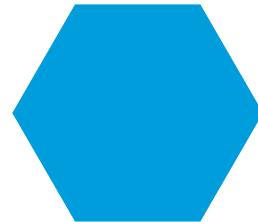
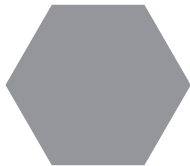




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MAPPING THE PATIENT JOURNEY

A Guide based on the Severe Asthma Study



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MAPPING THE PATIENT JOURNEY

A Guide based on the Severe Asthma Study

About Mapping the Patient Journey

A. Purpose of the Mapping the Patient Journey Guide

The purpose of the *Mapping the Patient Journey* is to provide a how-to-guide with the necessary documents and study structure to global organizations and partners studying specific patient population group(s) with a severe health condition of interest in order to map out the journey of the patient(s) with a severe health condition and to identify their key issues and areas of concern regarding the treatment and management they receive for their severe health condition through their local healthcare system.

B. Components of the Mapping the Patient Journey Guide

Mapping the Patient Journey is to be used by global and national organizations in collaboration with community partners and patient population group(s) of interest to implement the Severe Asthma Study in order to map out the patient(s) journey with a severe health condition.

Mapping the Patient Journey includes the following components:

1. Program Background: Including detailed information about the Severe Asthma Study, the conception of the study, goals and outcomes.
2. Operations of the Severe Asthma Study: Detailed information on the process taken to implement the Severe Asthma Study.

C. Supports for the Implementation of the Severe Asthma Study

1. Operations of Severe Asthma Study: Information on the Severe Asthma Study, and the operations of the study.
2. Severe Asthma Study materials and tools: Materials and tools needed for all organizations and community partners to implement the Severe Asthma Study as follows:
 - Advisory Group tools and process: Includes the process on how to establish an advisory group, invitation letter and terms of reference template.
 - Materials and resources for various social media and communications platforms: Includes promotional flyer, the Asthma Society of Canada website alert/National Asthma Patient Alliance/Twitter alerts and telephone and email communications to asthma clinics for recruiting participants for the study.
 - Data collection tools and processes: Includes the data collection tools such as the online screener, online surveys and interview discussion guide templates, as well as consent forms for participants and oath of confidentiality form for facilitator.

The implementing organizations and community partners can modify the materials and tools as needed to implement the steps of this study based on the needs of their patient population group(s), as well as the content and design of the *Mapping the Patient Journey* guide and operational processes taken to implement the *Severe Asthma Study*. In order to achieve the effectiveness and outcomes similar to this study it is important to follow the implementation process as provided in *Mapping the Patient Journey*, however implementing organizations are asked to note any key challenges and additional steps included to better improve the process of implementing a study similar to the *Severe Asthma Study*.

Study Background

A. What is the Severe Asthma Study?

The burden of Severe Asthma on the Canadian health system has neither been well-understood from the patient perspective nor well-recognized within national and regional health system priorities. Asthma is one of the most common diseases in Canada, the third most common chronic disease, affecting 2.4 million Canadians over the age of 12¹ and a further 485,700 of children between the ages of 4 and 11 years of age². Despite the high prevalence, asthma remains greatly misunderstood, and its impact on peoples' health and quality of life underestimated by both those living with the disease as well as the general public. It is estimated that somewhere between 150,000 and 250,000 Canadians are living with Severe Asthma while representing only between 5 and 10% of people with asthma, constituting a considerable health care concern. Up to an additional 500,000 Canadians suffer from moderate asthma, with almost 50% experiencing uncontrolled symptoms. In addition, some studies indicate that up to 53% of Canadian patients with asthma are poorly controlled, further lowering their health outcomes and quality of life^{3 4 5 6}. Uncontrolled asthma and Severe Asthma leads to a burden on our healthcare system, economy and well-being. Most surprisingly to many people, asthma can be fatal and approximately 250 adult Canadians die each year from asthma⁷.

In 2006 a survey entitled, *Asthma control in Canada remains suboptimal: The Reality of Asthma Control (TRAC)*, was conducted and showed that 47% of asthma patients surveyed had controlled disease according to symptom-based guideline criteria, only 11% of patients had written action plans, and one-half of patients with action plans did not use them regularly (Fitzgerald et al, 2006). The comprehensive study conducted by the Asthma Society of Canada (ASC) in 2013 entitled: *Asthma Matters: A Study on Adult Canadians Living with Severe and/or uncontrolled Asthma*, targeted adult Canadians, aged 18 and over, living with severe and/or uncontrolled asthma. The Asthma Society of Canada developed the Severe Asthma Study by adapting the *Fighting for Breath - A European Patient Perspective on Severe Asthma* (2004), conducted in Europe by the European Federation of Allergy and Airway Diseases Patients Association, *Severe Asthma in Ireland and Europe: A Patient's Perspective* (2007) by Asthma Society of Ireland and *Fighting for Breath: The hidden lives of people with severe asthma* (2010) by Asthma UK models. These models were designed to look at the patient experience and focused on children as well as adults with asthma and Severe Asthma across Europe, whereas, the Asthma Society of Canada modified the methodology used in the European studies to further address the evidence gap by providing an up-to-date understanding of severe and/or uncontrolled asthma in Canada. The methodology used focused on gathering information from the patients' perspectives on their experiences living with Severe Asthma from childhood to adulthood. The Severe Asthma Study explored in-depth the prevalence, burden, needs, and expectations of patients with asthma further asking questions on motivation, or lack thereof, for compliance and adherence to asthma management plans. This study was also the first step towards establishing national and provincial/territorial perspectives on the social and economic impact of severe and/or uncontrolled asthma in Canada. This was to be used by health care professionals, pharmaceutical companies, researchers, governments and policy makers in Canada to address severe and/or uncontrolled asthma.

