## ANNUAL ASTHMA SURVEY REPORT



### A SNAPSHOT OF ASTHMA IN CANADA



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## A MESSAGE FROM OUR CEO

When Asthma Canada began preparing to launch our 2020 survey, we had no idea what the year would have in store for us. It is safe to say that 2020 is a year unlike any other. The voices of our asthma community including patients, parents, caregivers and healthcare providers — are especially important during these difficult times, and Asthma Canada continues to meet the changing needs of our community.

Our annual survey gives us an invaluable opportunity to gain insight into the unique challenges our community members face. This feedback directly informs our strategy to ensure that every Canadian with asthma gets the care and support they need to live healthy and symptom-free lives.

Our 2020 survey results indicated that while most respondents were satisfied with the quality of care they received from their healthcare provider, more than half still felt that they are not receiving *enough* information or education needed to properly manage their asthma. Results also showed there is a clear disparity between people's perception of asthma control versus the clinical definition of control: a major barrier in optimizing asthma care.

People living with asthma continue to experience mental health challenges as a result of their symptoms. A large majority of respondents reported feeling anxious and stressed because of their asthma. It is imperative that asthma care includes supports to address mental health needs.

A crucial aspect of asthma care is for every individual to have an official diagnosis, with proper and accurate testing, followed by comprehensive management, including an Asthma Action Plan.

We need to do more to address these issues — but together, we know we can do just that.

Vanessa Foran President & CEO, Asthma Canada

## EXECUTIVE SUMMARY

Asthma is a chronic lung disease which restricts the airflow into the lungs, making it difficult for nearly 3.8 million Canadians to breathe. It is the third most common chronic disease in Canada. Asthma symptoms are triggered by many environmental factors that cause symptoms such as shortness of breath, chest tightness, wheezing and coughing which constrict the airways (bronchial tubes). It is estimated that nearly 300 Canadians are diagnosed with asthma every day, and roughly 250 Canadians die from an asthma attack each year.

Asthma Canada continues to listen to the voices of those living with asthma, providing continuous support and guidance during an unprecedented time when a global pandemic has caused anxiety and fear for many living with asthma. Data on how the coronavirus SARS-CoV-2 (hereafter referred to as COVID-19) affects those with asthma is still unfolding.

The purpose of the survey is to listen to the patient voice and in turn raise awareness by highlighting the challenges and gaps that exist within the Canadian healthcare system for individuals with asthma. This 2020 survey not only captures the ongoing struggle and challenges that Canadians with asthma and their caregivers face in accessing appropriate and timely healthcare and treatment services, but also how a global pandemic has impacted their lives.

Living with asthma can have a huge impact on one's mental health. The fear of having an asthma attack can leave individuals feeling anxious and scared. The uncertainty of not knowing what might happen with a global pandemic can also increase emotional stress. The majority (79%) of people living with asthma reported having some form of health-related anxiety and 74% reported feeling emotionally stressed due to their asthma. It's not surprising that this was also felt when individuals were asked about their asthma during the COVID-19 pandemic.

A majority of respondents living with asthma reported having some form of health-related anxiety.



### **Executive Summary continued**

Individuals living with asthma can feel stigmatized, isolated, stressed and sometimes, even hopeless. Asthma impacts the quality of life of those affected by the disease, and can have a devastating impact and cause challenges for individuals when completing daily activities or interacting with others in society. More focus needs to be given to the mental health and emotional well-being of individuals living with asthma, particularly at this time where there is so much uncertainty around COVID-19 health outcomes.

Timely access to quality health care, treatment and education is crucial for proper asthma management and to keep symptoms under control. Yet, close to half (44%) of respondents reported that their current drug coverage is insufficient and 24% of people have skipped filling a prescription because they were not able to afford it. Family doctors, pediatricians and emergency room doctors are the first to diagnose (63%) compared to asthma specialists (23%), however, the primary source for care and management for those living with asthma still continues to be a family doctor or pediatrician (52%), followed by an asthma specialist (23%). Issues of access, wait times to see a specialist, lack of information and education provided on managing asthma and referrals and follow up after emergency care are all priorities for our community. In a pandemic, this can be even more challenging and of concern when considering the impact that increased safety measures and the anxiety and fear associated with COVID-19 has on patients accessing care.

The survey also highlighted that there is a clear disparity between people's perception of asthma control versus the clinical definition of control. This can be a major barrier in optimizing asthma care, even during a global pandemic. While 83% of respondents believe their asthma is moderately to very well controlled (63% during COVID-19), 59% report trouble sleeping due to asthma symptoms and 71% report avoiding exercise or physical activities due to asthma symptoms.

In this survey — similar to the 2019 Annual Asthma Survey — three at-risk groups were identified: Canadians between the ages of 24 and 44 (note in the 2019 survey this age group identified was between 18 and 34); people living with Severe Asthma; and those with an annual income less than or equal to \$29,000 (note in the 2019 survey the annual income was less than or equal to \$19,000). There are various factors that can affect the burden of asthma, including the social determinants of health.

Improving access to affordable medications, accurate testing and diagnosis along with early diagnosis and management can lead to a better quality of life for those living with asthma.



In the 2020 survey, three at-risk groups were identified:

- Canadians aged 24-44
- People living with Severe Asthma
- Individuals with an annual income less or equal to \$29,000

## SURVEY Methodology

The survey was launched online using Survey Monkey and shared with our Asthma Canada Member Alliance (ACMA) via email on the 12th of May 2020. Data collection period lasted for seven weeks, closing on the 30th of June, 2020. Overall we received a total of 270 responses with a 67% (177) completion rate. Criteria for participation were to be living in Canada and either have asthma or be a parent or caregivers of someone with asthma.

