to take my asthma medication at school, and they would call me a druggo." [Indigenous, 20-54]

"Well, you learn to live with it. It is a bloody nuisance." [55+]

"I try and ignore the fact that I have asthma." [Indigenous, 55+]

"It is just an inconvenience and I take puffers regularly. I can do some things at one stage of the day and not others. I just have to balance my life." [55+]

"A lot of people play it down and think it's just like the common cold. Give them a puffer and they'll be fine. But it is life threatening and it is serious." [Parent]

"She was not sleeping at night, and was falling asleep in class. Her work was suffering and kids picked on her and the kid gets depressed." [Parent]

"They think that asthma is just a big joke." [Indigenous parent]

"Even just to talk about it with other people helps, because you can't talk about it with the kids because they just don't want to know. They're sick of it. They've had enough of it." [Indigenous parent]

"I can't do what I want to do and I get irritable." [55+]

"I don't really care. It doesn't really bother me. It doesn't make me stop doing stuff I want to do." [Teenager]

Asthma management

"When I was a kid, I was diagnosed with asthma. I haven't had a single test or anything since then." [35-54]

"I went to a chemist and they sat down with me and went through all the side effects. No doctors told me that it stuffs your sleep up, I actually found out off a chemist." [18-34]

"When you go on school camps and that sort of thing, you wouldn't have to take your Ventolin everywhere [if you managed your asthma better]." [Teenager]

"If I didn't do it [manage my asthma], I wouldn't be here." [55+, severe]

"If the asthma is not really bad then I forget about it until next time really, because it is usually mild." [55+]

"If I thought asthma was under control and it wasn't really a factor in my life at the time, then I probably wouldn't want to [learn more about asthma]." [Indigenous, 20-54]

"'Steroid' is something you think the footballers use to beef up with." [Parent]

"The thing that makes me distrust it the most is when I get the shakes from the medication. It makes you think 'hmm, this is not necessarily good for me'." [35-54]

"You don't know how really how much is still in there [puffer]. You shake it, you can't hear anything, you can't feel it, you've just got to guess it." [Indigenous, 20-54]

"Because he can get a puffer for $14, whereas he will pay almost 30 bucks for a preventative." [18-34]

"You pay so much [for medication] and they give it to you then you pay it off, because they're not cheap." [Indigenous parent]

"The rules there are that the puffer has to be kept in the office, but I have spoken to them and said that I want his puffer in his bag, where he is a minute away from it." [Parent]

"I got told that at school he would have to nebulise himself and I didn't think that a 5 year old had the dexterity to snap it open and pour it in, particularly if he's gasping for air and I just got told point blank 'we are not allowed to administer medication' and I just thought 'oh my God, the kid has to do it themselves'." [Parent]

"You send them to school with their asthma medication, tell them 'don't do this' and 'don't do that', but the teachers don't help them." [Indigenous parent]

Written asthma action plans

"It might prevent it getting worse, so that people know when to consult their doctor or when to do something else. So, more preventative … in terms of knowing when things are getting worse." [35-54]

"I think my GP should have had something saying 'this is the typical asthma management plan and I suggest that you adjust it'…do you know what I mean? I had to write it all out from memory for the school because I wasn't handed any written information, and I think that would have really helped." [Parent]

"It's complicated enough to remember to carry a puffer around, let alone to have a plan stuck up on the fridge that you have to fill out." [35-54]

"If I was a child, maybe. They're still learning, so yes, it would be educational. But for people who've been dealing with it for years and years, you know what works for your body." [18-34]

"I'm managing it now, why make it more complicated? That's my point of view." [18-34]

Information and education

"A lot of people when they go to the chemist, they say 'what does it do?'. Because I've seen them there at Redfern there, not only Aboriginal but white too, 'what does this tablet do, what's it for?'. They go in there and ask questions, because the doctors are not telling you the truth." [Indigenous, 55+]

"I would ask them about the drugs that the doctor has prescribed. You ask your pharmacists because that's what they studied for." [Parent]

"It's hard to have a conversation when you know that there are other people waiting to get their scripts filled." [18-34]

"Half the time you don't get to see the chemist. You just get to see the checkout chick at the front, and I'm not leaving my child's safety and health to that person. The guy hasn't got time to see you." [Parent]

"I had my mum to tell me about it, because I had my older brother and he had it." [Indigenous, teenager]

People with asthma-like symptoms

Barriers to management

"There certainly seemed to be more people now at my age ... complaining about similar type things, and feeling as if they are restricted in their breathing, or tight in the chest."

"Yeah, I don't get around to [seeing a GP] because at the moment, I don't find it life-changing."

"It wasn't intense enough for me to go to a doctor."

"I never have [thought I might have asthma], because I saw what my brother went through and I wasn't as bad as him. He would be crippled over, gasping for air, couldn't breathe, like a croup type of sound, couldn't get air in."

"I know lots of people who have got it, and lots of children and teenagers who have got it and go madly puffing, puffing, puffing away, and what I was experiencing didn't seem to match that."

"I have a bit of a phobia about doctors. I'm scared that they might find something really bad, so I don't want to go."

GPs and pharmacists

Diagnosing asthma

"A lot of people my age would say 'yes, I used to get bronchitis a lot', which these days would be diagnosed as asthma. So I think it's better diagnosed now." [GP]

"Mildest cases are the hardest because people don't always need treatment ... or when they've got a cold then they show reversibility changes, but the rest of the time they're alright ... are they asthmatic or do they just have viral-induced airway irritability?" [GP]

"There's grey areas and overlap with late onset asthma, emphysema and COPD." [GP]

"In an older person, I think that it becomes a bit problematic sometimes to pick between what might be more asthma or what might be part of a broader issue with airways restriction that is fixed as well as variable." [GP]

Knowledge

"I feel as if I know enough to get by on a day-to-day basis and to educate patients and to always consider it as a diagnosis for undifferentiated respiratory conditions." [GP]

Asthma management

"There is a role for us … we can only have a small imprint, we're a small player." [Pharmacist]

"It's sort of like you can have a bit of a feeling whether the customer is being treated well, or whether their asthma needs to be checked with the doctor." [Pharmacist]

"Sometimes you pick up a trend – like if they buy Ventolin three times a month or something and you pick that up and suggest they go back to see their doctor." [Pharmacist]

"Where the funding is based on a patient's decision to return or not, it was doomed to failure." [GP]

"I can't just ignore five other people who want something. You might be able to do it, but not for very long because you're so busy. If you had someone who was a dedicated asthma specialist or something." [Pharmacist]

"There's also very negative stigma of the use of steroids for any kind of medication and they have a fear of using it." [GP]

"I have told all my staff that asthma is something we need to ask about regardless of the type of over the counter medication a customer is buying. My big concern is that asthmatics buying Nurofen at the supermarket won't get the same care when having their packet scanned at the checkout." [Pharmacist]

"So I guess the background barriers are totally huge in everything, and asthma management would be just one tiny part of the huge obstacles that people have getting organised in their life to do anything." [GP, Remote Indigenous]

"I think pride in your work is important. It's nice to be able to say, well, none of my asthmatic patients have died this year, or most of my asthmatic patients are living fulfilling lives." [GP]

Written asthma action plans

"It's not just for emergency situations. It's also what to do, how to recognise if your symptoms are getting worse and what actions need to be taken." [GP]

"Getting people to want to actually do it and people who need it to want to do it. That's the first step. Once you're there, it's easy enough." [GP]

Information about asthma

"The only information we tend to get to our face is via drug reps, which is always skewed, so you've got to be a bit cautious." [GP]