

# THE TASMANIAN ASTHMA DISCOVERY PROJECT

## Community Consultation Consumer Snapshot

### WHAT'S LIFE LIKE WITH BREATHING PROBLEMS AND ASTHMA IN TASMANIA?

Everyone experiences asthma differently. Different things work for people in managing their asthma and there are challenges, highs and lows.

We wanted to go further than the obvious prevalence and associated data about asthma in Tasmania and build a more detailed and consumer-based picture of local community responses to asthma management.

In partnership with consultants Healthy Tasmania Pty Ltd, we set out to hear what life is like for people experiencing asthma in Tasmania and to determine where and how future asthma supports and programs are best delivered for the greatest impact.

### Aims



**Understand** the community experience of asthma in Tasmania



**Determine** the current gaps and identify problems, challenges and potential solutions



**Gather** insights into the wants and needs of Tasmanians and the problems we need to solve in partnership with the community

### Advertising and Media



Community newspapers



Social media



Community radio



Television

### CONSULTATION ENGAGEMENT



177 online surveys



5 emails



5 phone calls



9 postcards



focus groups consisting of 8 people across 3 locations



### THEMES



**Experience with asthma:**

What people know about asthma and how they feel about it



**Services and supports:**

The experience with health professionals and the health system



**Challenges and needs:**

How life with asthma could be better

## WHAT DID WE FIND OUT?

People feel they understand their asthma and are managing yet they also tell us they **can't participate in life** as fully as they would like.



This tells us that there's a mismatch between what people know about their asthma, what they do to manage it and the best possible health and wellbeing outcomes.

**“My 10 yr daughter was diagnosed around 5 years ago. It is still **controlling her life!** We have and still battle to keep under some kind of control.”**

*It is heartbreaking to watch the impact it has on her life, and at her age, she really does not totally understand Asthma and the effects, all she knows is that she wishes it would just go away, so she can run around, dance and do all the things that asthma takes from her.*

Many people with asthma **put up with poor quality of life** when even small changes can be life changing. Often people experience regular flareups but feel that it's a normal part of having asthma so they 'just live with it'.



This tells us that people need support to see how easy asthma is to manage well and live freely.

**“I really haven't sought out help from other avenues when I should have done, probably my shyness (anxiety) and possibly embarrassment has stopped me from doing that in the past. As I deteriorate, those [asthma] problems seem to get worse.”**



Many **underestimate its seriousness**, yet they feel that the broader community doesn't appreciate the seriousness and they want more support around them.



This tells us that people with asthma need supportive environments to reduce stigma and anxiety around asthma.

**“Lack of specialists and poor community awareness make it an **illness with a stigma.**”**

People prioritise their GP as a trusted source of information, but with the current limitations of the health system with its pressures and strains, they are also **struggling to access timely, continuous and affordable care.**



This tells us that people value locally-based programs that can provide more care options in their community.

**“A designated go-to person to help walk through the rough bits who KNOWS what to do next without navigating my way through appointments with my overstretched GP would be such a comfort.”**

Air quality is a top-order concern for people with asthma, with many taking the opportunity to express their anxiety when faced with woodheater smoke, seasonal burning and bushfires.

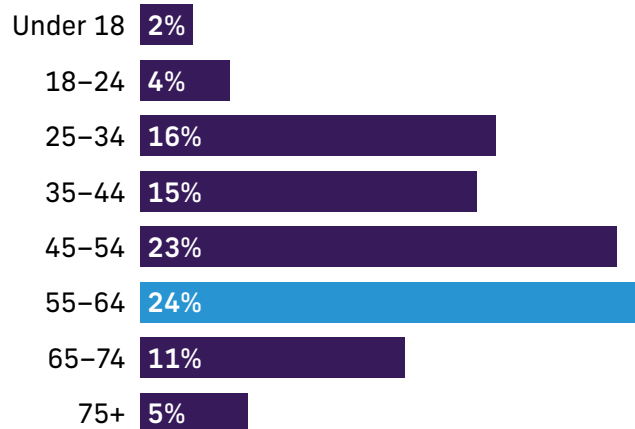
This tells us that supporting people with up-to-date air quality information is critical in helping people take action at peak times.