Of those who had completed the survey, more than half (53%) of the survey respondents did not participate in Asthma Canada's 2019 Annual Asthma Survey, compared to 22% who had participated and 25% who were unsure if they had participated. Half (50%) of the respondents indicated that they had moderate asthma. The percentage of respondents indicating mild and Severe Asthma was 23% and 27% respectively.

The majority of the survey respondents (41%) were in the 45-64 age-group followed by the 24-44 group (25%) and 65+ (19%). Respondents in the younger age groups 17 & under and 18-24 represented 10% and 5% of the respondents respectively.

A majority (83%) of the respondents were from three provinces: Ontario (56%), British Columbia (16%) and Alberta (10%). Response from Quebec was only 4%. Responses from the Atlantic provinces was comparatively low - collectively accounting for just (8%) of the respondents. Response from Manitoba and Saskatchewan was also low - representing 3% each. No response was received from Nunavut, the Northwest Territories and the Yukon.

Less than half (44%) of the respondents reported that their income level was less than \$59,000 and 42% were living in a suburban area compared to 39% in urban areas and 19% in a rural area.

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

We would like to offer our sincere thanks to everyone who took the time to complete the survey.



Asthma Canada offers our sincere thanks and gratitude to all those who took the time to complete the survey. This feedback from our community is incredibly important to us.

## SURVEY FINDINGS

### **Quality of Life: The Impact of Asthma on Mental Health**

Asthma affects the overall health and well-being of those living with asthma. The survey indicated that a significant majority of respondents reported feeling health-related anxiety (79%) and (74%) reported feeling stressed due to their asthma. More than half of the respondents reported feeling isolated and like they were missing out on opportunities (59%) and less confident (58%) due to their asthma. It was also not surprising that 48% of respondents also felt being singled out or stigmatized due to their asthma.

It is well established that mental health issues like depression and anxiety impact the quality of life among people with asthma. It has also been determined that risk factors such as stress may cause asthma symptoms to worsen and cause feelings of fear among those with asthma. Stress is a daily part of life that can be triggered by a variety of causes including major stressors that can occur in one's life including job loss, increased financial obligations, death of a loved one, chronic illness or injury, relationship issues, too many deadlines, lack of support or life changing events that might not be in one's control.

As of November 2019, the lives of many changed due to COVID-19, a pandemic that swept across the globe, having an impact on the mental health and well-being of countless people living with asthma, as well as their caregivers. The difficulty in coping with the situation and uncertainty around COVID-19 and asthma has led to a lot of stress and anxiety. Majority (78%) of the survey participants felt anxious about their asthma during COVID-19. It is important that during these difficult times, focus is given to the mental health and well-being of individuals living with asthma, especially among the most vulnerable population groups.

The survey specifically highlights higher reporting of health-related anxieties and feeling stressed among. middle-aged Canadians between the ages of 25 and 44; people living with moderate to Severe Asthma; and those with an annual income less than or equal to \$29,000.

#### From our community:



**6** During this time with COVID-19, he is extremely anxious and super concerned about things opening up again. To the point of absolute fear of the outside world."

### **Quality of Life: The Impact of Asthma on Mental Health**

Majority (87%) of the respondents aged between 25 and 44 reported feeling health-related anxiety due to asthma. In addition, 80% reported that they felt stressed, 74% felt less confident, and 60% reported that they felt isolated or like they were missing out on opportunities due to their asthma. More than half of the respondents reported feeling stigmatized (53%) or hopelessness (51%) due to their asthma.

Majority of the respondents with Severe Asthma reported feeling health-related anxiety (88%), isolated or like they were missing out on opportunities (76%), less confident (70%) and hopelessness (68%). Interestingly, 79% of respondents with moderate and Severe Asthma both reported feeling stressed due to their asthma. Individuals with Severe Asthma experience poorer quality of life and are at an increased risk of exacerbations, hospitalizations and death due to poor disease control and more often have poor mental health outcomes.

Stressors such as job loss, increase in financial obligations or living in a low income household can also have a huge impact on a person's asthma. This can lead to lack of affordable housing, access to medications and the possibility of working in precarious jobs with dangerous working conditions, subsequently leading to poor mental health and well-being.

When analyzing income-level, nearly half (44%) of the respondents with an annual household income of \$29,000 or less reported feeling health-related anxiety due to asthma most of the time - the highest percentage among all the income groups. This group also had the highest proportion of respondents reporting that most of the time they felt stressed (39%), isolated and missing out on opportunities (37%), less confident (31%) and stigmatized (22%) due to their asthma.



Those in the higher income bracket (\$120,00-\$119,999) did not feel that their health and well-being was affected most of the time due to their asthma, but it is important to note that they did feel that their health and well-being was affected *some* of the time due to their asthma.

#### From our community:

More than *half* of respondents felt that living with asthma interfered with the quality of their social interactions.

### **Quality of Life: The Impact of Asthma on Mental Health**

Asthma affects the person, but it also affects personal relationships with parents, spouses, coworkers and caregivers. This can have an emotional impact on the individual living with asthma. More than half (62%) of respondents felt that living with asthma interfered with the quality of their social interactions. This was felt more often by respondents with Severe Asthma.



#### From our community:

In all honesty, my biggest problem is lack of treatment and education, so I've panicked when I didn't need to. Now, I'm scared to see medical professionals because of COVID."

