

# The Path to Diagnosis of Severe Asthma-A Qualitative Exploration

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**Purpose:** Severe asthma poses a significant health burden in those with the disease, therefore a timely diagnosis can ensure patients receive specialist care and appropriate medication management. This study qualitatively explored the patient experience of adult Australians with severe asthma regarding specialist referral, to identify potential opportunities to streamline the process of severe asthma diagnosis and treatment and optimise referral pathways.

**Patients and Methods:** Adults currently being treated with medication for severe asthma were invited to participate in this study. Participants were interviewed and asked to describe initial diagnosis of their asthma or severe asthma, and how they came to be referred to secondary care. Interviews were transcribed verbatim, coded by two members of the research team and thematically analysed.

**Results:** Thirty-two people completed the study; 72% were female. Mean interview length was 33 minutes. The major themes generated were patient-related factors contributing to seeking a severe asthma diagnosis; perceptions of health care provision; diagnosis of severe asthma and the referral journey. Key findings were that both patient and healthcare provider attitudes contributed to participants' willingness to seek or receive a referral, and referral to respiratory specialists was often delayed. Contributing factors included a mismatch between patient expectations and general practice, lack of continuity of primary care, and a lack of patient understanding of the role of the respiratory specialist.

**Conclusion:** Timely severe asthma diagnosis in Australia appears to be hampered by an absence of a clear referral process, lack of general practitioner (GP) knowledge of additional treatment options, underutilisation of pharmacists, and multiple specialists treating patient comorbidities. Directions for future research might include interviewing healthcare providers regarding how well the referral process works for severe asthma patients, and researching the time between referral and when a patient sees the respiratory specialist.

**Keywords:** respiratory, patient, referral, diagnosis, comorbidities

## Introduction

Severe asthma is defined as asthma that remains uncontrolled despite regular treatment with high-dose inhaled corticosteroids plus long-acting beta2 agonist or with maintenance oral corticosteroids (GINA Step 4 level treatment), or asthma that requires this level of treatment to prevent it from becoming uncontrolled<sup>1</sup> and after optimisation of possible contributing factors including medication adherence and associated comorbidities. It is estimated that between 3% and 10% of people with asthma have severe disease.<sup>2</sup> Severe asthma is associated with high morbidity and mortality and poses an economic burden on both individuals and society.<sup>3,4</sup> People with severe asthma also experience a significant health burden as a result of their asthma, with an increased rate of hospitalisation, daily symptoms resulting in poor quality of life and often, poor functionality.<sup>4,5</sup>

There has been a recent focus on acknowledging heterogeneity within asthma and the clinical manifestation of different phenotypes and treatable traits.<sup>6,7</sup> This adds complexity to the diagnosis and management of asthma- in particular for individuals with severe asthma. Due to symptom severity and the complex nature of this heterogeneity, the management of severe asthma in Australia is primarily undertaken by specialist respiratory physicians working in tertiary health care settings. This approach facilitates access to complex treatment pathways, which are often required for people with severe asthma. However, people with less severe, but still complex asthma, who are mainly managed in primary care, may miss out on these treatment approaches, thus contributing to a hidden burden.<sup>8</sup>

The challenges in diagnosing severe asthma and ensuring that patients receive required specialist care, including medication management, have been acknowledged.<sup>9,10</sup> The correct identification of disease phenotype can ensure appropriate targeted treatment, maintenance of symptom control, and a consequential reduction in health care utilisation and associated costs.<sup>10</sup> Several studies have demonstrated that care from an asthma specialist reduces asthma exacerbations, including hospitalisations.<sup>10</sup>

In practice, referral pathways for asthma from primary care to secondary care are often unclear and poorly implemented, with many patients taking years to reach needed secondary care.<sup>11</sup> An investigation into asthma deaths in the United Kingdom found 1 in 5 related to avoidable factors associated with delayed referrals; over half the patients were not under specialist supervision prior to their deaths.<sup>12</sup> Participants in a recent Canadian study on best practice for optimal referral of people with severe asthma strongly agreed that pharmacy services can play an important role in identifying uncontrolled patients for follow up and referral.<sup>13</sup>