**“It is just frustrating feeling like I am trapped in my own home a lot of the time and can't go outside for more than very short periods of time.”**

*It can be hard to hung up washing, go for a walk, do the shopping, even go to the Dr's. I can't even open the house up for fresh air for approx 6mths of the year.*

# WHO DID WE HEAR FROM?

## Age of respondents (n=177)



## Age of child with asthma (n=43)

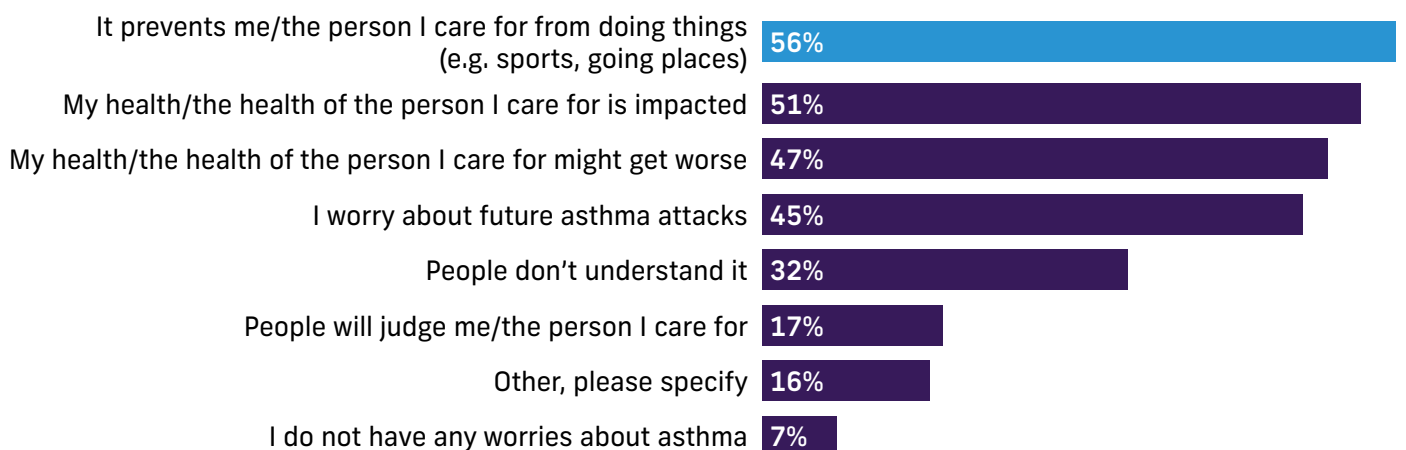


# THEME 1: EXPERIENCE WITH ASTHMA

## Thinking about your asthma/the asthma of the person you care for, how much do you agree with the following statements? (n=177)

	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree
I understand what is happening in the body when I/the person I care for experiences asthma symptoms	3%	11%	16%	55%	15%
I understand how asthma medications work to help control asthma	3%	10%	9%	55%	23%
I know how to use asthma devices (puffers) correctly	1%	2%	5%	58%	34%
I know what to do if I/the person I care for is having trouble breathing	2%	5%	10%	61%	23%
My/their asthma is usually manageable	2%	8%	10%	66%	15%
I know about where asthma support is available in Tasmania	11%	38%	21%	24%	7%
I know what can trigger an asthma flare-up	1%	8%	8%	56%	25%