## Quality of Life: Addressing Lack of Participation and/or Avoidance

Asthma can negatively impact the psychological and social-well-being of those living with asthma, resulting in avoidance and lack of participation in physical activity. Majority (71%) of respondents indicated that in the past 12 months their asthma symptoms prevented them from participating in outdoor and/or physical activities. This was seen in 81% of respondents with Severe Asthma, 76% with moderate asthma and 49% with mild asthma.

It has been shown that people with Severe Asthma can have poor quality of life that impacts their ability to complete daily activities and participate in outdoor and/or physical activities. They may also experience a loss in productivity at work or school and can be limited in their leisure and lifestyle. One major limitation is not being able to participate in sports and vigorous activities and is more common in individuals with uncontrolled asthma. Based on the survey participant responses, COVID-19 has not made it any easier for individuals living with asthma to get active. People living with asthma may be more hesitant to venture to the pharmacy to pick up medications, or even go for a walk. (See p.24 — *The Impact of the Global Pandemic on Asthma Care.*)



#### From our community:

"I exercise indoors at home and have stopped going to yoga classes to lessen my exposure to viruses. I stopped riding my bike and hiking because it's too hard on me. Also I've cut way back on gardening and when I do, I wear a mask."

"Pollen sees me confining my activities indoors. Frigid winter days have me bundling up and using cabs rather than transit & walking."

### "I had an asthma attack while caring for my client because of the humidity in the pool room to complete his therapy."

Asthma is the leading cause of absenteeism (which is time taken off/missed) from school and one of the leading causes of work loss through both absenteeism and presenteeism (which is the loss in productivity). Absenteeism from school is more prevalent among low-income and racial/ethnic minorities. Differences associated with asthma control, such as access and quality of health care, adherence to medication use, and social factors such as psychosocial stressors also contribute to absenteeism.

In the past 12-months, (43%) of respondents missed work or school because of their asthma symptoms, 67% with Severe Asthma and 82% were 17 years of age and younger. The loss of productivity at school or work due to being sick or feeling unwell in individuals with asthma, can lead to a decrease in performance or quality of work or schoolwork. This is known as presenteeism and it is often overlooked and it has been reported that productivity loss in work and school can be avoided by achieving and maintaining control of asthma, which can sometimes be difficult in individuals with Severe Asthma. Less than half (39%) of respondents said the performance or quality of their work or school work in the past 12 months was affected by their asthma symptoms. Asthma impacting productivity can further have a negative impact on the financial and emotional consequences burdening people with Severe Asthma and their families.

#### From our community:

**L** "I miss at least five days a month."

"Every March I get bronchitis, and my asthma gets worse."

"I ended up with pneumonia in February; worked from home but missed my night school classes."

"Many of my coworkers smoke, and the lingering second-hand smoke when they return can my trigger asthma symptoms."

## **Quality of Life: Diagnosis**

Best practice for diagnosing asthma includes completing a detailed history and examination for asthma when an individual presents with respiratory symptoms, alongside conducting a spirometry test (a pulmonary function test that measures the amount of air you can breathe in and out). Conducting spirometry and lung function testing is important to avoid both the under-diagnosis and over-diagnosis of asthma from occurring. In over half, (63%) of respondents had their asthma diagnosed through physical exam, followed by (48%) of cases that were diagnosed through spirometry testing. A chest x-ray was used in (41%) of cases.

- Over half of the survey respondents (62%) indicated that their official diagnosis came from a Family Doctor/Pediatrician or Emergency Room Doctor,
- Twenty-three per cent (23%) said they were diagnosed by an Asthma Specialist/Respirologist/Allergist,
- Overall, (47%) of respondents indicated that they were diagnosed in adulthood and 31% reported being diagnosed as an infant or at a preschool age (one to five years).

### **Quality of Life: Asthma Control**

Most people living with asthma say they have their asthma under control, yet their symptoms tell another story. Nearly (83%) of respondents indicated that their asthma was moderately to very well controlled, while (6%) said their asthma was not controlled at all. However when looking at the key parameters of asthma control, nearly half of the respondents reported that they experienced trouble sleeping, used a rescue inhaler frequently, were less likely to participate in outdoor and/or physical activities and missed work or school in the past 12 months due to their asthma symptoms.

## There is a clear difference between respondents reporting that their asthma was controlled compared to it actually being controlled.

A majority (82%) of respondents with self-reported moderate asthma and nearly (75%) of those with self-reported mild asthma indicated that their asthma is controlled. However less than half (43%) of those with self-reported Severe Asthma indicated their asthma is controlled.

More than half (64%) of respondents with an income level less than \$29,000 reported having trouble sleeping because of their asthma symptoms such as wheezing, persistent cough, shortness of breath or tightness of the chest and (67%) of adults ranged from 25-44 years of age reported having trouble sleeping because of asthma symptoms. It has also been shown that those individuals whose asthma is not well controlled are more likely to use their rescue inhalers for quick relief of asthma symptoms rather than the long-term prevention provided by controllers. In this survey, (33%) of respondents said they use their rescue inhaler more than four times a week and (50%) use it before exercise.

