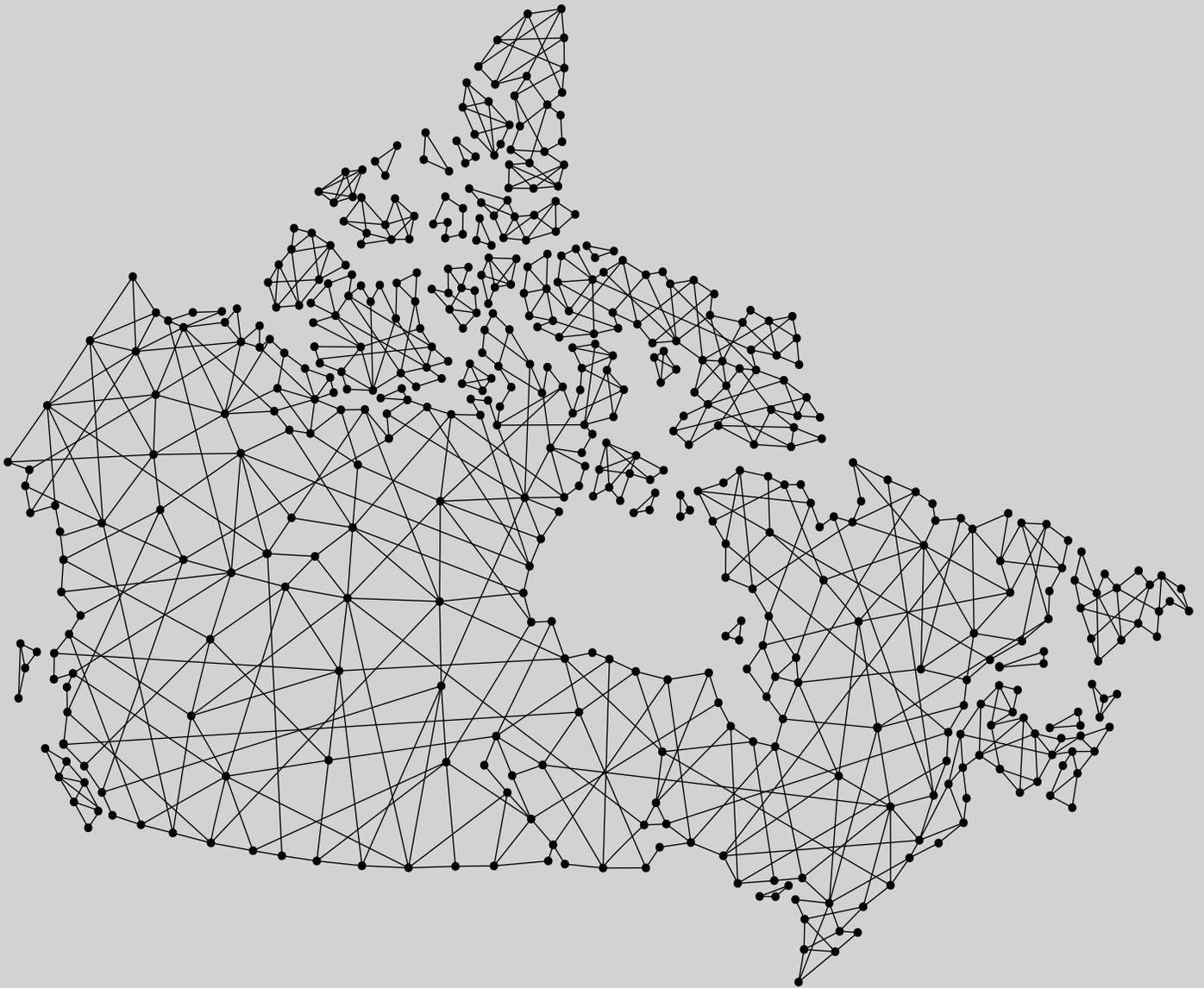




Asthma.ca[™]

Asthma Canada



A Snapshot of Asthma in Canada

2019 Annual Asthma Survey Report

Foreword

From the CEO

As I read through the results of our first annual asthma survey, one mother's response struck me. She had written, "I am extremely anxious if I cannot get my daughter to stop coughing. As a parent, I fear for my child's life."

As a parent to a child with asthma, I understand this sentiment – the ever present danger that an asthma attack could take away that which you care about most. There are more than 3.8 million Canadians currently living with asthma. It is more important than ever to hear their voices and share their stories.

People with asthma should be living healthy, active lives, and be in control of their disease with current treatment options and proper management – yet far too many are not. There is a disconnect in what proper asthma control is and what people are actually experiencing. Reading respondents' comments about work and school absences, loss of social life, increased anxiety, and hardships with affording medications, reinforces the important work of Asthma Canada. We are taking steps, together with people living with asthma and their families, healthcare professionals and policy makers, to have asthma issues prioritized. We are seeing progress – patients are demanding access, asthma is losing its stigma, schools are supporting their students – but much more still needs to be done.

It is time for a national conversation on access to medicines. Too many Canadian families are having difficulties affording medications and having to prioritize between medicine, food or rent. No one should have to choose between feeding their families and breathing. This is unacceptable.

We know that our environment is directly linked to health. Air pollution and environmental destruction are leading to worsening wildfires, extreme temperatures, and longer allergy seasons, all of which negatively affect health outcomes for people with asthma. Asthma Canada, together with partners around the world, are calling for governments and industry to step up to improve and protect the air we breathe.

In order for Canadians with asthma to live symptom-free, it's crucial for every individual to have an official diagnosis, with proper and accurate testing, followed by comprehensive management, including an Asthma Action Plan.

Our survey highlighted three particularly vulnerable groups: people with low income, those with Severe Asthma, and young adults between 18 and 34 years old. As my daughter enters this age group, along with countless others and they begin their independent lives, they are at a higher risk of falling through the cracks of our healthcare system. We need to do more, and together we can do more.

As Asthma Canada moves through our 45th year providing support, education and resources to people living with asthma, their families and caregivers, healthcare professionals, schools and more, we are asking you to join our movement. It is time for Canadians to Breathe Easy™.



Vanessa Foran
President & CEO
Asthma Canada

CONTENTS

02.	Foreword from the CEO
04.	Executive Summary
05.	Study Methodology
06.	Survey Findings
06.	Quality of Life Impact of Asthma on Mental Health Lack of Participation/Avoidance Absenteeism/Presenteeism
11.	Diagnosis and Control Diagnosis Control: Perception vs. Reality
14.	Management and Lifestyle Control Asthma Action Plan Affording Medicines
17.	Treatment and Emergency Care Healthcare Professionals Barriers to Access & Care Accessing Emergency Care Oral/Systemic Corticosteroids
23.	Conclusions
25.	Tips for our Community
26.	Policy Recommendations
27.	References
28.	Acknowledgements
28.	About Asthma Canada

Executive Summary

Breathing is something that most people take for granted, but for those living with asthma it is often a struggle. Asthma is a major public health concern in Canada with more than 3.8 million individuals living with the disease. As a lifelong respiratory illness, asthma affects the quality of life, work productivity, and mental health/psychological wellbeing of 10.8% of the Canadian population.

Asthma Canada's first Annual Asthma Survey was open to all individuals with asthma residing in Canada (as well as parents and caregivers). The focus was to raise the voices of our community to highlight the gaps within the healthcare system and the challenges associated with living with a chronic disease.

Nearly three quarters (74%) of people with asthma reported having some form of health-related anxiety. The challenges of living with asthma often lead to feelings of stigmatization, isolation, stress and hopelessness. Limiting activities, exercise and social engagements, and missing school and work (or having to completely withdraw), can have a devastating impact on the individual, family and society at large.

Access to medications is crucial for proper asthma management and to keep symptoms under control. Yet, close to one-third (30%) report that their current drug coverage is insufficient and 21% of people have skipped filling a prescription because they were not able to afford it. Family doctors are the primary source for care and management for those living with asthma (51%), followed by respirologists (37%). Issues of access, wait times, referrals and follow up after emergency care are all priorities for our community.

“Asthma is an invisible disease...It's seen as someone that just needs a puffer occasionally. Society as a whole does not realize that for a patient and their family it affects every aspect of their life.”

There is a disparity between people's perception of control versus the clinical definition of control. While 47% of respondents believe their asthma is controlled, 60% report trouble sleeping due to asthma symptoms and 65% report avoiding exercise or physical activities due to asthma symptoms. Our goal is to ensure that every Canadian is in control of their disease, which means zero symptoms.

Improved access to proper and accurate testing and diagnosis, comprehensive management including the use of an Asthma Action Plan, and affordable medications will lead to more empowered patients and improve their quality of life.

Our survey revealed three at-risk groups: younger Canadians between ages of 18 and 34; people living with Severe Asthma; and those with an annual income less than or equal to \$19,000. Combined with other social determinants of health, our survey shows these three groups are disproportionately impacted by asthma, resulting in poor health outcomes.

Survey Methodology

The survey was launched online using Survey Monkey as well as shared with our Asthma Canada Members Alliance (ACMA) on the 23rd of April 2019. Data collection period lasted for three weeks, closing on the 16th of May 2019. Overall, we had received a total of 353 responses with a 70% (246) completion rate. Criteria for participation was to be living in Canada and 1) have asthma or 2) be a parent or caregiver of someone with asthma. Nearly half (48%) of the respondents indicated that they had moderate asthma. The percentage of respondents indicating mild and Severe Asthma was 27% and 25% respectively.

The majority of the survey respondents (53%) were in the 35-64 years age-group followed by the 65+ group (21%). Most respondents in the younger groups (17 & Under, and 18-34) were 13% each. Most of the survey respondents (76%) were females.

A majority (85%) of the respondents were from four provinces of Ontario (53%), British Columbia (14%), Alberta (11%), and Quebec (7%). Response from the Atlantic Provinces was comparatively low - collectively accounting for just 7% of the respondents. Response from Manitoba and Saskatchewan was also low - representing 4% each. No response was received from Nunavut, the Northwest Territories and the Yukon.