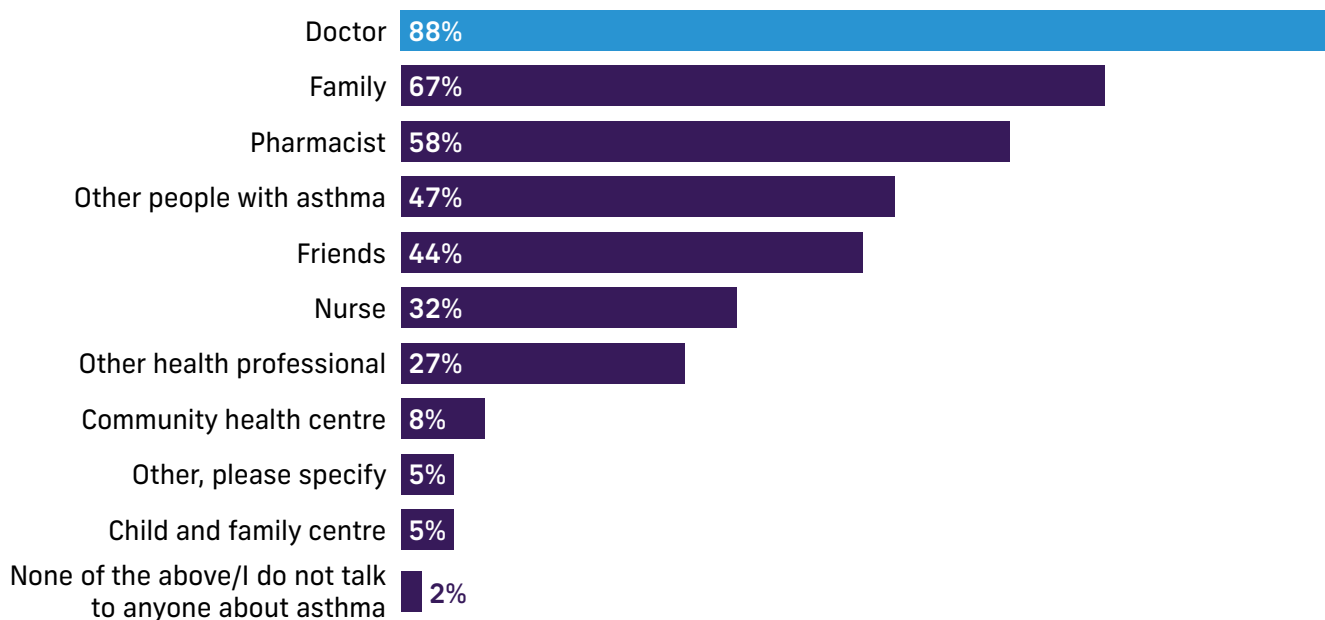
## What worries you about living with asthma or caring for someone with asthma? (n=177)



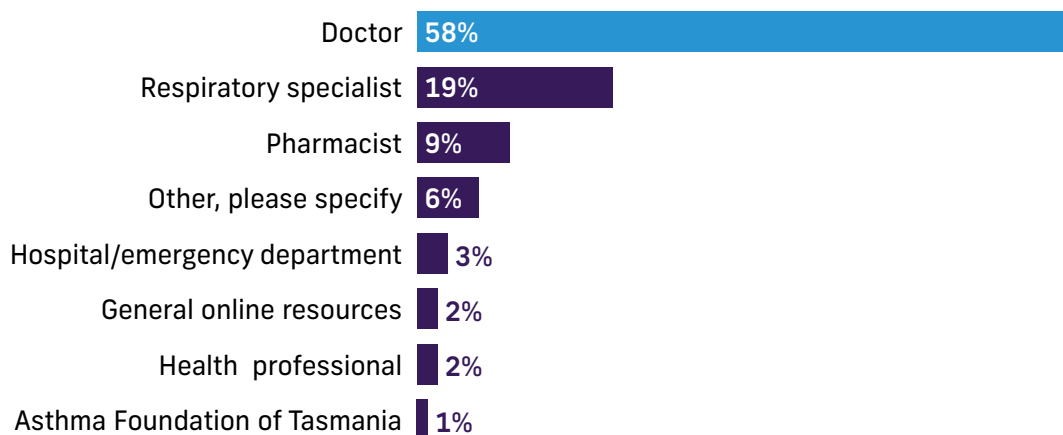
Thinking about how you feel about asthma and how the people around you think about asthma, how much do you agree with the following statements?	Strongly Disagree (1)	Disagree (2)	Neither (3)	Agree (4)	Strongly Agree (5)
I/the person I care for is embarrassed by asthma <b>(Embarrassed)</b>	18%	43%	19%	18%	3%
I/the person I care for try to hide asthma from people <b>(Hide)</b>	17%	40%	15%	27%	2%
I/the person I care for avoid places or situations that make asthma worse <b>(Avoid)</b>	1%	8%	18%	55%	18%
Asthma stops me/the person I care for from doing things I want to do <b>(Stops)</b>	5%	18%	16%	48%	14%
People around me/the person I care for don't understand asthma <b>(Understand)</b>	5%	26%	27%	33%	9%