Several research gaps remain when it comes to exploring the lived experience of people with severe asthma. People with severe asthma have previously detailed how they are most concerned with how asthma impacts their quality of life, but these concerns often get neglected when clinical assessments are made.<sup>14</sup> Incorporating quality of life outcomes into clinical assessments and introducing public health measures to raise awareness of the impact of severe asthma have subsequently been recommended to address these patient concerns.<sup>15,16</sup>

Although these are important strategies, the path to diagnosis is complex, and due to the unstructured way asthma is managed in many primary health care environments worldwide,<sup>17</sup> management often remains reactive, with the onus on the person with asthma to seek care.<sup>18</sup> If this continues to be the case it is critical to gain an understanding of the journey and experiences that people with severe asthma have undertaken to obtain their severe asthma diagnosis, to identify additional opportunities streamline the process leading to severe asthma diagnosis and treatment and optimise referral pathways. This study aims to explore the patient experience with regard to specialist referral of adult Australian patients with severe asthma.

## Materials and Methods

### Recruitment

Respiratory physicians within our practice-based research network in Australia were approached directly via Email offering them an opportunity to invite their severe asthma patients to participate. Respiratory physicians that expressed interest in the study were provided with:

- a recruitment poster to display in their waiting room and/or
- an email/letter template to send to all relevant people with severe asthma on their database, informing them of the project and asking them to register their interest in participating.

Potential participants were asked to contact the research team directly to express their interest. Potential participants were not known to the research team and were not required to inform their doctor if they had chosen to participate or not. Informed consent was obtained from participants who were eligible and willing to participate. Participants received a grocery shopping voucher to compensate them for their time taken for the interview.

## Participants

Inclusion criteria for this study were as follows:

- Doctor (respiratory specialist) diagnosis of severe asthma. Researchers did not have access to medical details and were reliant on self report and confirmation of diagnosis from participants.
- Currently being treated with medication for severe asthma (Step 5 GINA).
- Felt comfortable communicating in English.
- Aged 18 years or older.

## Study Design

The study involved a qualitative exploration of patients' experience of their journey from their first memory of having asthma to the time they received a severe asthma diagnosis.

Using a phenomenological approach, participants were asked to describe their asthma, and how they came to be referred to secondary care and/or diagnosed with severe asthma. A semi-structured interview guide ([Supplementary Table 1](#)) developed from our empirical understanding of the patient experience with severe asthma and the phenomenological theoretical framework which aims to further understand the interviewees' experiences regarding their severe asthma diagnosis journey, was created and was adapted as new insights emerged from later interviews. Interviews were conducted by BC and SD, who are researchers at the Woolcock Institute of Medical Research and have no clinical relationship with participants. In order to be COVID safe, all participants were given the option of conducting the interview by Zoom or phone only. Interviews continued until data saturation ie no new themes occurred. With participant consent interviews were audiotaped and transcribed verbatim.

## Data Analysis

Data analysis was informed by a phenomenological approach<sup>19</sup> whereby “significant statements” that represent how participants first experienced the phenomenon of a severe asthma diagnosis, as well as their referral journeys were identified as codes using a mixed deductive-inductive approach. The mixed analysis approach identified themes arising from the identification of codes from known knowledge (deductive) as well as from the analytical reading of the data for any organically generated concepts (inductive). This process of analysis enables the generation of novel codes, which were categorised into themes to describe the participants' experience of severe asthma diagnosis and referral pathways.

Different experiences and journeys described (such as negative or deviant cases) were explored and integrated into the analysis. Thematic analysis was conducted by BC and SD and performed in accordance with COREQ recommendations.<sup>20</sup> Multiple stages were involved including independent initial coding of early interviews by BC and SD, subsequent coding of the entire dataset by SD, review of coding by BC, SD and SBA, identification of themes/subthemes and further refinement.

## Ethics

Ethics approval was received from the University of Sydney HREC [Approval 2020/522]. The Woolcock Institute of Medical Research was formerly under the auspices of the University of Sydney. This study complied with the Declaration of Helsinki. All participants provided informed consent to include publication of anonymised responses.

## Health System and Medicine Access in Australia

Australians benefit from free or subsidised health services through a national scheme called Medicare. In addition, the Pharmaceutical Benefits Scheme (PBS) is a government program that subsidises medicines to make them more affordable. To be eligible for subsidised treatment with biological agents, adult patients with severe asthma must be treated by either a respiratory physician, a clinical immunologist, an allergist, or a general physician with expertise in managing asthma.