Due to the small sample size interpretations must be made with caution.

We would like to thank those who completed the survey for their contributions.

SURVEY FINDINGS

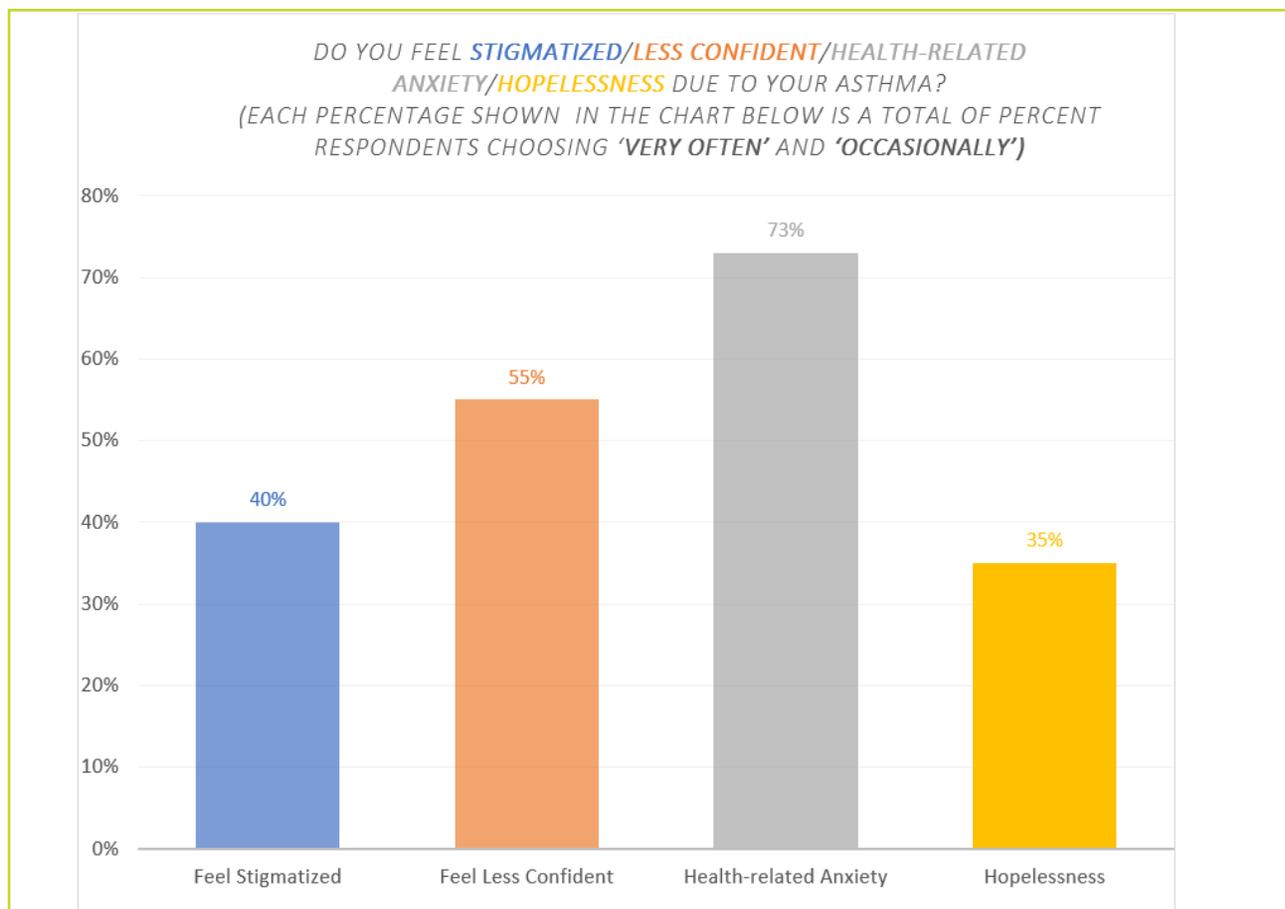


Quality of Life

The Impact of Asthma on Mental Health

The survey indicated that a significant majority (73%) of respondents reported having health-related anxiety due to asthma. More than half of the respondents reported feeling less confident (55%) and isolated (54%) due to their asthma.

“ My daughter feels different and out of sync with her class and teammates. They often minimize her condition and say she is attention seeking. ”



This trend is consistent with findings that exist in current scientific literature. Studies have shown that anxiety and depression are 1.5 to 2.4 times more common in people with asthma than people without asthma.

In people with Severe Asthma, this link is even stronger. Alongside poor control, mental health issues like depression and anxiety can greatly contribute to impairing the quality of life among people with asthma. Some risk factors associated

with worse asthma outcomes include smoking, poor self-management, reduced treatment adherence or overuse of rescue medication, low physical activity, fear in response to asthma symptoms, and negative thoughts and emotions.

While the link between asthma and

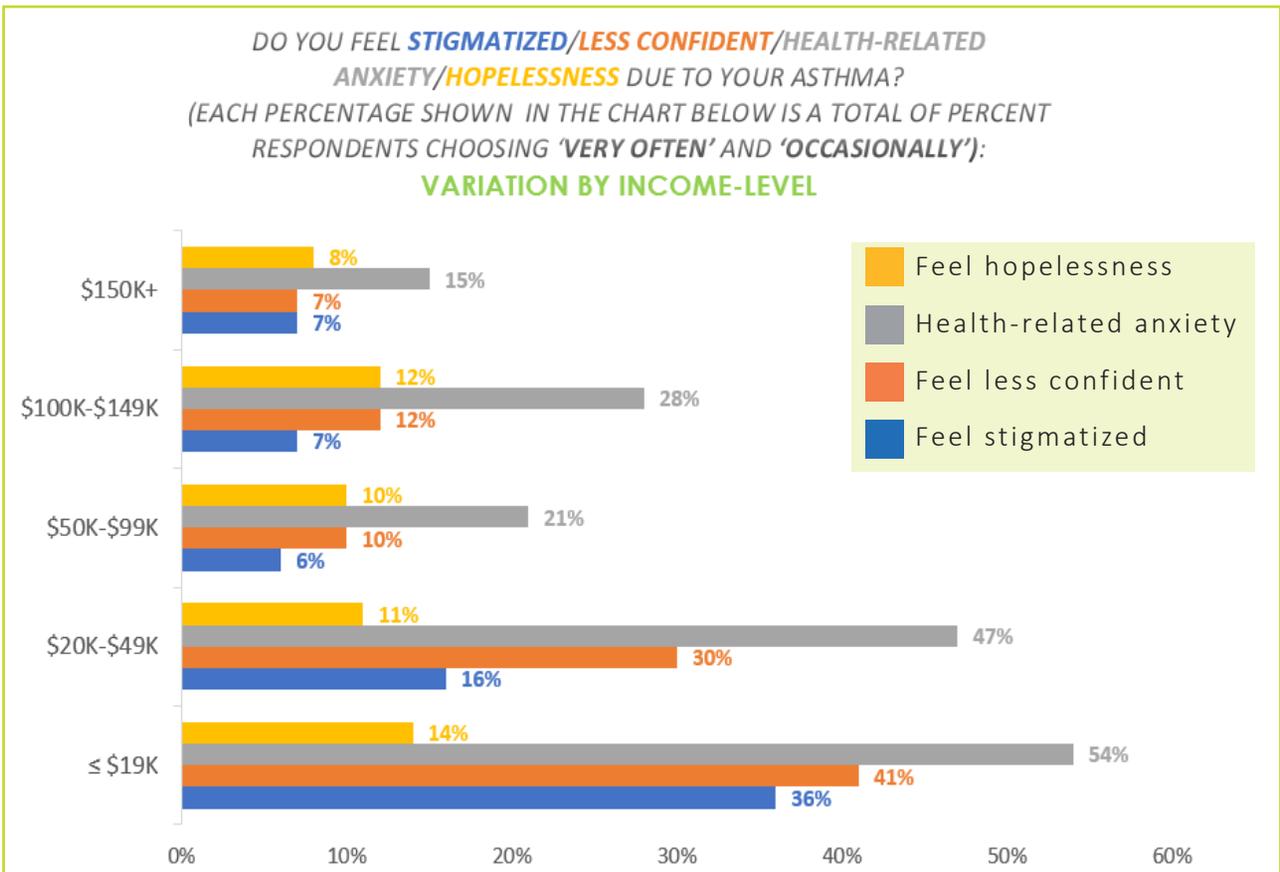
“ He never gets to have any close friends, misses birthday parties and some parents don’t want him for play dates. ”

mental health is clear, there is not enough evidence to conclude that one causes the other, but conditions such as depression, anxiety and stress can exacerbate asthma and therefore it is imperative to pay

special attention to the mental wellbeing of vulnerable groups.

Our survey specifically highlights higher reporting of health-related anxieties among: younger Canadians between ages of 18 and 34; people living with Severe Asthma; and those with an annual income less than or equal to \$19,000.

“ I just feel like the world has no time or patience for sick people or people that struggle with a chronic illness. Can leave you feeling isolated and sometimes ignoring your symptoms. ”



We noted an overwhelming majority (80%) of the respondents aged between 18 and 34 reported feeling health-related anxiety due to asthma. In addition, nearly 45% reported that they feel stigmatized, a surprising 73% feel less confident, and almost 42% reported that they feel hopelessness due to their asthma. Children and adolescents, along with their parents and families, need stronger supports to manage their condition.

Not surprisingly, more than two-thirds of respondents with Severe Asthma reported feeling stigmatized (70%), less confident (72%), health-related anxiety (82%), and hopelessness (66%). Nearly half (46%) of respondents indicated that experiencing an asthma attack led them to fear for their life. 50% feel that living with asthma interferes with the quality of their social interactions.