Respondents' perception of the level of their asthma control	Respondents' self-reported data on the key parameters of asthma control		
<ul> <li>More than a quarter (29%) indicated that they believe their asthma is 'controlled'; 15% indicated it is 'very well controlled'</li> <li>More than one-third (39%) indicated that they believe their asthma is 'moderately controlled'</li> <li>Only 6% of respondents reported that they believe their asthma is 'not controlled'</li> </ul>	<ul> <li>In the last 3 months, more than half (59%) of respondents have experienced trouble sleeping because of asthma symptoms such as wheezing, persistent cough, shortness of breath or tightness of the chest.</li> <li>One-third (33%) of respondents said they use their rescue inhaler more than four times a week and 50% use it before exercise.</li> <li>Majority (71%) of respondents indicated that in the past 12 months their asthma symptoms prevented them from participating in outdoor and/or physical activities.</li> <li>In the past 12-months, less than half (43%) of respondents missed work or school because of their asthma symptoms</li> </ul>		

#### Asthma Control: Perception vs. Reality



Though the majority of the respondents felt anxious about their asthma during COVID-19, over half (63%) of respondents indicated that they felt their asthma was the same, even during a pandemic. However, (34%) of respondents also indicated that they had not gone to an appointment or utilized the health care system because of COVID-19. It is not clear whether the anxiety or fear of leaving the house due to COVID-19 impacted access to proper care and treatment during the pandemic. Maintaining proper asthma control is key to reducing the frequency of asthma symptoms and preventing asthma attacks. The symptoms of asthma can vary day to day and from person to person and that is why it is important to work with a healthcare provider to tailor an Asthma Action Plan that meets the needs of the individual. An Asthma Action plan is a personalized treatment plan that outlines steps a person with asthma needs to take to monitor the frequency of asthma symptoms and to avoid triggers, flare-ups and exacerbations. This personalized plan should be developed in collaboration with a healthcare provider to ensure that it meets the needs of the individual patient.

In this survey, (58%) of respondents reported that they didn't have an Asthma Action Plan, while (21%) of respondents reported that they had one and either used it regularly or had not used it or updated it in a long time. In addition, of those who self-reported as having Severe Asthma, (21%) of respondents didn't have an Asthma Action Plan and (62%) of respondents aged 18 and older did not have an Asthma Action Plan, compared to those younger than 17 years of age, where (27%) did not have an Asthma Action Plan.





*Fifty-eight per cent* of survey respondents indicated they **did not have an Asthma Action Plan.** 

### **Management and Lifestyle: Affording Medication**

Affordable access to asthma medication has a significant impact on the health outcomes of those living with asthma and especially those living in lower income households. Nearly (44%) of respondents indicated that their current drug coverage isn't enough to control their asthma symptoms and feel that they need more support and (72%) of those respondents with an income level less than \$29,000 required a government drug plan compared to those in the \$30,000-\$59,000 income group.

Individuals in the higher income group were more likely (26%) to pay out of pocket and received (33%) partial and government funding. In comparison to those who earned over \$90,000 were more likely (76%) to receive full or partial drug coverage by their employer.

Of these respondents who require a little to a lot more support in paying for their medication and helping to keep their symptoms under control, (46%) had self-reported as having Severe Asthma and (49%), moderate asthma.





Almost one-quarter (24%) of respondents indicated that they have skipped filling a prescribed asthma medication because they were not able to afford it, compared to (76%) who said they did not skip filling their asthma medication. Of those respondents who skipped filling a prescription for their asthma medication due to the inability to afford it, (37%) of respondents were in the less than \$29,000 income level compared to over a quarter of respondents with an income level between \$30,000-\$119,000 that have also skipped filling a prescription due to cost.



Over *one third* of respondents with Severe Asthma indicated they had skipped filling their prescription.

### **Management and Lifestyle: Affording Medication**

When looking at age variation, respondents between 25-44 years of age (38%) reported having skipped filling their prescription compared to (25%) of respondents who were 24 years and younger. Of those in the 45-64 age range (22%) and in the 65+ age range (16%) reported skipping filling their asthma medication prescription. Similarly, of those respondents who self-reported as having Severe Asthma, over one-third (35%) indicated that they had skipped filling their prescription.





It is clear that additional assistance and funds are needed for individuals in the lower income bracket, those less than 44 years of age and with Severe Asthma to cover their asthma medication and treatment. Without proper asthma medication it becomes very difficult for individuals with asthma to control their asthma symptoms and prevent flare ups/exacerbations.

#### From our community:

66 "As a single parent when my children lived at home, money was very tight. I often did not take my medication at the rate I should have, as I could not afford it."

"Prior to having the current insurance that I do, I had to pay more for my prescriptions and would ration or skip doses to try to make the medication last longer."

"Some drugs cost a lot — and not all are covered due to special authorization requirements. These take a long time to get filled out, as a specialist has to fill them. It is hard to get into see a specialist, there are long wait times, and they can be difficult to contact via phone. When they get processed they are often declined, even if they are the best thing that works for me. The requirements for coverage are too restrictive."

#### **Treatment and Emergency Care: Healthcare Professionals**

Healthcare professionals play a key role in the education, management and treatment of asthma. Nearly, twothirds (63%) of respondents indicated that their asthma was first diagnosed by a family doctor, pediatrician or emergency room doctor, compared to (23%) by an asthma specialist, respirologist or allergist.

Similarly, more than half (52%) of respondents have their asthma managed primarily by a family doctor or pediatrician and (23%) are managed by an asthma specialist, respirologist or allergist. The continuity of care received from the onset of diagnosis can greatly impact the management and control of asthma long-term.

A large majority (92%) of respondents indicated that they have timely access to a family doctor in their area and (56%) were satisfied with their asthma-related care provided by a family doctor. Similarly, when asked about access to an asthma specialist, respirologist or allergist half (50%) of respondents indicated that they had timely access to a specialist or asthma clinic and (46%) were satisfied with the asthma-related care provided by an asthma specialist, however, (41%) also indicated that they didn't visit an asthma specialist for their asthma-related care.