## Results

All participants learnt about the study from five specialists (three in New South Wales and two in Victoria). Fifty nine people expressed interest in participating-32 completed the study. The reason for withdrawal of 27 potential participants was that they changed their mind or reported they were no longer able to participate. Of the 32 participants, data were available regarding age for 24 participants, with mean age 63 years (range 36–85 years) and 23 were women (72%). Interviews ranged from 16 to 56 minutes; mean length of interviews was 33 minutes.

Major themes generated were patient related factors contributing to seeking a severe asthma diagnosis; health care provision; diagnosis of severe asthma and the referral journey/pathway.

Themes and subthemes are displayed in [Figure 1](#).

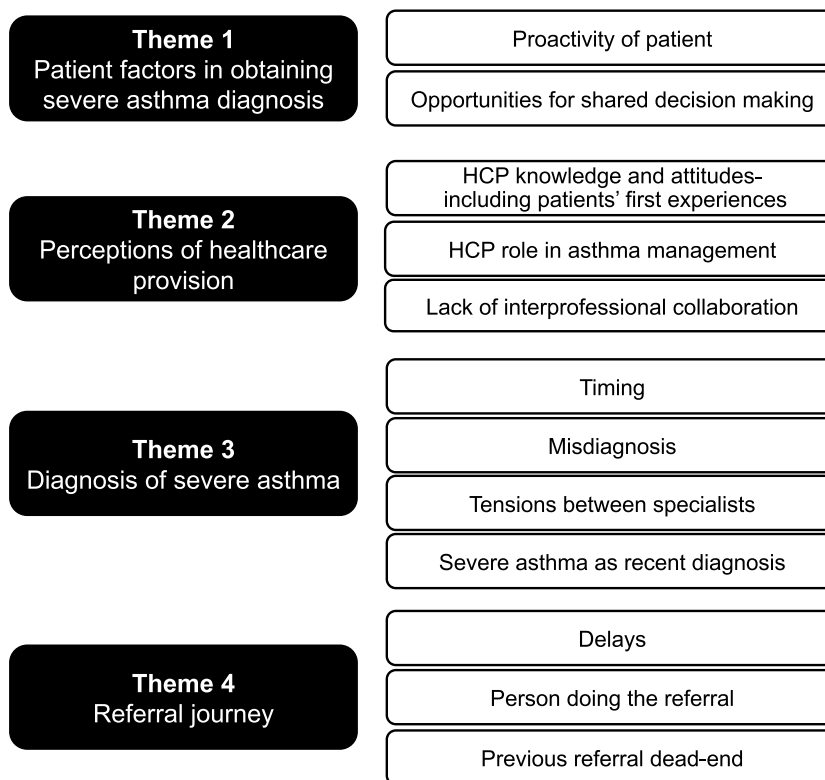
### Theme 1: Patient Factors in Seeking Severe Asthma Diagnosis

Participants reported a range of factors which affected their decision to seek a severe asthma diagnosis including adaptation to the status quo; other comorbidities; and availability of support network.

#### Subtheme 1.1: Patient Proactivity

On reflection some participants realised that earlier specialist intervention may have been useful but they, the patients themselves, had not prioritised this due to acceptance of their condition, complacency or other issues happening within the family. Others were more proactive:

I knew it was getting worse, rather than better. I really initially just wanted to go to see a respiratory physician to see if there was anything else that I could add to what I was currently doing. Because my GP is not great, to be honest, in terms of that sort of thing. I don't really have a good GP that I see regularly, well at the time I didn't, I do now. So, I just thought, look, I'm going to go and see someone, make sure, because I'm getting older, I don't want to muck around with my lungs. #2046 aged 52



**Figure 1** Themes and subthemes.

### Subtheme 1.2: Opportunities for Shared Decision Making in Asthma Management

Participants reported that their GP either made treatment decisions for them or did not actually engage in actively seeking the patient's input, and there was little opportunity to explore their feelings in depth. However, others they felt comfortable in raising issues with the GP

you go to your GP first, they need to listen and accept that if you've been an asthmatic all your life, you know when you're sick, and to take notice. ... #2040

## Theme 2: Participants' Perceptions of Healthcare Provision

People with severe asthma perceived GPs and various other medical specialists to be integral to their asthma care and reflected on their healthcare interactions with these providers over their lifetime.