In addition, low annual income is associated with multiple sets of risk factors that can exacerbate a person's asthma. Poor quality housing, inability to afford critical medications, and longer working hours are some of the potential risk factors that are prominent among people in lower-income brackets, subsequently leading to poor quality of life in general with asthma.

When analyzing responses based on income-level, we discovered that more than half (53%) of the respondents with an annual household income of \$19,000 or less reported health-related anxiety due to asthma – the highest percentage among all the income groups. This group also had the highest proportion of respondents reporting feeling stigmatized (36%), less confident (41%), and hopeless (14%) due to their asthma.

Has having an asthma attack left you fearing for your life?

“ It was a number of years ago, but I will never forget the terror of not being able to breathe. I think my experience with asthma was the reason why I decided to become a CRE and work with asthma patients. ”

“ It's like I'm drowning. Fighting for air. Panic sets in. ”

“ Sometimes not being able to breathe is just too scary for a child to endure. ”

“ The terror of a sudden attack haunts me, the feeling of disappearing from life leaving my 4 children behind, terrifies me. ”



Quality of Life

Lack of Participation/ Avoidance

Nearly two-thirds (65%) of the respondents indicated that in the past 12 months, their asthma symptoms prevented them from participating in outdoor and/or physical activities.

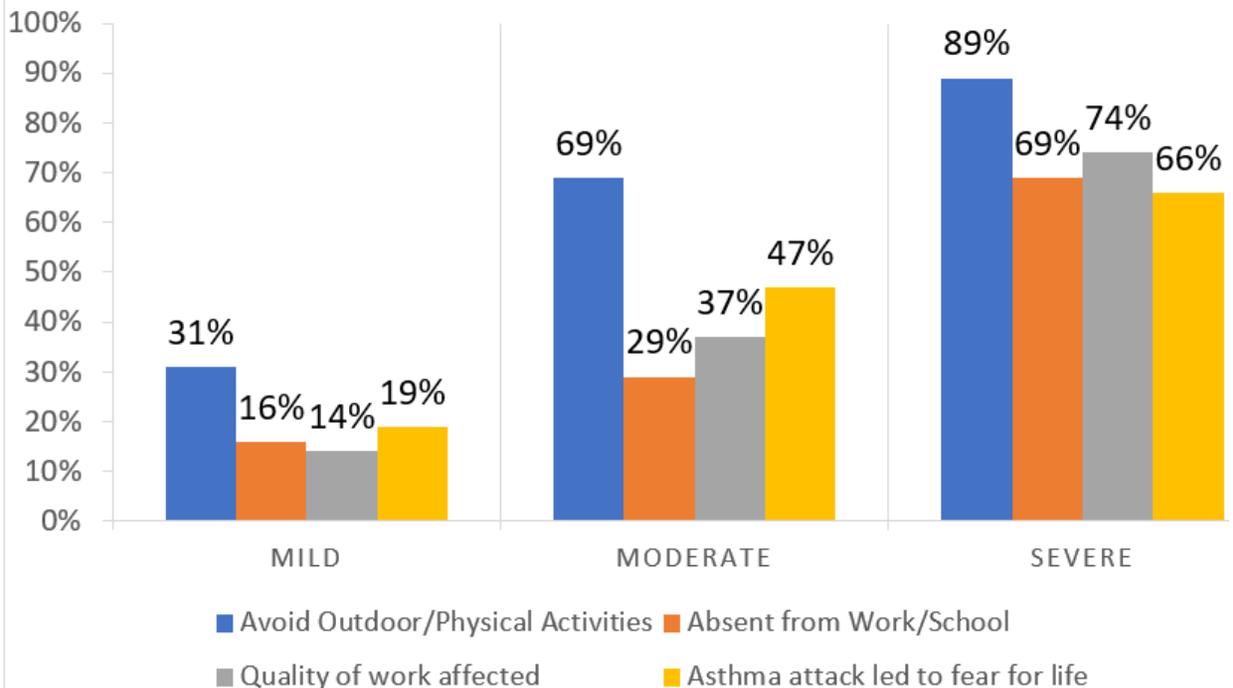
Low annual household income also appears to have an adverse effect on the quality of life with asthma with an overwhelming majority (91%) of the respondents with annual income ≤\$19,000 or less, and 71% of those with annual household income between \$20,000 and \$49,000 reporting that they avoid outdoor/physical activities due to asthma, compared to a 65% average of all income groups. Clearly, for people with asthma, a low annual household income corresponds with adverse outcomes for mental health and quality of life in general.

What type of activities do you avoid because of asthma?

“Cutting my lawn. Sitting on the deck enjoying the sun. Just going out for doing anything.”

“I wasn't able to play active games with my children, I had to drive to places I would usually be able to walk to, take elevator instead of stairs.”

ASTHMA AND THE QUALITY OF LIFE: VARIATION BY ASTHMA SEVERITY LEVEL





Quality of Life Absenteeism / Presenteeism

Asthma is a significant cause of absenteeism from school and the workplace. The real burden of asthma is difficult to track since so much goes unreported and undiagnosed, but for the individual living with asthma, or for parents and caregivers, asthma can limit normal functioning and activities. It also affects the quality of life of the families of individuals with asthma and can cause financial strain due to absence from work, and the need to care for children with asthma who are absent from school.

More than one-third (37%) of the respondents indicated that in the past 12 months, their asthma symptoms caused

them to be absent from work or school. More than half (56%) of the respondents aged 17 and under, and almost 70% of those with Severe Asthma reported absenteeism from work or school due to asthma.

However, a focus on just absenteeism omits the full picture. Presenteeism is when people show up for work or school but are feeling unwell or distracted due to their asthma and unable to fully commit to the task at hand or limit their activities. **Over 41% of respondents indicated their quality and performance at work or school suffered in the past 12 months due to their asthma. 89% of respondents with Severe Asthma indicated that they avoid outdoor/physical activities, and nearly 75% reported that asthma affects the quality or performance of their work.**

How often did you miss work (or school)?

“ Oh wow, he has so far missed over a month of school. ”

“ I missed four weeks of work when I was in ICU for asthma for five days and five days on pulmonary unit. ”

“ She has missed 18 days of school this year due to asthma related issues. ”

“ I missed almost six weeks of work due to a severe asthma flare. ”

How was your ability to perform at work (or school) impacted?

“ 70 yrs old, not working but have been disabled for 43 years, previous medical malpractice, couldn't get asthma treated also high blood pressure, couldn't work, marry, have a family, too sick to do anything.”

“ My daughter was unable to 'play' and be a normal kid when her asthma was acting up. ”

“ Couldn't stay at my last job with my asthma due to the environment. ”

“ Difficult to sleep at night or focus at work. ”

“ Hard to concentrate when you are having difficulty breathing ”



Diagnosis & Control

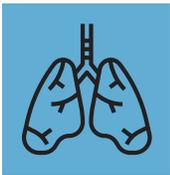
Diagnosis

Best practices for diagnosis of asthma is undergoing spirometry (a pulmonary function test that measures the amount of air you can breathe in and out). However, in practice many diagnoses are based on symptoms and history only. This is leading to both an over-diagnosis and an under-diagnosis situation. In 77% of cases,

“ My GP could not diagnose me originally and landed up in hospital, so I changed my GP and use a respirologist for my asthma now. ”

physical exams were conducted to give the official diagnosis of asthma, followed by only 53% of cases where diagnosis included spirometry testing. A chest x-ray was used in 50% of cases.

Approximately half of the survey respondents (52%) indicated that their official diagnosis came from a family doctor/general practitioner, followed by 19% who indicated they were officially diagnosed by a respirologist and 6% by an allergist. Overall, 47% respondents indicated that they were diagnosed with asthma in adulthood, 20% were diagnosed between 6 and 19 years old, while one-third (33%) reported that they were diagnosed as an infant or in preschool (1 to five years).



Diagnosis & Control

Control: Perception Vs. Reality

Asthma Control: Perception vs. Reality	
Respondents' perception of the level of their asthma control	Respondents' self-reported data on the key parameters of asthma control
<ul style="list-style-type: none"> ➤ More than a quarter (28%) indicated that they believe their asthma is 'controlled'; 20% indicated that it is 'very well controlled' ➤ More than one-third (38%) reported that it is only 'moderately controlled'. ➤ Only 6% of the survey respondents reported that they believe their asthma is not controlled. 	<ul style="list-style-type: none"> ➤ As high as 60% of the respondents indicated that they have <u>trouble sleeping</u> due to their asthma symptoms. ➤ Nearly one-third (31%) of the respondents indicated that they use rescue inhaler <u>more than 4 times a week</u> ➤ Half of all the respondents indicated that they use rescue inhaler <u>before exercise</u>. ➤ Nearly two-thirds (65%) of the respondents indicated that in the past 12-months, their asthma symptoms prevented them from participating in outdoor and/or physical activities. ➤ More than one-third (36%) of the respondents indicated that in the past 12-months, their asthma symptoms caused them to be absent from work or school.

Nearly 94% of respondents indicated their asthma was moderately to very well controlled but when asked questions as measured by objective tests (like the Asthma Control Test), they report frequent symptoms. There exists a disconnect between feeling that one is in control of their asthma and the actual severity of the symptoms currently experienced. Many people living with asthma actually think their asthma is under control when, in reality, it is not (see chart above). Perceptions of asthma control often vary between patients and healthcare professionals which can be a major barrier in optimizing patient asthma care.