When looking at the level of satisfaction of care provided by a family doctor and age group, more than half of the respondents who were 24 years of age and older indicated that overall they were satisfied with the care provided by their family doctor and more than a quarter of those younger than 17 years of age indicated overall dissatisfaction with the care provided by their family doctor.

When looking at the level of satisfaction of care provided by an asthma specialist and age group, more than half (56%) of the respondents who were younger than 17 years of age indicated that overall they were satisfied with the care provided by their asthma specialist compared to (26%) of respondents between 18-24 years of age.





### **Treatment and Emergency Care: Healthcare Professionals**

The lack of knowledge and education on how to properly use an inhaler — whether that is a controller or reliever inhaler — can lead to inadequate management of asthma, especially in an individual whose asthma is already not well controlled. Healthcare providers need to provide appropriate education on proper inhaler techniques.

A majority (78%) of respondents indicated that their healthcare provider helped them correctly use all of their current types of inhaler(s) or device(s) before they started using them, compared to (22%) of respondents who reported that their healthcare provider did not help them correctly use all of their inhaler(s) or device(s).

When respondents were asked if the pharmacist ever checked their inhaler technique when filling their asthma prescription, the numbers were reversed and (79%) of respondents said no, their pharmacist did not teach them how to use an inhaler, while (21%) said they did.



Overall, nearly two-thirds (64%) of respondents were satisfied with the information and education they had received regarding their asthma care from their primary source of care. However, more than half (56%) still felt that not receiving information or education on managing their asthma prevented them from receiving the asthma care, support and treatment required. Therefore, quality of care and continuity of care provided by a healthcare provider is an important element for optimal asthma care.

#### From our community:

66

"I didn't receive much information [from my healthcare provider] at all. I had to ask her to prescribe them to me and she did not tell me when or how to use the inhaler. I had to read the instructions carefully. The pharmacist told me to take the 'blue first' and then the orange."

#### **Treatment and Emergency Care: Barriers to Access and Care**

According to the survey, the following prevented respondents from receiving the asthma care, support and treatment they required: Inadequate air quality regulations for workplaces (60%), lack of information/education on managing asthma (56%), and long wait times to see a specialist (53%). It is not surprising that many felt that they were not receiving adequate asthma care, support and treatment due to inadequate air quality regulations in workplaces. This has a huge effect on those who are working long hours in precarious jobs and dangerous working conditions that may contain asthma triggers making it harder for those with asthma to manage and control their symptoms.

<b>We asked:</b> How often have the following prevented you from receiving the asthma care, support and treatments you require?				
Parameter	Most of the time	Some of the time	Not at all	
High cost of inhaler medications or devices	11%	22%	66%	
High cost of newer medications like biologics	14%	13%	73%	
No referral to a specialist	19%	22%	59%	
Long wait times to see a specialist	25%	28%	47%	
Lack of information/education on managing asthma	18%	38%	44%	
Difficulty in locating asthma or respiratory educators	23%	25%	52%	
Inadequate air quality regulations for workplaces	26%	34%	40%	

A large majority (92%) of respondents indicated that they have timely access to a family doctor and (56%) were satisfied with their asthma-related care provided by a family doctor. Similarly, when asked about access to an asthma specialist or an asthma clinic half (50%) of respondents indicated that they had timely access to a specialist or asthma clinic directly, though half of the respondents needed a referral from a physician and (46%) were satisfied with the asthma-related care provided by an asthma specialist, however, (41%) also indicated that they didn't visit an asthma specialist for their asthma-related care.



#### **Treatment and Emergency Care: Barriers to Access and Care**

It is important to note that individuals aged between 18-24 are at a greater risk of not having timely access to specialized healthcare. Three-quarters (75%) of respondents indicated they had timely access to a family doctor, however only (25%) had timely access to an asthma specialist or an asthma clinic. Similarly, those aged between 25-44 reported having timely access to a family doctor (84%), however only (40%) to an asthma specialist or asthma clinic, with (22%) needing a direct referral from a physician.

Lack of coverage for critical medications and lack of access to appropriate healthcare services can create problems for individuals living with asthma. While coverage is an essential factor in access to care, barriers also prevent individuals with asthma from getting timely care to manage their asthma and prevent symptoms.

Even though nearly two-thirds (64%) of respondents were satisfied with the information and education they had received regarding their asthma care from their primary source of care, more than half (56%) still felt that not receiving information or education on managing their asthma prevented them from receiving the asthma care, support and treatment required.



There were noticeable differences in attaining timely access to asthma care across the Canadian provinces. Approximately (94%) of the respondents living in Alberta, British Columbia, Manitoba, New Brunswick Prince Edward Island and Saskatchewan indicated that they have timely access to a family doctor. In Ontario, this was slightly lower (92%) compared to other provinces, while in Quebec more than a half (56%) have timely access to a family doctor.

In comparison, when respondents were asked if they had received timely access to an asthma specialist or an asthma clinic those living in Manitoba, New Brunswick, Nova Scotia and Prince Edward Island were not able to access an asthma specialist or an asthma clinic directly and had to be referred by a physician. Also, surprisingly, (100%) of respondents from Prince Edward Island had timely access to a family doctor and also needed a direct referral to see an asthma specialist or an asthma clinic. Similarly, though (75%) of respondents from Nova Scotia had timely access to a family doctor, however, only (25%) could access an asthma specialist or asthma clinic based on referral and (50%) had no access to an asthma specialist or an asthma clinic.