1 Canadian Community Health Survey (2010), Statistics Canada

2 Life and Breath, Respiratory Disease in Canada (2007), Public Health Agency of Canada

3 Asthma Control in Canada; No improvement since we last looked in 1999. McIvor RA, Boulet L-P, FitzGerald J, Zimmerman S, Chapman KR. Canadian Family Physician 2007;53:672-7

4 Suboptimal asthma control: Prevalence, detection and consequences in general practice. Chapman KR, Boulet L-P, Rea RM, Franssen E. European Respiratory Journal 2008;31:320-5

5 Asthma control in Canada remains suboptimal: the Reality of Asthma Control (TRAC) study, Fitzgerald M, Boulet L-P, McIvor RA, Zimmerman S, Chapman KR. Can Respir J 2006;13:253-9

6 Examining asthma quality of care using a population-based approach, Klomp H, Lawson JA, Cockcroft DW, et al. Can Med Assoc J 2008;178:1013-21

7 Admissions to Canadian Hospitals for acute asthma: A prospective, multicenter study, Can Respir J. 2010 Jan-Feb: 17(1): 25-30

B. What was the Study Goal and Objectives?

Study Goal

The main goal of the proposed study was to gain a better understanding about the experiences of Canadian adults, aged 18 and over affected by severe and/or uncontrolled asthma and their needs and priorities in asthma management. This was done by capturing the patients' voice and experience through personal descriptions of their journey with Severe Asthma, the patient's characteristics and behaviours, the patients' perspective and their management and treatment of Severe Asthma.

Study Objectives

There were two objectives to this study:

1. The first objective was to undertake a mixed design (qualitative and quantitative) study involving Canadians with Severe Asthma, mapping out their journey with asthma, to ultimately ensure that the patient voice and patient experience was heard by:
 - The Canadian public to educate them on the personal, social and economic cost of Severe Asthma in Canada;
 - Public policy makers through a call to action to governments in Canada to create provincial, territorial and national asthma strategies and meet the needs of Canadians with Severe Asthma;
 - The pharmaceutical and medical device industries to promote innovation and better therapeutic treatments to provide greater options and alleviate the suffering of people with Severe Asthma;
 - Health care professionals to draw attention to patient needs, desires and priorities;
 - Canadian asthma researchers to focus research efforts on stated patient concerns;
 - Asthma Society of Canada stakeholders, funders and partners to focus attention on the severity and the burden of illness faced by people with Severe Asthma in Canada.
2. The second objective was to provide the foundation for a quantitative study to verify the qualitative study, assess regional and demographic differences, and identify further key issues and areas of concern, from the patient perspective, regarding the treatment and management of Severe Asthma in the Canadian Healthcare system.

C. What Outcomes did we want to Achieve?

The outcomes of the proposed study included the following:

- To have a better understanding about the needs of adult Canadians living with severe and/or uncontrolled asthma and their priorities in asthma management
- To use this understanding in developing Asthma Society of Canada resources and programs to educate the Canadian asthma community on the importance of proper asthma control
- First step to providing guidance for a quantitative study based on qualitative trends
- Build a case for a call to action for governments to address issues affecting those living with Severe Asthma
- Raise public awareness about the burden of severe and/or uncontrolled asthma

D. What was the Success Criteria?

The criteria that allowed us to confirm that the study had been delivered successfully was the following:

- Recruited participants who were adult Canadians 18 and above living with severe and/or uncontrolled asthma, using screener questions
- Representation from selected regions (Ontario, Quebec, Alberta), because of existing partnerships and collaborations within these regions through the Canadian Severe Asthma Network, the National Asthma Patient Alliance and asthma clinics across Canada
- Obtained data on each of the outcomes

- Developed resources and deliverables that were effective and useful

E. What was the Participant Eligibility Criteria?

The eligibility criteria included the following:

- Study participants were identified as Canadian
- Adults 18 years and above
- Lived with severe controlled or uncontrolled asthma
- Diagnosed with asthma by a physician

All potential participants were evaluated through a strict screening process and only qualifying applicants were contacted for the qualitative in-person interview phase. All participants who qualified for the in-person interview were given the option to not participate after being provided with details on the in-person interview at the end of the online screener. They were also provided with a consent form that was completed prior to the in-person interview that provided participants with the option to withdraw from the study at any time and informed them that only information gathered prior to the withdrawal would be used for the purpose of the study.