### Subtheme 2.1: Health Care Providers Knowledge and Attitudes

Regarding GP attitudes, some participants mentioned apathy and lack of empathy and how annoyed they were that their concerns were often downplayed or dismissed, leading to dissatisfaction with their care. General practitioner knowledge about, and interest in, asthma management varied and to an extent reflected management strategies available at the time of consultation:

I think throughout my late teens and in my twenties most of the doctors I saw were - I'm not going to say not educated in asthma but it was like oh, okay, you're asthmatic so okay, asthmatics take Ventolin and when they get sick this is what they take and this is how it's dosed. #2054 aged 52

For some older participants (poor) first experiences of having asthma as a child and interactions with Health Care Professionals (HCPs) may have influenced their perceptions in regard to current HCP experiences; some of our participants remember their parents being taken to task by the medical profession regarding the cause of their child's asthma. In addition, people we spoke to reported that there was a belief that asthma had a strong psychological component.

my parents had been told when I was quite young, asthma is psychological. That's what my parents were told... #2005 aged 74

By contrast, other participants had more positive experiences whereby healthcare providers appeared to be invested in patient outcomes:

I've been really, really lucky with the doctors that I've had. Both the doctors, the nurses, the clinicians and the specialists; their real keen interest is that you survive with your disease, and you live with your disease #2050 aged 71

### Subtheme 2.2: Participant Perceptions of Healthcare Providers' Role in Asthma and Severe Asthma Management

Although some participants expressed that their GP did a good job regarding asthma management. Others questioned whether it was within the role of the GP, arguing that asthma treatment needs a specialised rather than a generalised approach. Some participants expressed that even respiratory specialists did not have all the answers:

Unfortunately, I have heard from a lot of people that they want to - The GP wants to look after them. GPs are wonderful, they have their use but I think asthma's specialised and they should seek specialist treatment. #2005 aged 74

Opinions regarding pharmacists as part of the asthma management team were varied. Although acknowledged by several participants as medication experts, other participants questioned pharmacists' role in asthma management:

I go to a very good chemist that I've known for years but I haven't really spoken much about the asthma to her #2027 aged 73

### Subtheme 2.3: Lack of Interprofessional Collaboration

Some participants felt that their asthma care was fragmented, with a perceived lack of continuity of care, disconnect between different healthcare professionals, and exacerbated at times by the location of care. By contrast, for a few participants HCPs were perceived to collaborate to support people with severe asthma:

They just don't seem to want to pass on that information to the specialists and go backwards and forwards. ....So I think that that constant one person - one on one is really important. But it's very hard to get. #2002 aged 75

They keep in touch with each other. They keep in touch with my GP, both [hospital] and the Eye and Ear. I have wonderful support with my GP and at the clinic. #2058 aged 64

## Theme 3: Diagnosis of Severe Asthma

Participants described how their severe asthma diagnosis came about in terms of the timing and location, and also barriers that affected a timely diagnosis, including comorbidities and the lack of alternative treatment options:

### Subtheme 3.1: Timing

The timing of a diagnosis of severe asthma varied considerably between participants depending on the age of the participants, asthma management strategies in place at the time, and comorbidities present. Diagnosing asthma itself initially, as opposed to severe asthma, was equally problematic:

when I was a child, I remember going into [hospital] seeing a specialist there. I'm sure I would have - then I'm sure even with my GP at first that I'm sure I blew into the old spirometry machines where they have a bit of graph paper on the machine, and it sort of drew a line sort of thing. So, I'm sure I did that occasionally when I was - before I was an adult as well. #2033 aged 52

I went to the doctor, would have been early 2000s, somewhere in there, and he said - I couldn't get rid of this cough because I couldn't stop coughing and he said, I'll put you onto asthma medication. I said don't be silly, I'm not an asthmatic. He said just try. So I tried it, and it was like a game changer, for me. It changed my whole life. But we didn't diagnose asthma. #2045

### Subtheme 3.2: Misdiagnosis

Misdiagnosis of asthma itself was reported quite frequently by older participants in our study, often as bronchitis or chronic obstructive pulmonary disease (COPD), and some participants felt this delayed appropriate referral:

through my childhood before that, I do recall having bronchitis quite a lot. I remember my mother putting me over the back of the dining room chair to do some like physio on my back to help lodge mucus and so on and but it was never ever at that stage diagnosed as asthma #2034 aged 65