#### **Treatment and Emergency Care: Accessing Emergency Care**

For many with uncontrolled asthma, having poor knowledge about their asthma, use of medication or lack of a primary care physician can lead to frequent visits to the emergency department. Nearly a third (32%) of the respondents indicated that in the past 12 months, they had received unplanned or emergency care for their asthma.

Of these respondents, when asked whether they were satisfied with the following during their emergency care: wait-time, cost of treatment, instructions, recommendations for follow-up care and overall care during the emergency, nearly half (50%) of respondents indicated overall satisfaction with wait-time and overall care received during the emergency, while (13%) expressed dissatisfaction with instructions/recommendations for follow-up care, and (10%) with wait-time. Only (4%) indicated that they were overall dissatisfied with the cost of care when (46%) indicated they were satisfied.



#### From our community:

**66** "

"Before my son was diagnosed with asthma we had a very hard time with our emergency care. It was honestly twice a week we were going due to my son struggling to breathe. They would take X-rays and say it was pneumonia and gave him medication. It wasn't until we saw our specialist that we got our answers! It's very frustrating as a parent that no one can tell you what's wrong with your child."

### **Treatment and Emergency Care: Oral/Systemic Corticosteroids**

Oral and systemic corticosteroids play an important role in managing asthma, and specifically Severe Asthma. More than a third (36%) of respondents indicated that they had used an oral/systemic corticosteroid once per year and (29%) indicated they have never used or required an oral/systemic corticosteroid. However, more than a quarter (28%) indicated they have used an oral/systemic corticosteroid once or more per year.

Less than a third (31%) of respondents with a household income of less than \$29,000 reported that they used an oral/systemic corticosteroid at least once or more per year. It was also noticed that (50%) and (41%), respectively of respondents between 18 and 24 years of age and younger than 17 years of age reported using oral/systemic corticosteroids once or more per year.

Oral/systemic corticosteroids are often used to manage asthma. However the over-use of these drugs can also lead to health-related adverse effects, such as osteoporosis and bone fractures, cataracts, adrenal failure, diabetes, and hypertension, and impaired immunity.

Fifty-two per cent of those respondents who self-reported as having Severe Asthma used oral/systemic corticosteroids once or more per year.



#### The Impact of the Global Pandemic on Asthma Care

The COVID-19 pandemic brings feelings of anxiety, stress and fear to many living with asthma. COVID-19 is known to affect the nose, throat and lungs — a virus that might exacerbate asthma symptoms, lead to an asthma attack; and possible further complications like pneumonia and acute respiratory disease. At this time, there is no prevention treatment or vaccine for COVID-19 and the best way to prevent illness is to avoid being exposed to the virus. An overwhelming majority (98%) of respondents reported that they had not been diagnosed with COVID-19 by a healthcare provider, however (78%) of respondents did feel anxious about their asthma during COVID-19 and majority (88%) of those respondents had self-reported as having Severe Asthma.

It is important not only for those living with asthma, but also friends, family members and caregivers to those living with asthma to continue to take the necessary precautions to protect themselves from COVID-19 and minimize the spread of the disease. Our survey respondents reported following precautions such as washing their hands more frequently and keeping a social distance of 2 meters from everyone. The majority of the survey respondents who self-reported as having moderate asthma and respondents 25 years and older were taking precautions, compared to those who self-reported as having mild or Severe Asthma and those who were 24 years and younger.

Sixty-three per cent (63%) of respondents indicated that they felt their asthma was the same even with the ongoing COVID-19 pandemic. However, (34%) of respondents also indicated that they had not gone to an appointment or utilized the health care system because of COVID-19. Eighty-two per cent (82%) of respondents reported that they took their medication as usual, while (11%) reported taking more of their current medication. Similarly, (95%) of respondents also did not require any changes to their treatment or medications by a healthcare provider because of COVID-19. Moreover, (92%) of the respondents also did not have trouble affording their asthma medication because of the pandemic and made changes to how they overcame barriers in accessing their asthma medication because of COVID-19.

#### From our community:

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"I use the phone in place of a visit for medication repeats."

"All my appointments have been done via Zoom."

"I haven't done blood work that my general practitioner (GP) ordered several months ago, as I don't want to go anywhere near a lab right now. But all my specialists have arranged either video or phone appointments. I don't have a GP where I'm currently living, and haven't needed to contact my home GP."

"Regular monthly appointments with my respirologist have been over the phone instead of in person."

### The Impact of the Global Pandemic on Asthma Care

When looking at access to asthma medication and treatment, a majority (82%) of respondents also mentioned that they took their medication as usual, (95%) did not require any changes to their treatment or medications by a healthcare provider and (92%) had no trouble affording their asthma medication because of COVID-19. It is also important to note that many respondents commented about the changes they made when accessing medication because of COVID-19 and were using the phone or online virtual platforms for healthcare appointments.

Individuals living with asthma already have to make changes to their lifestyle, which has a huge impact on the quality of their life, however those living in low-income households or those who are unable to travel or have limited internet access might have been greatly impacted by the social and physical restrictions placed due to COVID-19, placing them at an even higher risk when travelling to the pharmacy.

#### From our community:



"At the beginning of the pandemic (March), I ordered two extra inhalers to have on hand. They were sold out and I had to wait two weeks for them to come in. Luckily, I didn't need them, they were meant as backup in case the stores closed completely."

It's funny: during the outbreak my meds were limited to a 30 day supply as where most were on a 90-day supply before. This actually caused me to make more trips to a public place, putting me at a higher risk."

"I couldn't go to the pharmacy, one month's supply only, and had to keep track of myself in order to not to forget to refill my meds again on time. It was a hassle with deliveries."