F. What did the Study not Include?

The study did not include the following:

- Participants under the age of 18 (exclusion of children and youth)
- Provincially based information
- A large group of participant involvement
- A comprehensive quantitative study

Operations of the Study

This section of the *Mapping the Patient Journey* will describe a detailed outline of the implementation process for the Severe Asthma Study.



Step 1: Apply for Funding

It is important for any organization before conducting a study similar to the Severe Asthma Study to decide on the funding resources and secure funding prior to conducting the study. It must be taken into account when applying for funding to ensure the focus of the proposed project or activity is evident and to explain what the funding will be used for by being clear about the intended outcomes and scope of the study.

Step 2: Develop a Work Plan

A work plan should be developed through the following process:

- A. Meet with the implementation team to determine the following:
 - a. Main purpose of the project, goal(s) and objective(s)
 - b. Main purpose, goal, objectives of each committee/group identified to be important by the agency to implement a study similar to Severe Asthma Study, for example the Advisory Group
 - c. Terms of reference for each of the committees/groups outlining project details, objectives, responsibilities and timelines, main deliverables, specific tasks and timelines, personnel involved and updates
- B. Meet with the each of the committee/group members to determine the following:
 - a. Key objectives
 - b. Expected outcomes
 - c. Activities to be conducted
 - d. Project results and products to be achieved
 - e. Timelines
 - f. Staff Involvement/responsibilities
- C. Develop a flow chart/map

The work plan should be developed in order to assist the project team in outlining the key steps, activities, goals that need to be achieved during the planning, implementation, evaluation and dissemination phases of the study conducted. Furthermore, including time taken to complete each step identified by the implementation team is important because this allows the team to review the work plan on a regular basis to see if they are reaching the goals and milestones in a timely fashion. The amount of time allocated to each component of the process will depend on the time and resources the agency allocates to the study, the question being studied, scope of the study and the funding received. The overall time from inception to dissemination for the Severe Asthma Study was approximately 7 months. The implementation of step 1 through step 7 took three months and this was determined by the time and resources that were allocated towards the study.

Step 3: Literature Review/Environmental Scan

Complete a comprehensive literature review of relevant and appropriate surveys, studies, articles and programs (pertaining to the patient population group in question). The review should be conducted by the agency that is implementing the study. The literature review should be conducted using the following steps:

1. Choose the topic of study
2. Define the research question
3. Decide on the scope of the review, whether it will include regional, national, and/or global data. This will be determined based on the topic and research question your agency wants to study
4. Select the databases that will be used to conduct the searches
5. Conduct the searches and find the literature
6. Keep track of the searches
7. Review the literature

The greatest challenge faced with the literature review was that an in-depth literature review could not be conducted at the beginning of the study planning due to limited resources, but instead was conducted throughout the study steps. Ideally, the literature search should be conducted prior to implementing the study. This activity should be included in the work plan.

Step 4: Engage with Partners/Stakeholders/Organizations

Establish an Advisory Group (AG) through this process:

1. Recruit AG members
 - a. Advisory group members should be recruited based on the need and capacity to support the AG by the agency implementing the study (approximately 8 to 10 members).
 - b. Advisory group members should be able to represent the patient population group the agency is studying.
 - i. Individuals recruited should include but not be limited to:
 - having a medical/clinical background, local stakeholders and partner representatives with similar values and goals and individuals with lived experience on the health condition being studied. Note: it is important to recruit AG members from regions/communities your agency plans to study.
 - c. Once a list of potential AG members have been selected by the implementation team an invitation letter should be sent to those identified to take part in the AG (*Appendix A*)
2. Develop a terms of reference (ToR) (*Appendix B*)
 - a. The ToR will outline the following:
 - i. What the study is about, the duration of the study, and the level of commitment expected from the AG members
 - ii. What role the AG members will play in the study
 1. Provide advice and guidance to the implementation strategies
 2. Establish key definitions and scope of the project
 3. Address barriers and challenges
 4. Methodology of data collection tools
 5. Recruitment of participants
 6. Reporting and knowledge translation of results
 - iii. How many times the AG members will meet or communicate
 1. Communication through email, tele-conference or in-person meetings

3. Conduct AG meetings
 - a. Project team to establish the number of times to conduct AG meetings (example: biweekly meetings from the start to the end of the study implementation)
4. Reporting back to the AG members (example: determine who will take meeting minutes and when the meeting minutes will be distributed)

The advisory group members were instrumental in assisting the project team define Severe Asthma and review questions included in the qualitative and quantitative questionnaires and facilitators guide. It is important to note that during the Severe Asthma Study there were no individuals with lived experience on the advisory group and therefore it was felt that having the voice of the patients on the advisory group would have brought more insight into the study components. Furthermore, during the Severe Asthma Study a reporting back to the AG members was not conducted and the project team felt that this process is important because it allows the project team and AG members to look back on previous meeting notes to see what action items were discussed and what might still be outstanding.

Step 5: Define the Health Condition

When defining the health condition the literature review of key indicators to determine the level of control should be reviewed and identified and discussed between the project team and advisory group members. In case of the Severe Asthma Study, Severe Asthma was defined in order to develop the screening questionnaire. The indicators used to determine the level of control were based on a variety of indices of asthma control such as those listed by the Global Initiative for Asthma (GINA) and the Canadian Asthma Consensus Guidelines definition and reviewed by a team of expert advisors on the advisory group.