## THEME 2: SERVICES AND SUPPORTS

Who do you trust to talk to about your asthma/the asthma of the person you care for? (n=177)



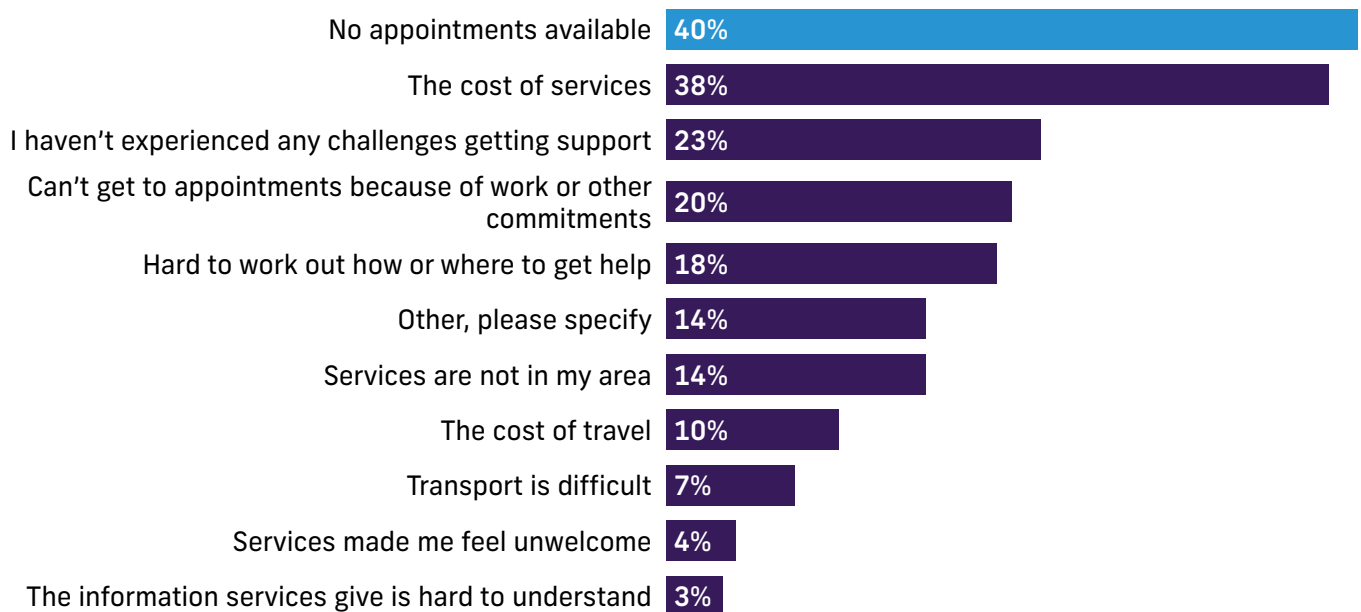
Most useful (n=174)