### Subtheme 3.3: Opportunistic Diagnosis

Some participants were diagnosed or referred to specialist opportunistically when being tested for a physical activity, or as part of a medical review for another condition, including pregnancy:

It was when I was expecting my daughter. My GP then, said that I had asthma. #2012 aged 72

### Subtheme 3.4: Tensions When Different Specialists Were Involved in the Diagnostic Process

Participants spoke about referrals to specialists other than respiratory specialists, such as immunologists for allergies, and ear nose and throat (ENT) specialists to deal with nasal polyps and sinus issues. For some participants relationships with several specialists were ongoing for years, and sometimes created tensions when individual clinicians had differing views from each other as to the cause of patients' symptoms, and uncertainty for the participants as to who was actually managing their asthma:

I then went to see a third ENT specialist and he said I could improve the looks of the picture, he said, but if I did another operation, I don't believe it would make any difference. So that was the stage where I gave up all together on the ENT specialist and moved to seek out the respiratory physicians. #2048 aged 82

### Subtheme 3.5: Severe Asthma as a Recent Diagnosis in the Biological Era

Participants often mentioned the word "severe" when describing symptoms and/or exacerbations as opposed to a diagnostic label per se. Although participants in this study talked about lack of effective treatment options until they commenced on biologicals, for some elderly patients that had asthma for their whole lives, severe asthma as a separate diagnosis was quite a foreign concept:

my asthma was still pretty bad so I was referred to lung function specialists at [Hospital] and my lungs weren't very good at all and so eventually the specialist, they did some research in America and they found that some of the injections they gave for severe asthmatics. #2027

Although there was no direct line of inquiry regarding pathological testing, there was limited mention of biomarkers by participants in this study. However, participants were well aware and willing to share information about the different medicines that they had used throughout their asthma journey, with many using multiple inhalers at a time in addition to oral corticosteroids. Most study participants seemed to believe that steroid use was part and parcel of having severe asthma. Only a handful of participants noted that they raised concerns with their GP about steroid adverse effects or lack of effect, and just one talked about the progression from regular steroids to a biological.

## Theme 4: Referral Journeys

Referral journeys reported by participants varied and were not necessarily linear. Although referrals to respiratory specialists were usually facilitated by the GP, some were opportunistic and not all achieved what the patient was hoping for at first.

### Subtheme 4.1: Delays in Referral

Participants reported that it sometimes took years before their primary care provider suggested referral to a specialist. Even when that referral decision had been made there could be access barriers to seeing specialists including waiting times for appointments and the perceived cost of seeing a private specialist.

actually he referred me to another specialist but I couldn't get in for a month and he realised I needed to go straight away so I got in to Specialist A after - fairly quickly and everything started getting better after that. #2027 aged 73

I think for some people it might also be monetary; it's expensive, obviously, seeing specialists and stuff like that and some people probably just think that you can get the same care at your GP. In some ways you can but in some ways you can't. I think when things go wrong, like really wrong, you really need someone on your side who's a specialist in the area rather than just a GP. #2011 aged 44

### Subtheme 4.2: Person Enabling the Referral

In terms of who did the referring, most participants reported this was facilitated by the GP, but also practice nurses on some occasions; for others requests for referrals were self-directed or suggested by family members, friends or work colleagues:

the nurse who was also there, she was writing up my asthma plan and she's called him in and they're both talking, and she said you've got to go. Then she actually recommended the particular doctor #2024 aged 70

Several people we spoke to mentioned seeing a specialist during or following hospitalisation:

Yes, yes and so any specialist I might have seen, to the best of my recollection, would have only been at hospital and anyone that saw me there as opposed to being referred by a GP #2026 aged 49



### Subtheme 4.3: Referral Dead-Ends

Some participants expressed that simply having a referral was not always an end-point, whereby the specialist visits did not go well and they had needed to change their specialist, of their own volition:

When I moved from that first doctor because the asthma wasn't improving and I shopped around to find Dr B. She tried various steroids, inhaled steroids. That didn't seem to improve the asthma any better and so then I moved on to respiratory physician number three and I got much more satisfaction from him. #2048 aged 82

## Discussion

This study qualitatively explored the referral journey of adult Australian patients with severe asthma. Key findings were that both patient and healthcare provider attitudes contributed to participants' willingness to seek or receive a referral, the time to diagnosis of asthma and severe asthma varied-often complicated by upper airway comorbidities, and referral to respiratory specialists was often delayed.