Step 6: Obtain Ethics Approval

Obtaining ethics approval is an integral part of research studies. The decision to obtain ethics approval should be determined early in the planning phase of the study, in particular determining the intent of submission to a journal. During the Severe Asthma Study, at first the decision was made not to publish the study and therefore ethics approval was not obtained until later in the planning phase. This decision changed when it was realized that working with participants who are providing confidential information on sensitive issues and topics would need to be protected and provided with enough details to make informed, autonomous decisions.

Step 7: Recruitment of Participants

Recruiting participants to take part in the study should involve a multi-pronged approach as follows:

1. Identify region, area, local community of interest (local community, city, province, country-wide)
2. Establish a screening process (*Appendix C*)
 - a. Define the health condition (for example Severe Asthma)
 - b. Outline eligibility and non-eligibility criteria
 - c. Develop an online screener or eligibility questionnaire
3. Identify key organizations, networks, health clinics and relevant healthcare centres accessed by the patient population group of interest
4. Develop key promotional materials such as a promotional flyer (*Appendix D*), website and twitter alerts (*Appendix E*), (*Appendix F*), and telephone (*Appendix G*) and email (*Appendix H*) communications to asthma clinics
5. Distribute promotional materials to key target audiences, organizations, networks, health clinics, healthcare centres via email and/or posting promotional materials through various social media platforms and/or at various locations within the community, city, or region health clinics
6. Develop a consent form for participants to complete prior to participating in any in-person interviews. The consent form should include information on: 1. Potential harm, risks, or discomforts, 2. Potential benefits, 3. Confidentiality, 4. Participation (voluntary), 5. Information on how the data will be recorded, and how long the data will be kept by the agency and when it will be destroyed (*Appendix I*)

During the Severe Asthma Study, the participant recruitment involved a multi-pronged approach involving direct outreach to members of the National Asthma Patient Alliance, the Severe Asthma Network as well as promotion through local asthma clinics and relevant healthcare centres. Project staff created promotional flyers which were distributed through clinics/health centres in target cities and via email to relevant contacts with the goal of reaching as many potential participants as possible in the target cities. All interested participants were directed to the Eligibility Questionnaire (available in English and French). All potential participants were evaluated through a strict screening process and only qualifying applicants were contacted for the interview phase. All participants were given the option of anonymity or to withdrawal as part of the online screening structure and provided with an additional consent form.

Step 8: Qualitative Study

- Develop interview questions with the AG members and project team by reviewing key assessment and test questionnaires for the health condition being studied
- Project lead to develop an interview facilitator guide (*Appendix J*) and oath of confidentiality signed by the moderator/facilitator conducting the interview (*Appendix K*)
- Project lead to establish interview dates/times/venue
- Project lead to invite participants who have completed the online screener to in-person interviews based on participants mode of contact provided
- The day of the in-person interview the facilitator will:
 - o Ask participants to complete a consent form (*Appendix I*)
 - o Inform participants and obtain permission to video tape the interview
 - o Conduct the interview (*Appendix J*)

The key objective of this study was to focus on the patients' personal journey with Severe Asthma. By taking a look at their quality of life, expectations, medication preferences and experience with primary care professionals' knowledge of their health condition, as well as experience with the healthcare system and access to diagnostics, treatment and medications. In order to assess their level of control, the questions included were determined from the following: the American Thoracic Society (ATS) such as the Asthma Control Test (ACT) the Childhood Asthma Control Test (C-ACT), the Asthma Control Scoring System (ACSS), the Juniper Asthma Control Questionnaire (ACQ), the Asthma Therapy Assessment Questionnaire (ATQQ), the 30-Second Asthma Test, and the Asthma Quiz for Kids.

- Key questions asked to assess the level of control included the following:
 - o Prevalence of asthma attack(s) in the last 12 months
 - o Hospital visits and admissions
 - o Limitations to physical activity
 - o Absenteeism at school or work
 - o Sleep disturbances
 - o Daytime symptoms
 - o Wheezing attacks
 - o Speech-limiting attacks
 - o Frequency of use of quick relief medications
 - o Lung function
- Other factors surveyed included the following:
 - o Adherence to Asthma Management Plans
 - o Preference for media (print, online, app) for Asthma Management Plans, asthma diaries
 - o Confidence in medical practitioners' knowledge and experience with asthma
 - o Preference regarding healthcare providers and asthma treatment (respirologists, allergists, family physicians, pharmacists, nurses, Certified Asthma Educators, nurse practitioners, respiratory technicians)
 - o Asthma control expectations
 - o Access to medications/burden of illness regarding both public and private benefit plans
 - o Cost of medications and hardware such as spacers and peak flow meters
 - o Asthma experience in the workplace as well as the home or other environments
 - o Stigma, stress and isolation experienced by people with asthma
 - o Regional differences

Overall, the interviews were a great success as all participants were highly engaged and open to speaking about their journey with Severe Asthma. During the interview the facilitator drew the journey timeline on a flip board chart paper and the participants could see their life journey with Severe Asthma captured right in front of them. The interviews were initially scheduled to take approximately 30 minutes, however nearly all interviews went over the allocated time, closer to 60 to 90 minutes. Therefore, it is important to note that going through someone's life journey with any health condition will take longer than 30 minutes to cover. It is important to allocate additional time in the in-person interview process.