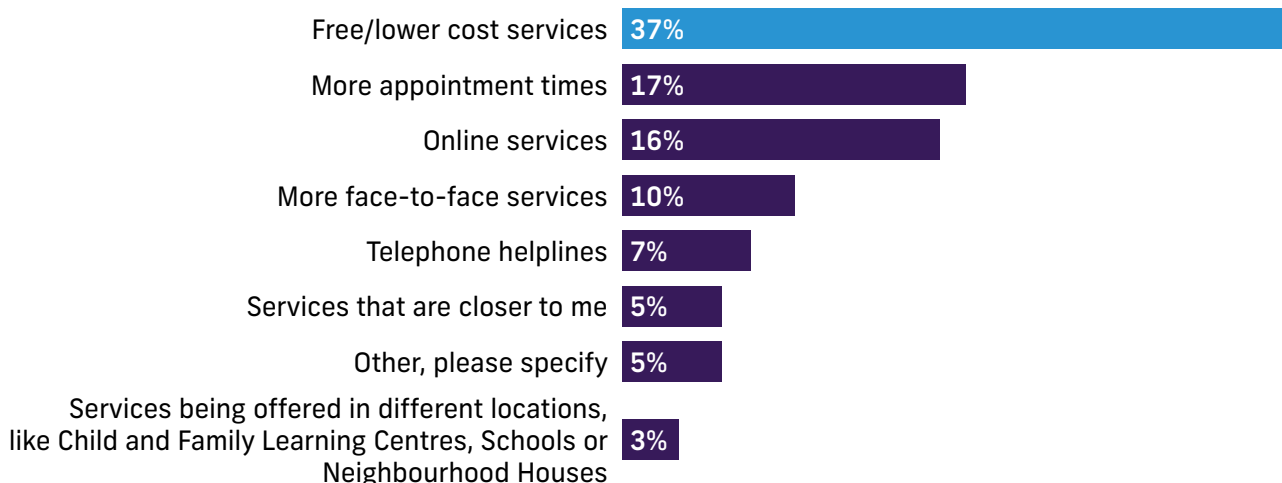
Thinking about your past experiences with Tasmanian asthma services or supports in general, please tell us how much you agree or disagree with the following statements. (n=171)	Strongly Disagree (1)	Disagree (2)	Neither (3)	Agree (4)	Strongly Agree (5)
The information and advice given by different services is the same ( <b>Consistency</b> )	2%	18%	49%	29%	2%
It is easy to contact someone for information or advice about asthma ( <b>Accessibility</b> )	4%	14%	51%	26%	5%
Services help me manage asthma ( <b>Helpfulness</b> )	5%	16%	32%	40%	6%
There is a wide range of support options in Tasmania (e.g., calls, websites, face-to-face) ( <b>Range</b> )	4%	19%	57%	18%	2%
Services provide high quality support ( <b>Quality</b> )	3%	10%	51%	32%	4%
Services know a lot about asthma care ( <b>Knowledge</b> )	2%	11%	47%	37%	4%
I trust the information and advice given to me ( <b>Trust</b> )	2%	5%	23%	61%	8%

## THEME 3: CHALLENGES AND NEEDS

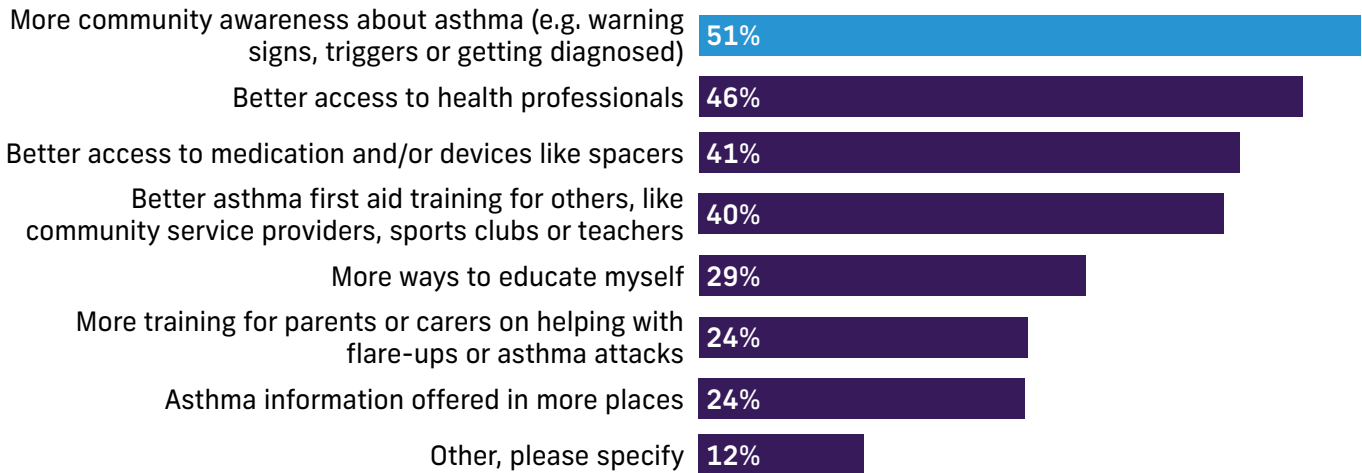
### Makes getting support for asthma harder? (n=177)