A majority (76%) of the respondents with self-reported mild asthma and nearly 45% of those with self-reported moderate asthma indicated that their asthma is controlled. However, only 18% of those with self-reported Severe Asthma indicated that their asthma is

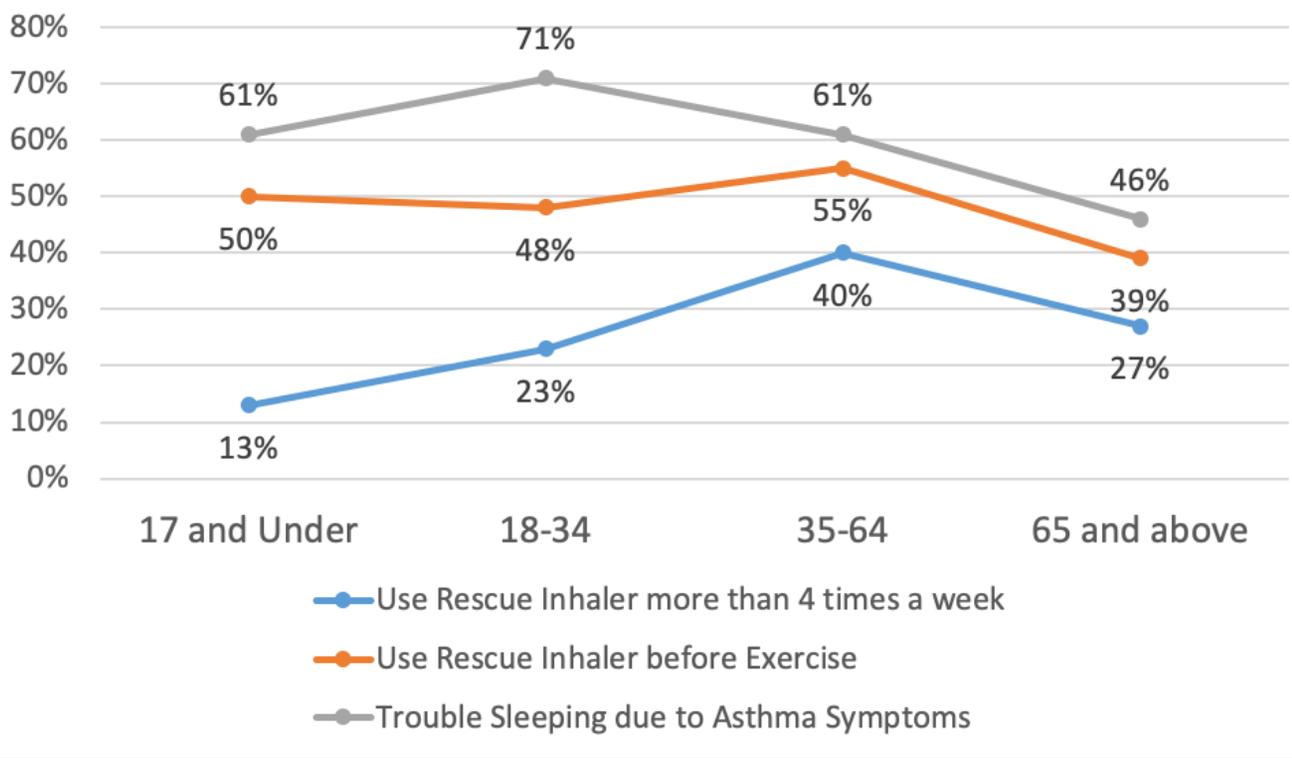
“ It’s tiring. No, it’s exhausting! Not just the asthma itself, but the managing of it. I am a fit, active, organized, intelligent and capable mother of four children (11-18). I work. I grow all our own food, make everything from scratch - I am a farmer’s daughter. All of these things are wonderful. I am not intimidated by any of it. Managing my asthma -and suffering from it - is the one thing that drives me over the edge into utter exhaustion, and complete frustration.”

controlled. As high as 86% of the respondents in the ≤\$19,000 income group reported that they have had trouble sleeping due to asthma-related symptoms such as wheezing and persistent cough and 71% of young people between 18-34 years of age reported trouble sleeping due to their symptoms. Patients who experience a high prevalence

of poor asthma control have an over-reliance on rescue inhalers which provides quick relief of asthma symptoms rather than the long-term prevention provided by controllers. This paradox in asthma management can lead to an increased likelihood of exacerbations; and high rates of emergency healthcare utilization, hospitalization and death.

“ I feel that I am being robbed of precious time and opportunity because my disease is being mismanaged. I was once a very adventurous person with a great quality of life but now I’m afraid to take risks in case something might happen to me. I use to travel alone but would never do that now because of fear of something happening to me. My zest for life has been taken from me. ”

Self-Reported Asthma Control Metrics -Variation by Age Group



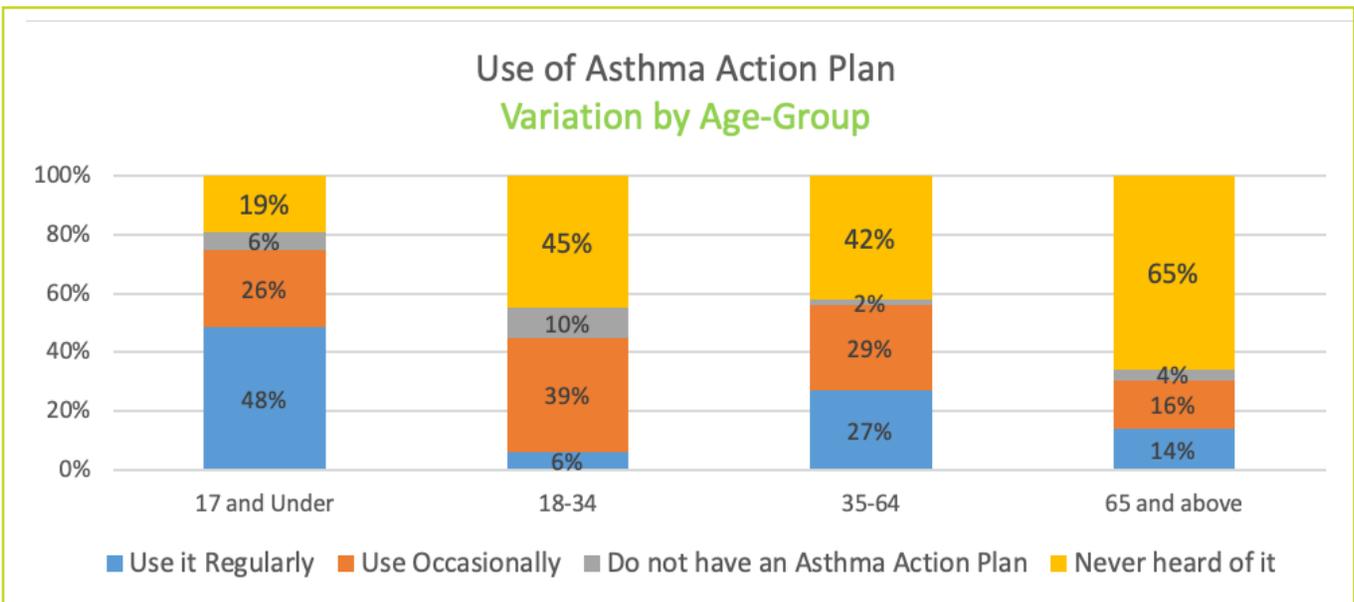
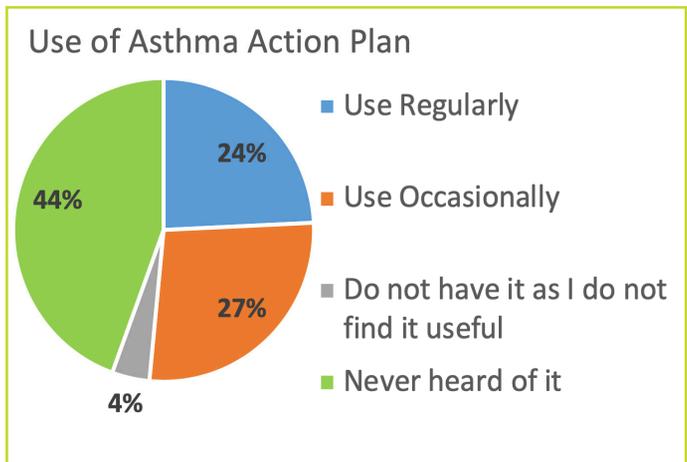


Management & Lifestyle Control Asthma Action Plan

A personalized written Asthma Action Plan is a vital tool through which a person with asthma can monitor the frequency of their symptoms and avoid flare-ups/exacerbations by adjusting their treatment. It is usually developed as a personalized treatment plan in close consultation with a healthcare professional. Studies have documented its effectiveness in helping individuals managing asthma at home.

In our survey we discovered that overall, almost 45% of the respondents reported that they had never heard of an Asthma Action Plan, including one-third (31%) of

those with Severe Asthma, and nearly two-thirds (65%) of those aged 65 and above. Only a quarter of the respondents reported using it on a regular basis. This issue is most concerning for those aged between 18 and 34 as only 6% of them report using the Asthma Action Plan on a regular basis.



“ I have never been given an action plan or tested with a peak flow meter. I didn't know either of those existed until looking stuff up online. The only education I have ever received about it was when I got whooping cough and my doctor gave me an additional inhaler and also advised upping the dosage... until the cough went away. ”



Management & Lifestyle Control

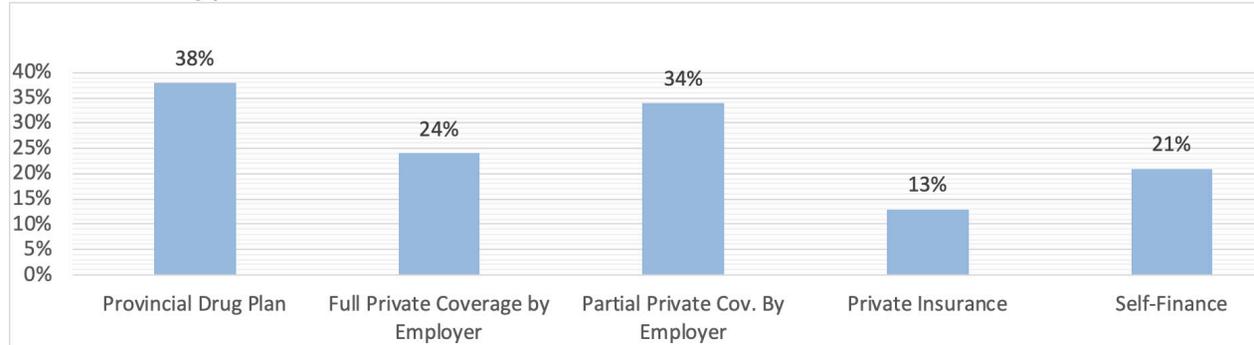
Affording Medications

Close to one-third (30%) of respondents indicated that their current drug coverage is not sufficient to help them keep their asthma symptoms under control.

highest proportion among all the income groups.