The context of asthma management has significantly changed over time; Australia's first asthma guidelines were published just over thirty years ago in 1989, when specialists had limited treatment options particularly outside the hospital setting. The experiences of some of the older participants in our study reflect this whereby they accepted the status quo of just feeling a certain way and recounted how they saw specialists and received treatment only with hospitalisation. Concurrently, there has been a major transition of care from a paternalistic model, with the clinician holding authority, to a more collaborative model moving toward provision of personalised and precision-based care.<sup>8</sup>

Our study identified a mismatch between patient expectations and GP practice. Australian care models for severe asthma suggest a pivotal role for primary care in early identification and management of uncontrolled asthma,<sup>21</sup> including performing spirometry, optimising therapy, therapy adherence, correct inhaler technique, treatment of comorbidities and addressing modifiable risk factors.<sup>21,22</sup> It was beyond the scope of this study to ascertain if GPs do all these things, however several participants felt that their GPs could have been better informed about asthma and they as patients could have had more agency regarding asthma treatment decisions.

Patient experiences captured in this study also suggest that GPs may fall short in their care for a person with severe asthma by not always encouraging or facilitating patient access to a respiratory specialist or explaining the additional options that a specialist may be able to provide such as biological agents. This perhaps is system-driven due to a lack of GP continuity for a condition which is chronic but can be acutely problematic. GPs in a recent Australian study of asthma care perceived that specialist opinions were not commonly needed for asthma- also reflecting a focus on acute care.<sup>23</sup>

Regarding continuity of care, participants told us they were often unable to see the same GP if attending a medical centre. The ideal collaborative model involving a very close co-operative relationship between clinician and patient,<sup>8</sup> is at odds with the patient lived experience of fragmented care of variable quality.<sup>24</sup> Participants in our study also reported poor communication between their specialists. Increased specialisation and a silo mentality may further fragment care. Practical solutions for HCPs to better understand the lived experiences of people with severe asthma may include online research-based testimonies from people with severe asthma.<sup>25</sup> Additionally, a clinical decision support system may support the diagnostic process, prompt dialogue, aid understanding and support shared decision-making.<sup>26</sup>

Our participants reported that referrals to respiratory specialists often took several years despite the need for optimal referral pathways for people with severe asthma being recognised in context of minimising oral corticosteroid toxicity,<sup>22</sup> and allowing access to additional health care resources and add-on therapies, such as biologicals, which cannot be prescribed in primary care. A lack of a standardised approach to triage of referrals has been an ongoing concern in Australia<sup>21,27</sup> and internationally.<sup>28</sup> A UK study examining asthma patients meeting guideline-based referral criteria found only 4% were referred during follow-up, with a median waiting time of 880 days between eligibility and referral,<sup>29</sup> bearing out the perceptions of our study participants. For several participants in this study a diagnosis of severe asthma or specialist referral resulted opportunistically from hospitalisation. Although historical hospital admissions in Australia did not warrant specialist referral due to limited treatment options outside of the hospital setting, patients requiring hospitalisation or Emergency Department presentation for an asthma attack should currently have a specialist assessment with a diagnosis of severe asthma considered.<sup>10</sup>



Solutions to address the lack of referral of people with potential severe asthma might include clinical guidelines for GPs containing specific referral criteria, and the use of pharmacists to identify possible candidates based on medication history. However, HCP adherence to guidelines and checklists may be suboptimal<sup>30</sup> due to lack of clarity of roles,<sup>31</sup> poor familiarity with guidelines,<sup>10</sup> and training and skills.<sup>32</sup> It is not practical for Australian GPs to be across guidelines for every disease, especially given the current system where appointments are short and not well rebated. Moreover, there is a current GP shortage, and guidelines are generally in the digital domain and are disease-specific, at a time when multimorbidity has become commonplace.