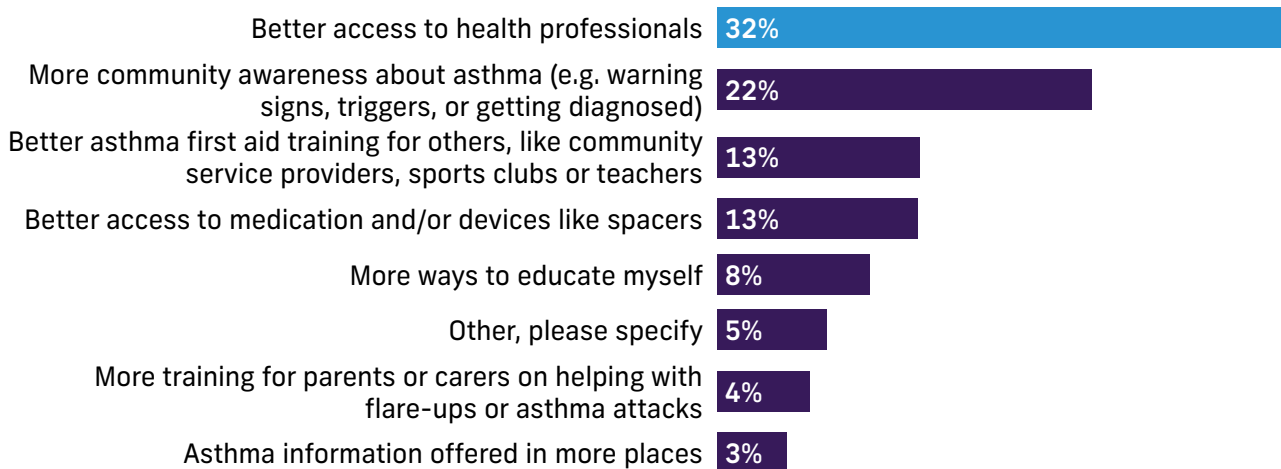
### Most likely to make accessing support easier? (n=105)



## Would make life better (n=119)



## Most likely to make life better (n=119)



## OUR ROLE IN TASMANIA

The survey results highlight the importance of Asthma Australia's specific role in Tasmania, in both supporting people living with asthma and improving community understanding of asthma.

People living with asthma in Tasmania need support, care and engaging information delivered in ways that suit them individually. It's important for them to see a future of a life lived well with their asthma.

We believe that consumer-centric asthma programs have the potential to dramatically ease the burden of asthma on the state's health system.

By supporting people to develop their capability and capacity to manage their own care, and engaging communities to support the wellbeing of their members, the burden and impact of asthma can be reduced.

## WANT TO KNOW MORE?

Sign up to our newsletter for future updates about the Tasmanian Asthma Discovery Project at [asthma.org.au/about-us/news-and-publications/on-air](https://asthma.org.au/about-us/news-and-publications/on-air) or get in touch with Jess Tyler on [jtyler@asthma.org.au](mailto:jtyler@asthma.org.au)

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