In addition, only 11% of those in the $\leq \$19,000$ income group, and 33% of those in the $\$20K-\$49,000$ income group reported that their employer covers their asthma-related expense either partially or completely through private insurance.

How is the cost of your asthma medication covered?

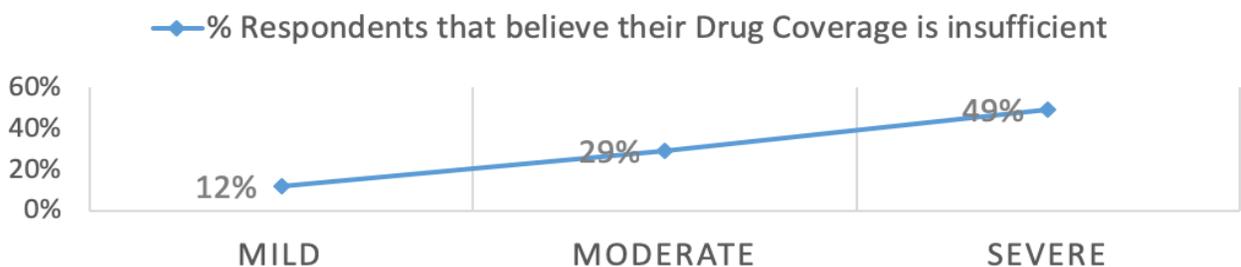


Not surprisingly, respondents in the lower income groups are most dependent on the provincial government's support to cover the cost of their asthma medications with almost 56% respondents in the $\leq \$19,000$ income group reporting that they rely on the provincial drug plan to cover the cost of their asthma medications as against 40% average of all income groups. **Additionally, 30% respondents in this group reported that they self-finance the cost of their asthma medications - the**

This is contrast to as high as 65% of the respondents in the $\$100K-\$149,000$ income group reported that the health/prescription coverage through their employer covers the cost of their asthma-

“The best medicine requires Special authorization to get coverage and only after completely trying all other medications.”

DRUG COVERAGE SUPPORT: VARIATION BY ASTHMA SEVERITY LEVEL



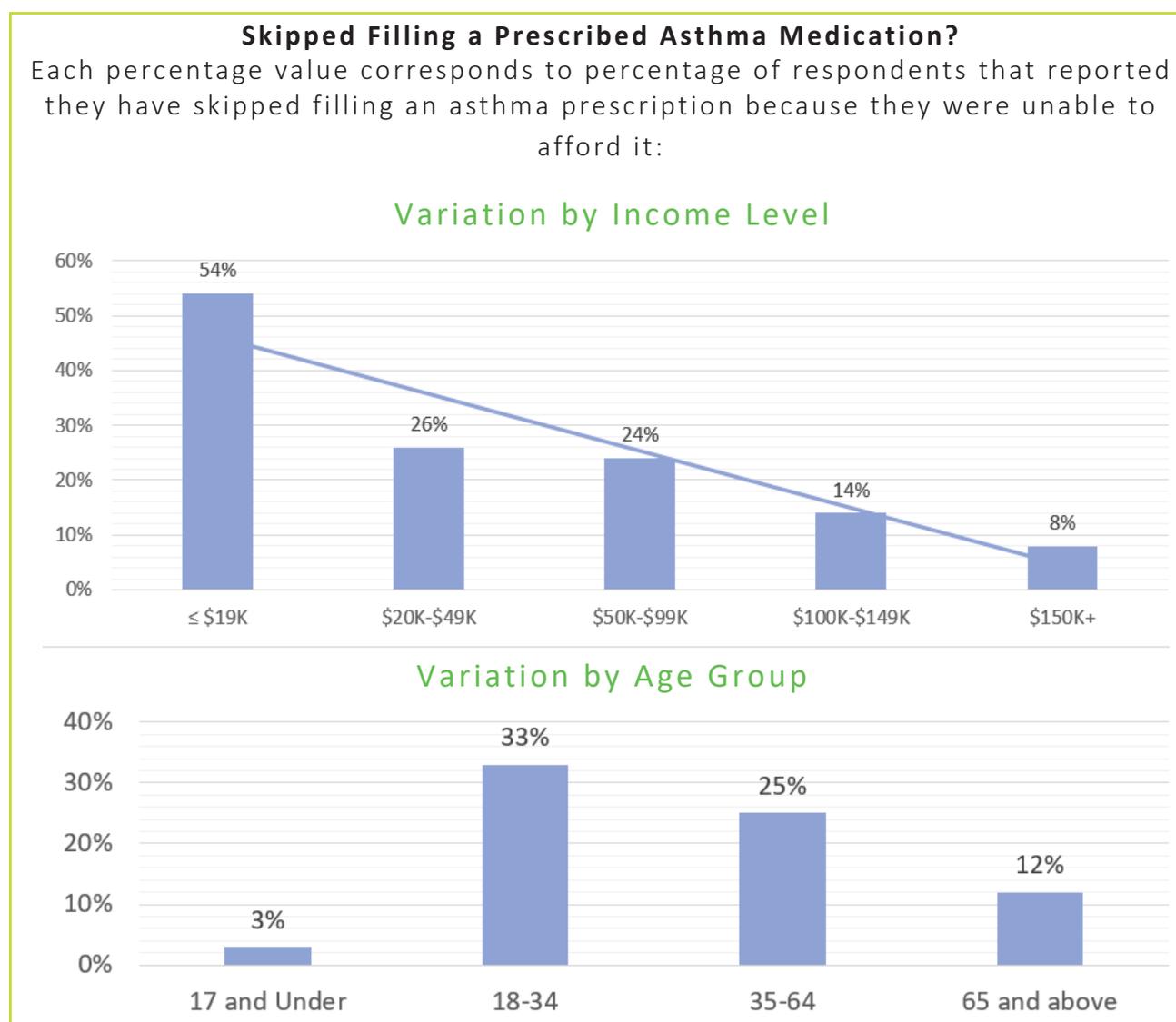
related medications either partially or completely.

Almost half of all respondents with self-reported Severe Asthma, and more than a quarter (29%) of the respondents with moderate Asthma indicated that their current drug coverage is insufficient, and they need more support to help them keep their symptoms under control.

Almost 21% respondents indicated that they have skipped filling a prescribed asthma medication because they were not able to afford it. Overall, 54% respondents with income \leq \$19,000 reported that they have skipped filling a

prescription for asthma medication due to inability to afford it and around a quarter of respondents with income between \$20-\$99,000 have also skipped filling a prescription due to cost.

One-third of the respondents aged between 18 and 34 reported that they had skipped filling a prescription for an asthma medication as they were not able to afford it – the highest proportion among all the age-groups. This chart (below) further demonstrates the vulnerability of the 18 to 34 age-group, including the impact of socio-lifestyle changes on health as one transitions into adulthood.



“ The cost of controller inhalers is insane. Thankfully, my family doctor gives me free samples so that I have the meds I need, otherwise would just rely on environmental control and my rescue inhaler, like many do. I had to leave my last job because it bothered my asthma too much and at that point, was on controller inhalers costing \$200 plus each. It’s something that very much needs to change for asthma patients, the cost of these medicines. ”

“ Asthma meds are too expensive for a person on minimum wage and no benefits. Eat or breathe, what a choice. ”

“ When I have been unable to afford coverage I have reduced my dosage to make it between paydays. ”

“ I had to take more of my medication and wasn’t able to refill it early, so I waited and used my kid’s asthma medication. ”