"I haven't been able to get a new prescription for my medication in a while. This is largely because my previous family doctor has retired and I haven't found a new one yet, but COVID-19 is making it more difficult."

"I self-isolated and had my husband make my asthma medication purchases."

"Initially there was a bit of a shortage, but fortunately it did not affect me. My pharmacy delivers free of charge which also helps, and my doctor does phone visits."

"I'm not able to visit pharmacies, lack of access to doctors to get special authorization to access provincial drug plans. I am paying out of pocket because I have been waiting for forms to get sent. I've cut the amount of medication I take daily so that I don't run out while I wait for coverage."

# CONCLUSIONS

**Canadians living with asthma continue to face several challenges.** In this survey, respondents continued to address how their mental health and well-being is affected on a daily basis because of their asthma. These results do not differ from the 2019 Annual Asthma Survey, even amidst a global pandemic where new challenges arise. Inability to participate in day-to-day activities has an impact on an individual's performance in school or work. This can lead to overwhelming stress, anxiety, feeling isolated or like they are missing out on things because of their asthma. This also negatively affects social interactions with friends, coworkers, family and caregivers.

Asthma management is not only about the disease itself, but social and environmental factors that contribute to poor health outcomes or health decisions made by individuals living with asthma.

Continuity of care from diagnosis to ongoing management is crucial for proper asthma control and use of asthma medications. An overwhelming, (83%) of respondents said their asthma was moderately to very well-controlled, but when the survey looked at how many times a rescue inhaler was used in a year, or whether they had trouble sleeping at night, the responses told a different story. Proper asthma management will result in better long-term asthma control, preventing asthma attacks and long-term health affects.

Education on basic asthma education and how to best control asthma symptoms can be done by a healthcare provider and through the development of an Asthma Action Plan and demonstrating how to properly use an inhaler at every doctor's appointment. Those living with asthma continue to struggle with accessing specialized care, which most often requires a referral from a family doctor. Timely access to a doctor or respirologist can decrease the number of visits an individual makes to the emergency department because of asthma symptoms or an asthma attack. The care provided in the emergency department is also quite stressful for those who have to wait a long time, or do not have proper follow up care after the emergency visit.

This survey highlighted three key at risk-groups who are most vulnerable and impacted by asthma: individuals in the lower income bracket, young adults, and those with Severe Asthma. More attention should be paid toward how best to support those in the most vulnerable population groups. Individuals living with asthma who live in low income households are at a higher risk of their asthma worsening over time due to poor quality housing and living conditions. The quality of care provided to young adults during the transition into adulthood has a huge impact on their overall health and well-being. Ongoing support is needed for those living with Severe Asthma who require more medical care and asthma medications that may not be readily available or affordable.

In a pandemic, this can be even more challenging and of concern when fear of exposure to COVID-19 can lead to less patients accessing care. Policy changes should focus on improving access to affordable medications, accurate testing and diagnosis, and education during early diagnosis and management by healthcare professionals for all people living with asthma.

## POLICY RECOMMENDATIONS

#### **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 toward 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.

#### **Improved 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. In this survey, (33%) of respondents they are using their reliever inhaler more than four times per week. 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.. 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.

#### **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.

#### Access to care (virtual care vs. in-person care)

To overcome barriers to healthcare access, the use of virtual, video-based technology platforms for asthma care is a potentially useful format to deliver optimal asthma care directly into patient homes. Public health requirements during the pandemic like physical distancing can interfere with how those living with asthma might make decisions about their health. During the pandemic when restrictions are in place and travel to a primary care physician/specialist or to the pharmacist may be affected, new ways of delivering optimal asthma care should be explored.

## TIPS FOR OUR Community



### Ask for help when you need it

Complete control of asthma means living symptom-free. This means zero symptoms: no time lost from work, school and play, no limitations on exercise or activity, and no emergency room visits.

We are here to help: our **Asthma & Allergy Helpline** offers bilingual and personalized support from Certified Respiratory Educators. Call **1-866-787-4050** or email *info@asthma.ca*.

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#### **Create and follow an 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. You can download an Asthma Action Plan by visiting *asthma.ca* 



#### Advocate for yourself

It's essential to know your rights and advocate for quality care when you're living with asthma. You can learn more about self advocacy on *asthma.ca* 



#### **Get Involved**

Join the Asthma Canada Member Alliance, share your story, donate to support the asthma community, connect on with Asthma Canada on social media!



Visit our website www.asthma.ca







Find us on Facebook www.facebook.com/AsthmaCanada

Like us www.instagram.com/asthma\_canada

# REFERENCES

Abrams, E. M., W't Jong, G., & Yang, C. L. (2020). Asthma and COVID-19. CMAJ, 192(20), E551-E551.DOI: https://doi.org/10.1503/cmaj.200617

Asthma Canada, "Asthma Action Plan," Asthma Canada, 2020. [Online]. Available: https://asthma.ca/get-help/asthma-3/control/asthma-action-plan.

Asthma Canada, "Asthma and COVID-19 (Coronavirus)", Asthma Canada, 2020. {Online}. Available: https://asthma.ca/asthma-and-covid-19 coronavirus/#:-:text=When%20people%20with%20asthma%20get,rare%20cases%2C%20life%2Dthreatening.