Step 9: Two Quantitative Studies

1. *Targeting a small population group n=150 (in-house):*
 - a. Online survey hosted by the agency implementing the study (*Appendix L*)
2. *Targeting a large Population Group n=800 (external): [Planned but not executed]*
 - a. Online survey conducted through a national public opinion research firm where participants will be recruited representing the target population of Canadian patient(s) of interest

The survey questions should be similar to the qualitative interview questions. During the Severe Asthma Study the questions determined for the online survey were based on the discussion areas of the in-person interviews, which were expanded to include more specific details. The main reason for conducting the quantitative study was to get broader reach of participants who were not captured in the in-person interviews, including participants across Canada not specific to the key provinces studied during the qualitative study. The second quantitative study targeting the larger population group was not conducted by the Asthma Society of Canada. This quantitative study was mentioned in the study protocol to conduct a larger study by a national public opinion research firm. However, the online survey targeting a larger external population group was not conducted because of the limited time and resources allocated to the study.

Step 10: Analysis and Report Writing

1. Identify an analyst to conduct qualitative and quantitative analysis using NVivo and SPSS software
2. Project team to write the final report with AG member input and review

Step 11: Dissemination of Results

Develop a dissemination plan and key communications strategy for internal and external partners and stakeholders:

1. Target key policy makers, bureaucrats at different levels of the government as well as health care professionals and health care informants
2. Hire a public relations firm to develop supporting materials to be distributed alongside the final results of the study, including press releases, website content, matte stories/editorials as well as direct engagement of key health journalists and publications

Step 12: Call to Action

1. Based on the results of the study engage with key elected officials, including Federal and Provincial/Territorial Ministers of Health, Opposition Health Critics, and Health Committee members along with relevant bureaucrats
2. Develop materials to support these lobbying efforts calling on government(s) to address the pertinent issues in the health field revealed in the study results

Key Challenges and Lessons Learned from the Study

The Severe Asthma Study was modelled after international studies, and it was the first study undertaken in recent years targeting Canadians living with Severe Asthma. The project team faced key challenges and learned a few lessons during the planning and implementation phases.

A. Developing the Definition of Severe Asthma

In developing the online screening questionnaire, the Advisory Group engaged in an active debate over the definition of Severe Asthma, either to use GINA guidelines or the Canadian Asthma Consensus Guidelines. The GINA definition of Severe Asthma relies on evaluation of the inherent symptoms of the disease and the patient's lung function before instigating any treatment relative to the assessment of its severity. However, the Canadian Asthma Consensus Guidelines assess asthma severity once the treatment has been instigated and use a combination of factors, many of which overlap with measures of symptom control. The final decision made by the expert advisors was to adopt the Canadian Asthma Consensus Guidelines definition.

B. Participant Recruitment

Patient recruitment for both the interviews and online survey proved far more time consuming and challenging than anticipated. The exact reasons were difficult to determine, but it might have been because many individuals who have been diagnosed with Severe Asthma may not necessarily view themselves as having Severe Asthma (either they were not told by their primary care physicians despite fitting the definition of Severe Asthma or their Severe Asthma was controlled). Many of the clinics were willing to display posters promoting the study, but were not willing to actively recruit through their patient list and thus limiting the potential reach. Furthermore, due to the short timelines it was also difficult to recruit and conduct in-person interviews. However, that was also the reason why the online quantitative survey was conducted in order to reach individuals who might not have qualified for the in-person interviews or were not from the provinces that the in-person interviews were conducted in.

C. Ethics Approval

Ethics approval and Research Ethics Board (REB) decisions should be made during the planning phase of the study. In the Severe Asthma Study ethics approval was not obtained until later in the planning phase prior to implementation this led to delays in being able to recruit participants and conduct in-person interviews because the study documents needed to be approved by the ethics board prior to conducting any in-person interviews.

D. Literature Search

At the end of the study, additional time and resources were allocated to expand the grey literature study to ensure a comprehensive picture was captured through the literature and to inform the key recommendations. This was done due to the lack of data available in the literature and therefore, additional time was needed to review relevant literature.

E. Time and Resources

The research lead for the Severe Asthma Study was hired to conduct the study in three months. This was not sufficient time to complete a comprehensive study. Therefore if more time and resources had been allocated to the study there would have been more time added to recruiting and interviewing participants. It is important to note that during the planning phase it is important to factor in additional time and resources to conduct the literature review and in recruiting participants.

Recommendations from the Study

Key recommendations and insights were summarized for health care professionals, pharmaceutical companies, patients, and government officials, including system level changes in order to improve the quality of healthcare Severe Asthma patients' receive across Canada.