Treatment & Emergency Care Healthcare Professionals

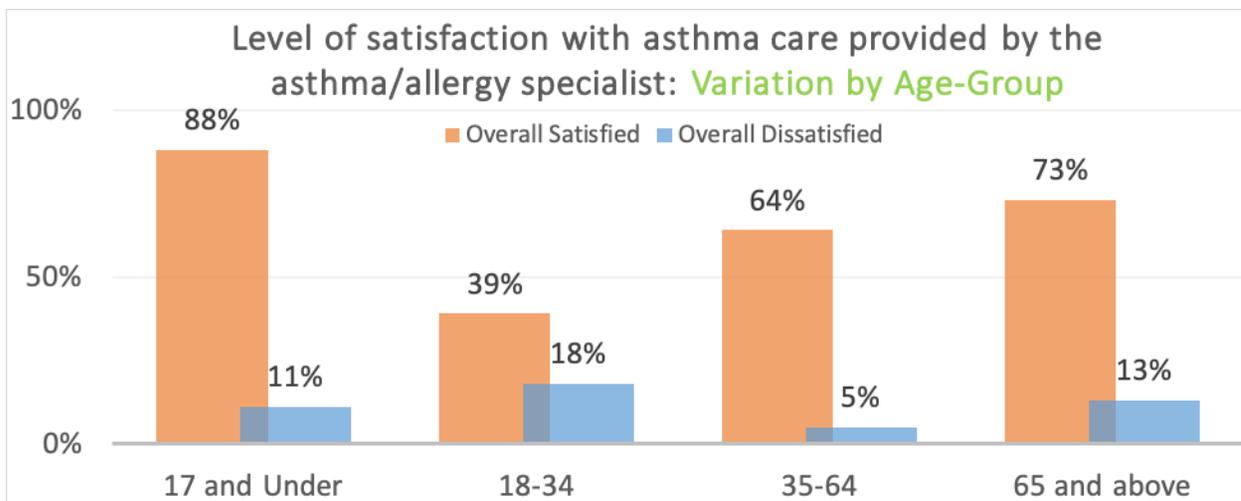
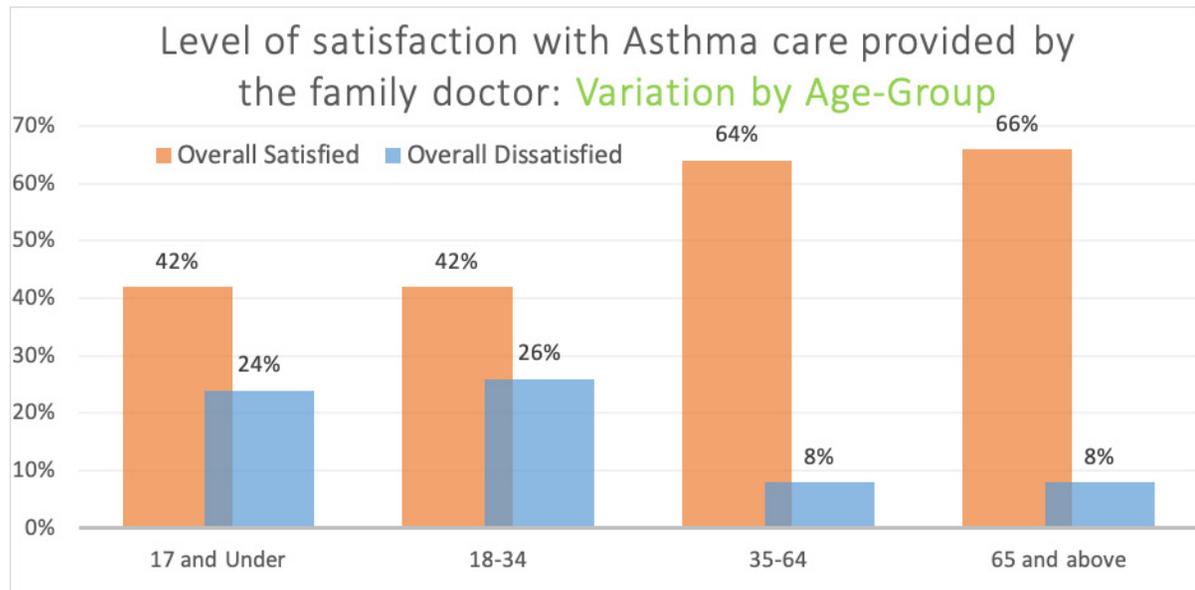
Just over half (51.27%) of respondents have their asthma managed primarily by a family doctor. 37% are managed by an asthma and allergy specialist/respirologist.

A large majority (84%) of respondents indicated that they have timely access to a family doctor; however, close to a quarter 21% of the respondents indicated that they do not have timely access to Asthma & Allergy specialists or asthma clinics.

We also inquired about the respondents’

level of satisfaction with their asthma and/or allergy specialist. Certain differences were notable. While an overwhelming majority (88%) of those aged 17 and under indicated satisfaction with their specialist care, a sharp drop was observed in the 18 and 34 group, with only 39% indicating satisfaction.

“ The single most helpful thing in managing my son’s asthma has been an asthma clinic we attended, but I had to ask for it and I hear it may not continue due to funding. ”

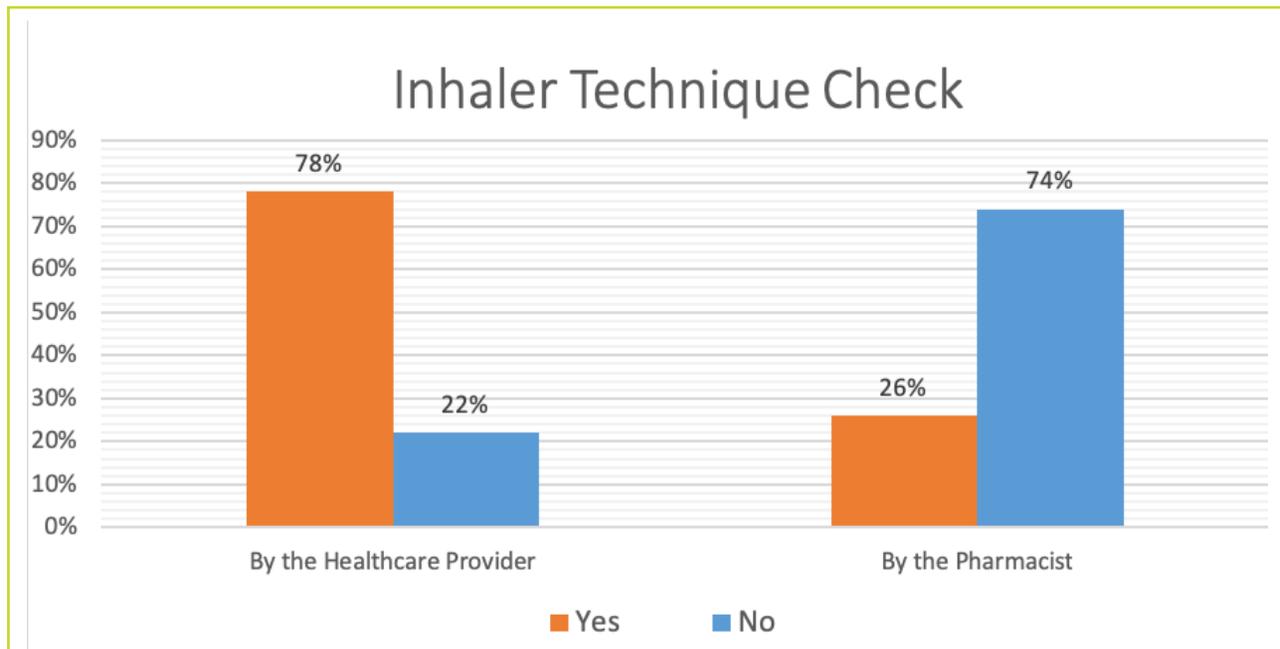


“ I just want to comment about my asthma diagnosis back in 2003. The family doctor suspected asthma... The respirologist I saw couldn't diagnose me and misdiagnosed me. Looking back, I am very lucky that I survived all the undiagnosed attacks that I had... I finally met a professional and personable respirologist in 2006. He is the best! He has also been my lifesaver ... I suffered many emotional setbacks in those earlier years. I now have a wonderful respirologist and ENT. They take a minute to listen to me and understand whatever concerns I may have. I also have a very good family doctor. ”

Nearly a quarter (22%) of the respondents reported that their Healthcare provider did not check their inhaler technique. A majority (75%) indicated that their pharmacist did not check for their inhaler use technique while filling their asthma prescription at the pharmacy.

Interestingly, more than two-thirds (68%) of the respondents indicated that they

are overall satisfied with the information/education they have received with regards to their asthma care, and only 11% indicated that they are overall dissatisfied. However, this trend varied across the age-groups - respondents between the ages of 18 and 34 indicated lowest levels of satisfaction (50%), and highest level of dissatisfaction (25%) among all the age-groups.



Treatment & Emergency Care

Barriers to Access & Care

We had asked: How often have the following prevented you from receiving the asthma care, support, and treatments that you require?

Parameter	Very Often	Occasionally	Not at all
High Cost of Inhaler Medications and Devices	11%	19%	70%
High Cost of newer medications like Biologics	16%	14%	70%
Long Wait-Times to see a Specialist	24%	32%	44%
Lack of information/education on managing asthma	19%	32%	49%
Difficulty in location asthma/respiratory educators	21%	26%	53%
Inadequate air quality regulations at workplaces	24%	27%	48%