Brown, R., Bratton, S. L., Cabana, M. D., Kaciroti, N., & Clark, N. M. (2004). Physician asthma education program improves outcomes for children of low-income families. Chest, 126(2), 369-374. DOI: https://doi.org/10.1378/chest.126.2.369

Costa, D. D., Pitrez, P. M., Barroso, N. F., & Roncada, C. (2019). Asthma control in the quality of life levels of asthmatic patients' caregivers: a systematic review with meta-analysis and meta-regression. Jornal de Pediatria (Versão em Português), 95(4), 401-409. DOI: https://doi.org/10.1016/j.jpedp.2019.04.005

Del Giacco, S. R., Cappai, A., Gambula, L., Cabras, S., Perra, S., Manconi, P. E., ... & Pinna, F. (2016). The asthma-anxiety connection. Respiratory medicine, 120, 44-53. DOI: https://doi.org/10.1016/j.rmed.2016.09.014

Ehteshami-Afshar, S., FitzGerald, J. M., Carlsten, C., Tavakoli, H., Rousseau, R., Tan, W. C., ... & Sadatsafavi, M. (2016). The impact of comorbidities on productivity loss in asthma patients. Respiratory research, 17(1), 106. DOI: https://doi.org/10.1186/s12931-016-0421-9

Global Initiative for Asthma. Global Strategy for Asthma Management and Prevention, 2020. [Online]. Available: https://ginasthma.org/wp-content/uploads/2020/04/GINA-2020-full-report\_-final\_wms.pdf

Goodwin, R. D. (2016). Toward improving our understanding of the link between mental health, lung function, and asthma diagnosis. The challenge of asthma measurement. DOI: https://doi.org/10.1164/rccm.201610-2016ED

Gruffydd-Jones, K., Thomas, M., Roman-Rodríguez, M., Infantino, A., FitzGerald, J. M., Pavord, I., Haddon, J.M., Elsasser, U., & Vogelberg, C. (2019). Asthma impacts on workplace productivity in employed patients who are symptomatic despite background therapy: a multinational survey. Journal of asthma and allergy, 12, 183. DOI: https://dx.doi.org/10.2147%2FJAA.S204278

Ilmarinen, P., Juboori, H., Tuomisto, L. E., Niemelä, O., Sintonen, H., & Kankaanranta, H. (2019). Effect of asthma control on general health-related quality of life in patients diagnosed with adult-onset asthma. Scientific reports, 9(1), 1-11. DOI: https://doi.org/10.1038/s41598-019-52361-9

llic, A. D., Zugic, V., Zvezdin, B., Kopitovic, I., Cekerevac, I., Cupurdija, V., Perhoc, N., Veljkovic, V., & Barac, A. (2016). Influence of inhaler technique on asthma and COPD control: a multicenter experience. International Journal of Chronic Obstructive Pulmonary Disease, 11, 2509. DOI: https://doi.org/10.2147/COPD.S114576

Johnson, S. B., Spin, P., Connolly, F., Stein, M., Cheng, T. L., & Connor, K. (2019). Peer Reviewed: Asthma and Attendance in Urban Schools. Preventing chronic disease, 16.DOI: https://dx.doi.org/10.5888%2Fpcd16.190074

# REFERENCES

Katsaounou, P., Odemyr, M., Spranger, O., Hyland, M. E., Kroegel, C., Conde, L. G., Gore, R., Menzella, F., Ribas, C.D., Morais-Almeida, M., & Gasser, M. (2018). Still Fighting for Breath: a patient survey of the challenges and impact of severe asthma. ERJ Open Research, 4(4). DOI: 10.1183/23120541.00076-2018

Labor, M., Labor, S., Jurić, I., Fijačko, V., Grle, S. P., & Plavec, D. (2017). Long-term predictors of anxiety and depression in adult patients with asthma. Wiener Klinische Wochenschrift, 129(19-20), 665-673. DOI: https://doi.org/10.1007/s00508-017-1203-1

Lin, N. Y., Ramsey, R. R., Miller, J. L., McDowell, K. M., Zhang, N., Hommel, K., & Guilbert, T. W. (2020). Telehealth delivery of adherence and medication management system improves outcomes in inner-city children with asthma. Pediatric Pulmonology, 55(4), 858-865. DOI: https://doi.org/10.1002/ppul.24623

McDonald, V. M., Hiles, S. A., Jones, K. A., Clark, V. L., & Yorke, J. (2018). Health-related quality of life burden in severe asthma. Medical Journal of Australia, 209(S2), S28-S33. DOI: 10.5694/mja18.00207

Miadich, S. A., Everhart, R. S., Greenlee, J., & Winter, M. A. (2020). The impact of cumulative stress on asthma outcomes among urban adolescents. Journal of Adolescence, 80, 254-263. DOI: https://doi.org/10.1016/j.adolescence.2019.12.007

Murphy, A. (2020). How to help patients optimise their inhaler technique. Evaluation, 14(47), 19.

Nurmagambetov, T., Kuwahara, R., & Garbe, P. (2018). The economic burden of asthma in the United States, 2008–2013. Annals of the American Thoracic Society, 15(3), 348-356. DOI: https://doi.org/10.1513/AnnalsATS.201703-259OC

Sadatsafavi, M., Rousseau, R., Chen, W., Zhang, W., Lynd, L., & FitzGerald, J. M. (2014). The preventable burden of productivity loss due to suboptimal asthma control: a population-based study. Chest, 145(4), 787-793. DOI: https://doi.org/10.1378/chest.13-1619

Stubbs, M. A., Clark, V. L., & McDonald, V. M. (2019). Living well with severe asthma. Breathe, 15(2), e40-e49. DOI: 10.1183/20734735.0165-2019

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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. **Our vision** is a future without asthma.



Asthma & Allergy HelpLine 1.866.787.4050



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