A. Global Health Organizations

Global professional organizations and international experts should produce guidelines, reports and other resources about Severe Asthma, which includes a consistent, clear, easy-to-understand definition of Severe Asthma that healthcare professionals and patients can understand and apply. The guidelines should incorporate evidence-based research to help improve asthma management and the lives of individuals living with severe and uncontrolled asthma across the globe and be rolled out to all physicians, including specialists in asthma and allergy through their respective governing bodies and/or colleges.

B. Non-for-profit Organizations

Non-for-profit organizations should bring forth the patients' perspectives into asthma management care and support programs and develop innovative tools and resources that their community would be able to access and use such as an electronic Asthma Management Action Plan. They may also consider providing those with Severe Asthma opportunities to join peer networking and support programs.

C. Health Care Professionals

Health care professionals such as physicians and specialists must be provided with and follow the standard guidelines with regards to testing and treatment of severe and uncontrolled asthma. There should be a clear consensus on what Severe Asthma is across all primary care physicians and asthma and allergy specialists. This is one way to ensure that all patients with Severe Asthma are receiving the same care. Furthermore, it is essential that healthcare professionals improve communication and information sharing between the patients and other specialists to provide consistent, high quality healthcare services. Patients should be provided with information on referrals sent to specialists and any results on the tests conducted, the Asthma Management Action Plans should be used and discussed with each patient, and patients should be involved in the decision-making process for treatment. It is also essential that information transferred from childhood to adulthood asthma healthcare services is a clear and smooth process for Severe Asthma patients.

D. Patients/Individuals with lived experience

Patients need to understand their rights and responsibilities and learn when to recognize that their asthma is not controlled. Furthermore, the compliance level of patients is important and this should be communicated by primary care physicians in order for the treatment to be altered to a regimen that can allow for better compliance. In this study, most patients were between 40 – 80 and for some, the initial diagnosis was missed by physicians, not everyone was diagnosed with asthma at childhood, but might have had symptoms of asthma at that time, and for others, it had not been a concern by parents to address this at a young age. Therefore, more education on what asthma is, how to diagnose it, treat it, and control it is needed.

E. Pharmaceutical Companies

Pharmaceutical companies need to conduct more research in developing new targeted medications and treatments as there is no one medication that works for all patients. Furthermore, it is important that pharmaceutical companies increase awareness about new options available to specialists and family physicians regarding the treatment of Severe Asthma. Many health care professionals are not up to date on treatment options and thus, are not providing this information to those with SA.

F. Government and Policy Officials

Government and policy officials should work towards developing policies around how to improve cross-sector access and transfer of medical records to ensure consistency of care for patients throughout their healthcare system experience. Government officials also need to increase funding for research and address the gaps in drug coverage to ensure all people with asthma can manage their disease, resulting in the best possible health outcomes.

Why Should Global Organizations Invest Money and Resources in a Project Similar to the Severe Asthma Study?

This study focuses on capturing the patients' voice throughout their life course and how asthma has impacted their experiences and daily activities from childhood to adulthood. There are very few studies that have been conducted which capture the patients' voice on Severe Asthma. This study was the first step to understanding what patients experience and feel every single day, and what the Canadian healthcare system provides in terms of appropriate asthma management and treatment. This study has also proved to be very beneficial in advocating for those patients who cannot advocate for themselves, or whose voices are not heard. It has further provided an opportunity to understand the gaps in the Canadian healthcare system with regards to chronic disease. For the Asthma Society of Canada it has helped shape our programs and services and changed the conversation within our community about Severe Asthma.

For more information, *Severe Asthma: The Canadian Patient Journey* is available at www.asthma.ca.

Examples of Materials and Resources Developed for the Severe Asthma Study

A. Advisory Group Invitation Letter

Insert Organization Logo

Dear XXX,

The Asthma Society of Canada (ASC) is currently undertaking a patient research project entitled: Asthma Matters: A Study of Adult Canadians Living with Severe Asthma. The project will be conducted by the ASC in collaboration with patient groups from the National Asthma Patient Alliance (NAPA), the Canadian Severe Asthma Network, as well as patients from asthma clinics across Canada.

We would like you to consider being part of the Project Advisory Group for Asthma Matters.

The main purpose of this project is to conduct a comprehensive study involving qualitative and quantitative approaches, which will provide an up-to-date understanding of severe and/or uncontrolled asthma in Canada looking at the prevalence, burden and needs and expectations of patients with asthma further asking questions on motivation, or lack thereof, for compliance and adherence to asthma management plans. The proposed initiative is also the first step towards establishing national and provincial/territorial perspectives on the social and economic impact of severe asthma in Canada that can be used by the governments and policy makers in Canada to address asthma.

We are looking for your assistance and participation as a member of our Project Advisory Group.

The Project Advisory Group Members will assist by:

- Defining definitions and with the scope of the project
- Addressing barriers and challenges
- Review of methodology including data collection tools and strategies
- Recruitment of participants
- Reporting and knowledge translation of results

Please find enclosed the “Project Protocol” for more detailed information on the project.

Thank- you for your attention to this request.

We look forward to your involvement in this project.