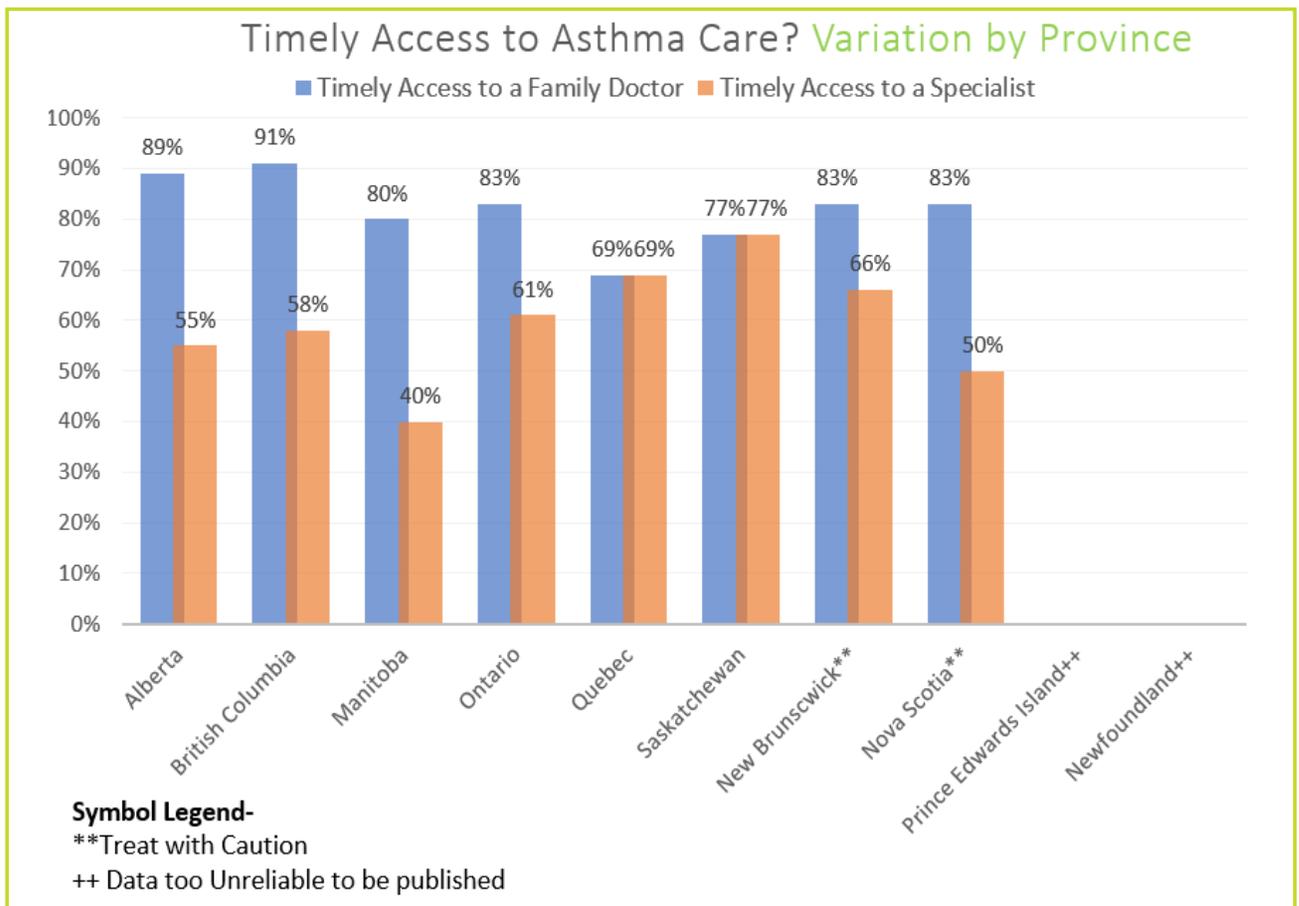
In gauging participants' perception of the most important barriers to good quality asthma care, we found that more than half (56%) of the respondents indicated that long-wait times to see specialist prevents them from receiving asthma care, support, and treatment either Very Often or Occasionally.

We have consistently observed that those aged between 18 and 34 are in a particularly vulnerable age-group. As an example, amongst the 17 & under group, as high as 84% of the respondents reported having timely access to a family doctor, and 78% reported having timely access to a specialist. However, a sharp drop in these figures was observed for the 18-34 years age-group, with 68% reporting having timely access to a family doctor, and only 35% reporting that they have timely access to an asthma and allergy care specialist.

Though it may be inconclusive, this anomaly might be explained by the fact that younger people in this age-group tend to start living independently, and many have limited budgets

and resources to dedicate to healthcare.

There were noticeable differences in attaining timely access to asthma care across the Canadian provinces. As high as 91% of respondents from British Columbia reported that they have timely access to a family doctor, however only 58% reported having timely access to a specialist. A similar trend was observed with respondents from Alberta. In Ontario, while the percentage of respondents reporting timely access to a family doctor was somewhat lower (83%) than that of the Western Canadian provinces of Alberta and BC, it fared marginally better with the timely access to a specialist, with nearly 61% respondents reporting having attained timely access to a specialist. In Quebec, the trend is inconsistent with most other regions. While only 69% report having timely access to a family doctor, a similar percentage also reported having timely access to a specialist. Saskatchewan had the highest proportion of respondents (77%) reporting they had timely access to a specialist.





Treatment & Emergency Care

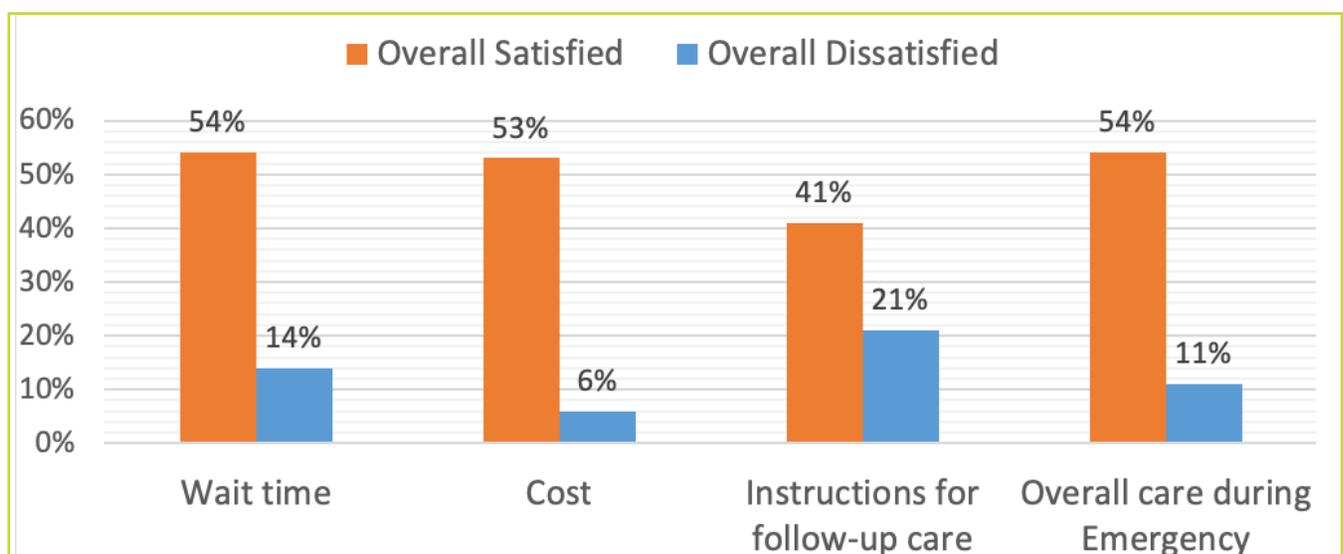
Accessing Emergency Care

Nearly a third (32%) of the respondents indicated that in the past 12 months, they had received unplanned or emergency care for their asthma.

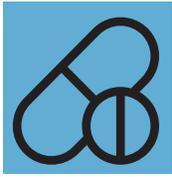
We asked those who indicated that they had received emergency/unplanned care to rate it on parameters such as cost, wait-time, and

information/recommendations regarding the follow-up care. More than half of the respondents indicated satisfaction with wait-time, and cost. While 14% expressed dissatisfaction with the wait-time, only 6% indicated that they were overall dissatisfied with the cost, which is an encouraging sign. However, an area of concern is the 'instructions for follow-up care', which had the lowest percentage of respondents (41%) indicating overall satisfaction, and highest percentage (21%) indicating that they were overall dissatisfied.

“ I was unable to breathe adequately and my husband took me the emergency department ... It was a terrifying experience as I was ... provided no treatment other than a chest X ray and [told] I was fine to go. Had I not advocated for myself I don't know what would have happened to me. I was not provided with any additional follow up like a referral to an asthma clinic but just told to follow up with my family doctor. ”



“ When my son was diagnosed, he was 1 year old and admitted to hospital. I was told at that time we would be referred to an asthma clinic which did not happen. There was very little follow-up following his hospitalization. ”



Treatment & Emergency Care

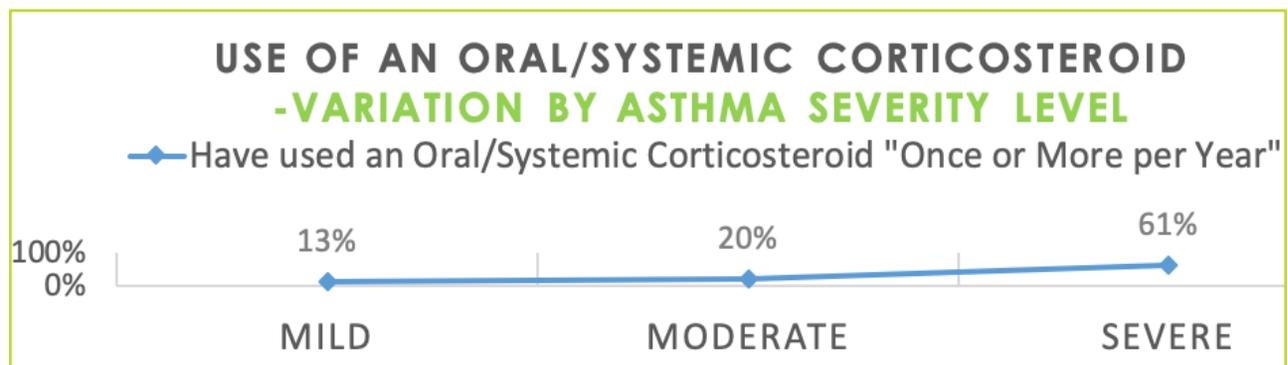
Oral / Systemic Corticosteroids

Most respondents (34%) indicated that they use an oral corticosteroid once or less per year and nearly 30% indicated they have never used/required it. However, more than quarter (28%) indicated they have used an Oral/Systemic Corticosteroid once or more per year.

More than a third (38%) of respondents with income \leq \$19,000 reported that they have used an Oral/Systemic Corticosteroid at least once or more per year- the highest percentage among all the income-groups.

More minors than adults reported using Oral/Systemic Corticosteroid 'once or more per year'. This is another area of concern, as the use of Oral Corticosteroids has been associated with psychiatric disorders such as mood & anxiety-related conditions and other serious side effects such as weight gain, diabetes, osteoporosis, glaucoma, cardiovascular disease and impaired immunity.

Not surprisingly, more than 60% of the respondents with self-reported Severe Asthma use Oral/Systemic Corticosteroids once or more per year, yet another indicator that people with Severe Asthma require specialized care and treatments plans.