Referral criteria for people with potential severe asthma have been suggested in the literature. However, such data require patient databases to extract the information, and the will and time to do so. Referral tools in practice overseas include the SIMPLES algorithm (UK), and the Asthma Referral Identifier (ReferID) tool (4-item questionnaire).<sup>33,34</sup> Improving knowledge of referral criteria, incentivising early review,<sup>33</sup> and joint protocols between primary and secondary healthcare might also be defined and initiated.<sup>27,33</sup>

Whilst most initiatives regarding referral have been directed at GPs, pharmacists can monitor asthma medication use and potentially identify patients for referral. Although pharmacists were acknowledged by study participants as having a role in medication management, they were generally not seen as part of the asthma management team. A role for pharmacists in identifying patients to see a respiratory specialist based on identification of excessive short acting beta agonist (SABA) use or repeat oral corticosteroid (OCS) scripts has been previously mooted.<sup>13,22</sup> Therefore, education of patients and primary care professionals around the potential role of the pharmacist in severe asthma identification and referral may be beneficial.

It has been suggested that once a referral is made, the optimal time delay to seeing the specialist is 4–8 weeks.<sup>13,35</sup> However, even with optimal referral pathways, it still may be difficult for some patients to access respiratory specialists due to long waiting times and fees.<sup>23</sup> Contributing to the long waiting lists are a lack of specially trained HCPs,<sup>9,21</sup> high service demand<sup>10</sup> coupled with insufficient resources,<sup>27</sup> insufficient referral details,<sup>21</sup> complex requirements of the Australian Pharmaceutical Benefits Scheme for access to biological therapies<sup>9,21</sup> and limited access to some biomarkers in many facilities. Moreover, geographic barriers can disproportionately burden financially disadvantaged severe asthma patients, who may require frequent reviews from their specialist and multidisciplinary team and are usually only available in urban centres.<sup>21,27</sup>

People with severe asthma in our study reported misdiagnosis and delayed diagnosis, possibly removing the opportunity to get all the necessary treatment. Diagnostic delays were in part due to a majority of participants reporting upper respiratory comorbid treatable traits such as chronic sinusitis and nasal polyps which necessitated involvement of specialists other than respiratory specialists and the perception that disagreements between specialists regarding primary diagnosis delayed their diagnosis of severe asthma. Comorbid treatable traits in people with severe asthma are recognised in the literature as needing to be reviewed and optimised over time, however interprofessional communication between specialists may need improving based on our participants' experiences. Respiratory specialists can assist by providing clear recommendations to colleagues in primary care regarding ongoing management, specify indications requiring further specialist review and ideally a streamlined referral pathway.<sup>21</sup> At the primary care level, severe asthma diagnosis needs to be appropriately flagged in patients' health records and other systems to ensure future HCPs are informed.

A strength of this study is that we interviewed people with severe asthma comprising a large age range, allowing us to understand the diagnosis and referral journey of patients in Australia over a long period of time. However, changes in asthma treatment over time with the availability of personalised treatments such as biological agents have vastly improved treatment for people with severe asthma. A limitation of the study is that participants with limited English or from Culturally And Linguistically Diverse (CALD) backgrounds may not have been recruited because we were not able to offer interpreter services within our limited resources. Our research was also limited by the fact that we interviewed patients with severe asthma, but not the healthcare providers who provide care for them. Also, the patients came from only a few specialist practices and we did not collect data in terms of whether patients were managed in public hospital outpatient setting or private respiratory specialist practices.

Directions for future research might include interviewing HCPs regarding their perceptions of how well the referral process is working for severe asthma patients, and researching the time taken from when a referral is made to when a patient sees specialist.

## Conclusion

In conclusion, the diagnosis of severe asthma in Australia appears to be severely hampered by lack of a clear referral process driven in part by lack of patient assertiveness, lack of GP knowledge of additional treatment options, under-utilisation of pharmacists, and multiple specialists treating patient comorbidities. GP education and upskilling of pharmacists may assist in earlier identification and referral of patients with potential severe asthma. We recommend national defined criteria for referral including acceptable waiting times.

## Abbreviations

GP, General Practitioner; GINA, Global Initiative for Asthma; PBS, Pharmaceutical Benefits Scheme; HCPs, Health Care Professionals; COPD, Chronic Obstructive Pulmonary Disease; ENT, Ear Nose and Throat; OCS, Oral corticosteroids.

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