Sincerely,

B. Advisory Group Terms of Reference

Insert Organization Logo

Advisory Group Terms of Reference

“Asthma Matters: A Study of Adult Canadians Living with Severe Asthma”

July 2013

Project Purpose

The ASC is undertaking a comprehensive study of severe asthma utilizing three survey approaches: 1. Qualitative survey (n=36); 2. Small quantitative survey (in house, n=150) and 3. Larger quantitative survey (n=800, if additional funding becomes available). The surveys will provide an up-to-date understanding of severe asthma in Canada looking at the prevalence, burden and needs and expectations of patients with asthma further asking questions on motivation, or lack thereof, for compliance and adherence to asthma management plans. The proposed initiative is also the first step towards establishing national and provincial/territorial perspectives on the social and economic impact of severe asthma in Canada that can be used by the governments and policy makers in Canada to address asthma.

Project Objectives

The main objectives of the proposed study include the following:

- To undertake a qualitative and quantitative study involving Canadian adults with severe asthma to ensure the patient voice and experience of living with asthma is analyzed and then disseminated thus being heard by policy makers and key opinion leaders in Canada;
- To further educate the Canadian public in the personal, social and economic cost of severe asthma in Canada;
- To prepare for a Call to Action for governments in Canada to implement provincial, territorial and national asthma strategies;
- To provide evidence for the pursuit, development and access to innovative and better therapeutic treatments by the pharmaceutical and medical device industries to alleviate the suffering of people with severe asthma;
- To add to the understanding of all ASC stakeholders regarding the severity and the burden of illness faced by people with asthma in Canada;
- To provide the foundation for future longitudinal comprehensive quantitative studies by identifying key issues and areas of concern, from the patient perspective, of the treatment and management of severe and uncontrolled asthma in Canada.

Project Team

Membership

Scope of Responsibility/Activities

The advisory committee will provide expert advice and guidance on the project implementation strategies including:

- Definitions and scope of project
- Addressing barriers and challenges
- Methodology including data collection tools and strategies
- Recruitment of participants
- Reporting and knowledge translation of results

Time Commitment

The Advisory Group members are expected to be available for a conference call every two weeks (duration of the call: one hour). The study will need to be completed by (Date for completion).

C. Online Screener Questionnaire

Insert Organization Logo

Eligibility Questionnaire

(Online Screener)

The Asthma Society of Canada (ASC) is conducting a study of Adult Canadians living with severe asthma. This short eligibility questionnaire is being conducted to see if you qualify to participate in a brief, 30 minute interview. Participants who qualify and complete the interview will be compensated.

1. What language are you most comfortable speaking? (Please check only one)
 English French Other – **Terminate**
2. Are you or is any member of your family employed by or in any way affiliated with? (Please check all that apply)
 An ad agency/public relations firm/marketing research firm
 Any government agencies involved with food, drug, environmental or trade regulation
 A manufacturer/retailer or wholesale distributor of pharmaceuticals
 None of the above
Terminate if check any one of the above
3. How many years have you been living in Canada?
 Less than 5 years – **Terminate** 5 plus years
4. In which age group may I place you?
 Younger than 18 – **Terminate** Between 18 and 80 years old Older than 80 - **Terminate**
5. Have you ever been told by a health care professional that you have asthma?
 Yes No – **Terminate**
6. Has the healthcare professional who treats you for your asthma, ever referred you to the following, a pulmonary function lab for a breathing test (spirometry)?
 Yes No
7. Are you currently prescribed medication for your asthma?
 Yes No – **Terminate**
8. What is the name of the medications you are taking for your asthma? (Please check all that apply)
 Budesonide (Pulmicort®) Fluticasone (Flovent®) Prednisone
 Prednisolone (PediaPred®) Dexamethasone (Decadron®) Salmeterol (Serevent®)
 Formoterol (Foradil®, Oxeze®) Symbicort® Advair®
 Pulmicort® Zafirlukast (Accolate®) Montelukast (Singulair®)
 TheoDur® Uniphyll® Phyllocontin®
 TheoLair® Venoterol hydrobromide (Berotec®)
 Salbutamol (Ventolin®, Apo-Salvent®, Novo Salmol®, Gen-salbutamol®, Alti-Salbutamol®, Airomir®)
 Terbutaline sulfate (Bricanyl® inhaler) Omalizumab (Xolair®)
 Ciclesonide (Alvesco®) None of the above – **Terminate**