Conclusions

This survey has brought to light some of the challenges and issues that the 3.8 million Canadians with asthma face everyday. Difficulty with accessing medication and lack of proper asthma management are leading to regular disruptions to day-to-day lives. People with asthma are having to forego activities and make unwanted compromises due to asthma symptoms. Feelings of isolation and stigmatization are prevalent. Personal lives as well as professional and school performance are being affected. More needs to be done to support the Canadian asthma community to aim for zero symptoms and zero quality of life disruptions.

Asthma is a lifelong condition. Presently, there is no cure; however, with proper management, symptoms can be kept under control and a good quality of life can be achieved. There has been little focus on managing issues that are associated

with asthma, such as the mental health conditions, especially anxiety. Comorbid conditions can have a major impact on the overall management of asthma and thus strategies must be developed to alleviate their influence. Reduced incidences of mental health concerns, and improved overall quality of life must be also be included as key indicators of success in any asthma treatment plan.

We also discovered that most respondents who had received emergency care had indicated their overall dissatisfaction with the information they had received for follow-up care. Close to a quarter of the respondents also indicated that they do not have timely access to an asthma/allergy specialist. Cost of care remains a concern; close to one-third of the respondents indicated that their current drug coverage is not sufficient to help them keep their asthma symptoms under control and

“As a child & into my college years my asthma impaired my quality of life & reduced my activity. As a young adult asthma drugs were being developed & introduced & as a result it basically disappeared. Answering these questions in my early years, I would have indicated negative responses - now I am totally positive - I even have a pet & am granddad to two large dogs with no ill asthma symptoms.”

close to a quarter also indicated that they have skipped filling a prescribed asthma medication because they were unable to afford it. Provincial support to cover the cost must be expanded, specifically to the vulnerable groups.

“I think asthma is rather unrecognized socially as a serious problem. It’s considered more of a nuisance than a disease.”

We have been able to identify critical gaps in asthma care in Canada. There are three groups most vulnerable and adversely impacted by asthma – individuals in lower income brackets, young adults, and those with Severe Asthma. Asthma disproportionately impacts their mental health and the overall quality of life. Lower annual income not only makes it difficult to afford prescription medicines,

it also leads to circumstances that can exacerbate asthma such as, poor quality housing/maintenance, and/or longer working hours.

Young adults in the 18 to 34 age-group had the highest proportion of respondents reporting mental health conditions, poor quality of life, and overall dissatisfaction with their family doctor as well as their specialist. This age-group also expressed the highest dissatisfaction with the information/education received for managing asthma. The several anomalies observed in this age-group could be explained by the fact many individuals in this age-group enter post-secondary education, and/or start living & working independently, and consequently their health gets relatively ignored. The transition period into adulthood and independence is critical with regards to personal health and must be given due importance in policy making.

Lastly, people with Severe Asthma clearly require additional supports to help them improve their overall quality of life, as well as support with the cost of medications.

Tips for our Community



PEOPLE WITH ASTHMA SHOULD AIM FOR ZERO

Complete control of asthma means living symptom-free. Zero symptoms, Zero night-time awakenings, Zero time lost from school, work and play, Zero exercise limitations, Zero emergency room visits.



SELF-ADVOCATE

Living with asthma, it is essential to know your rights and advocate for quality care.

“Asthma sufferers should not sit back and feel hopeless. If your Doctor is stagnant or not willing to try some of the newer biological, change Doctors. I did and what a difference. Finally found a specialist that understands and was willing to try something new.”



ASTHMA ACTION PLAN

Use a personalized Asthma Action Plan, developed with the healthcare professional who manages your asthma to achieve optimal control. Do not leave without a follow-up appointment.



ASK FOR HELP

Our Asthma & Allergy Helpline offers bilingual support from Certified Respiratory Educators. Call 1-866-787-4050 or [email info@asthma.ca](mailto:info@asthma.ca).



GET INVOLVED

Join the Asthma Canada Member Alliance, share your story, donate to support, connect on social media.

“In my opinion, asthma clinics and the information www.asthma.ca provides is key in managing asthma ... I'm glad I am educated and for resources like your site. I feel that I am making the right decisions for my son and it's dramatically improved his asthma to the point that he no longer misses school or activities.”

Policy Recommendations



Access to Medication

The inability to access and afford medications has adverse effects on already vulnerable populations and leads to poor health outcomes. It is essential that all levels of government work to eliminate this barrier and establish consistent support across the country that enables access to prescription medications and offers choice in treatments based on health outcomes, not cost.



Improvements in Asthma Management

It is vital that an effort to improve asthma management be made across Canada. We would like to see greater investments in patient education leading to better self-management through increased use of Asthma Action Plans, and a joint physician-patient effort to aim for zero symptoms. Specialist care must be made available in a timely fashion for those who require it. Additionally, those who go to ER need automatic referrals to specialists. Increased utilization of Certified Respiratory Educators would lead to improved management and patient education.



Proper Diagnosis

Developing and implementing clear and uniform standards for proper diagnosis through pulmonary function testing such as spirometry must become an established protocol in basic asthma care. Our study found that only 53% of respondents received spirometry testing prior to diagnosis. This is unacceptable. Everyone with asthma or suspected asthma must have ready access to objective lung function testing and adequate training must be provided to all healthcare providers to conduct such tests.



Specialized Care for Vulnerable Groups

Improved support and care must be provided to vulnerable groups such as low-income populations, young adults and those living with Severe Asthma. The prevalent models of care are not sufficient to meet the unique needs and challenges of these groups. An effort must be made to eliminate the use of oral corticosteroids among people with Severe Asthma, and move towards personalized treatments. The care of young adults must be tailored to meet their needs and situation. Access to care and medications must be expanded for those in low-income brackets.

References

1. Global Initiative for Asthma. Global Strategy for Asthma Management and Prevention, 2019. Available from: <https://ginasthma.org>
2. Asthma UK, "The reality of asthma care in the UK - Annual Asthma Survey 2018 report," 2018. [Online]. Available: <https://www.asthma.org.uk/578f5bcf/globalassets/get-involved/external-affairs-campaigns/publications/annual-asthma-care-survey/annual-asthma-survey-2018/asthmauk-annual-asthma-survey-2018-v7.pdf>
3. Asthma Society of Canada, "Severe Asthma: The Canadian Patient Journey," 2014. [Online]. <https://asthma.ca/wp-content/uploads/2017/06/SAstudy.pdf>
4. Govt. of Canada, "Asthma and Chronic Obstructive Pulmonary Disease (COPD) in Canada, 2018," 2018. [Online]. Available: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/asthma-chronic-obstructive-pulmonary-disease-canada-2018.html#exec>.
5. Asthma Canada, "Asthma Action Plan," Asthma Canada, 2019. [Online]. Available: <https://asthma.ca/get-help/asthma-3/control/asthma-action-plan>.
6. P. Gibson and H. Powell, "Written action plans for asthma: an evidence-based review of the key components," *Thorax*, vol. 59, no. 2, pp. 94-99, 2004.
7. R. D. Goodwin, F. Jacobi and W. Thefeld, "Mental disorders and asthma in the community.," *Arch Gen Psychiatry.*, vol. 60, no. 11, pp. 1125-30, 2003.
8. Perna, Bertani, Politi, Colombo and Bellodi, "Asthma and panic attacks," *Biol. Psychiatry.*, vol. 42, no. 7, pp. 625-30, 1997.
9. E. Brown, D. Khan and S. Mahadi, "Psychiatric diagnoses in inner city outpatients with moderate to severe asthma.," *Int J Psychiatry Med.*, vol. 30, no. 4, pp. 319-27, 2000.
10. J. Alonso, P. d. Jonge, C. C. W. Lim, S. Aguilar-Gaxiola, R. Bruffaerts, J. M. Caldas-de-Almeida, Z. Liu, S. O'Neill, D. J. Stein, M. C. Viana, A. O. Al-Hamzawi, M. C. Angermeyer, G. Borges, M. Ciutan, G. de Girolamo, F. Fiestas, J. H. Maria, J. M. Haro, C. Hu, R. C. Kessler, J. P. Lepine, D. Levinson, Y. Nakamura, J. Posada-villa, B. J. Wojtyniak and K. M. Scott, "Association between mental disorders and subsequent adult onset asthma," *J Psychiatr Res.*, vol. 59, pp. 179-188, 2014.
11. R. D. Goodwin, F. C. Bandiera, D. Steinberg, A. N. Ortega and J. M. Feldman, "Asthma and mental health among youth: etiology, current knowledge and future directions," *Expert Review of Respiratory Medicine*, vol. 6, no. 4, pp. 397-406, 2012.
12. S. C. Corullón, S. Valero-Moreno, M. P.-. Marín, I. Montoya-Castilla and A. Escribano-Montaner, "Asthmatic adolescent anxiety and adaptation to illness," *European Respiratory Journal*, vol. 52, no. 62, p. 1279, 2018.
13. Amemiya and T. Fujiwara, "Association of Low Family Income With Lung Function Among Children and Adolescents: Results of the J-SHINE Study.," *J Epidemiol.*, vol. 29, no. 2, pp. 50-56, 2019.
14. A. Arif and P. Korgaonkar, "The association of childhood asthma with mental health and developmental comorbidities in low-income families," *Journal of Asthma*, vol. 53, no. 3, pp. 277-281, 2016.
15. N. Bidad, N. Barnes, C. Griffiths and R. Horne, "Understanding patients' perceptions of asthma control: a qualitative study," *European Respiratory Journal*, vol. 53, no. 6, 2018.
16. E. S. Brown and P. A. Chandler, "Mood and Cognitive Changes During Systemic Corticosteroid Therapy," *Prim Care Companion J Clin Psychiatry*, vol. 3, no. 1, pp. 17-21, 2001.

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About Asthma Canada

Asthma Canada is the only national, volunteer-driven charity, solely devoted to enhancing the quality of life for people living with asthma and respiratory allergies. For more than 45 years, Asthma Canada has proudly served as the national voice for Canadians living with asthma.

Our mission is to help Canadians with asthma lead healthy lives through education, advocacy and research.



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