9. In the past 2-4 weeks, on how many days did you experience daytime symptoms (coughing, wheezing, chest tightness, shortness of breath) because of your asthma?
 Less than 2 days/week - **Terminate** Greater than 2 days/week Multiple times per day
10. In the past 2-4 weeks, have you had any limitations to activities such as exercise or daily activities because of your asthma?
 None – **Terminate** Some Limitation Extremely limited
11. In the past 2-4 weeks, how often did you wake up at night or early morning because of your asthma symptoms (wheezing, persistent cough, shortness of breath or tightness of the chest)?
 None – **Terminate** Less than 2 nights/week More than 2 nights/week
12. In the past 2-4 weeks, how often have you used your reliever or your rescue medication because of your asthma?
 Less than 2 days/week – **Terminate** More than 2 days/week Several times a day
13. How often have you used or required an oral or systemic corticosteroid because of your asthma exacerbations?
 Never – **Terminate** Once or more per year
 One a month Once a week
14. Are you comfortable in participating in a live interview and talking about your experiences with asthma, its treatments and the overall affect it has had on your life with an interviewer?
 Yes No – **Terminate**
15. What is your highest educational level achieved?
 Elementary School - **Terminate** High school diploma College Degree
 University Degree Post-Graduate Degree
16. Which of the following best describes your current employment status?
 Employed full-time Employed part-time Retired
 Unemployed Not working due to disability Stay at home parent
 Student
17. Have you ever participated in a focus group, individual interview, or any market research study?
 Yes – **Continue to questions 18 - 20** No – **Skip questions 18 - 20**
18. How many times have you participated in market research?
 Once Twice 3 plus – **Terminate**
19. When did you last participate in this type of study?
 Less than 3 months ago – **Terminate** More than 3 months ago
20. If more than 3 months ago what was/were the topic or topics of discussion? (Please write your response in the space provided)

21. Please specify which Province or Territory you reside in:
 Alberta Manitoba Newfoundland and Labrador
 Nova Scotia Ontario Quebec

- British Columbia
- Saskatchewan
- Yukon

- New Brunswick
- Northwest Territories

- Prince Edward Island
- Nunavut

22. Do you live in the greater Montreal, Toronto, or Edmonton areas?
- Yes
 - No - **Terminate**

Disqualification message:

Thank you for your interest in this study, however at this time you did not meet the requirements to participate in this study! However, we often conduct market research studies and would like to keep your email address on file for future opportunities. If you are interested potentially participating in a market research study please provide us with your email address below.

Contact Information:

Qualification message:

The Asthma Society of Canada (ASC) is conducting a study to learn more about adult Canadians aged 18 and over living with severe asthma. The ASC would like to hear your experiences with asthma, your treatment regimen and exposure to the healthcare system.

The interview will take approximately 30minutes to complete and you have the choice of not answering any questions or withdrawing at any time. The interview will be videotaped and you will be asked to complete a consent form at the beginning of the interview. Participants will receive a reimbursement (value of \$50) each for their participation in the interview.

Confidentiality:

- During the interview the ASC will be recording the interview. The recordings will include video and audio recordings.
- There will be no names attached to the video and audio recordings and there will be no identifying information or names used in any written reports.
- The video and audio recordings obtained during the interview will be kept anonymous and will not be revealed or used for any other purpose except for the purpose of this study.
- Confidentiality regarding the information that you provide will be assured by the ASC and your name will not be shared or presented in any way that would identify you as the source.

After reading the information above are you still interested in participating in this study?

- Yes
- No – **Terminate**

If Yes,

Thank you very much for agreeing to help us with this study and to participate in the live interview. To set up a date and time for the interview please email at: (insert email) or call our toll free number: (insert number).

Or

Please provide your name, phone number and/or email address that you can be contacted at and a member of the ASC team will be in contact within 2 business days between 9am and 5pm to set up a date and time for the interview.

Do You Have Asthma?

The Asthma Society of Canada is conducting a study of Adult Canadians Living with Severe Asthma

Who are we looking for?

Canadian Adults between the age of 18 and 80 living with severe asthma

Tell Us Your Story

We would like to hear from you about your experiences about your journey with asthma, your treatment preferences, and your experience with healthcare priorities and the healthcare system. You will be asked to complete a short eligibility questionnaire to see if you qualify to participate in a brief 30 minute live interview. Individuals who qualify and complete the interview will receive a compensation of \$50.

Please complete this short eligibility questionnaire to see if you can be part of this study

Asthma Study
Eligibility
Questionnaire
www.asthma.ca/study2013

Asthma Study
Eligibility
Questionnaire
www.asthma.ca/study2013

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Eligibility
Questionnaire
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Asthma Study
Eligibility
Questionnaire
www.asthma.ca/study2013

Comprehensive Study of Adult Canadians with Severe and/or Uncontrolled Asthma

Étude globale des Canadiens adultes souffrant d'asthme aigu ou non

Do you have Asthma?

The Asthma Society of Canada (ASC) is conducting a study to learn more about adult Canadians, aged 18 and over, living with severe and/or uncontrolled asthma. During the first phase of this study the ASC would like to hear from you about your experiences, your journey with asthma, your treatment preferences and your experience with health care professionals and the healthcare system.

You will be asked to complete a short eligibility questionnaire to see if you qualify to participate in a brief 30 minute individual interview.

Individuals who qualify and complete the interview will receive compensation of \$50.

Please complete this short questionnaire to see if you qualify to be part of this study: www.asthma.ca/study2013

Following the completion of the initial phase of this study, the ASC will conduct an online survey of adult Canadians with severe and/or uncontrolled asthma.

Êtes-vous asthmatique?

La Société canadienne de l'asthme (SCA) mène une étude auprès d'adultes canadiens souffrant d'asthme aigu ou non maîtrisé. En premier lieu, la SCA souhaite savoir comment vous vivez avec l'asthme, quels traitements vous préférez et comment vous composez avec les professionnels de la santé et le système de soins de santé en général.

On vous demandera d'abord de répondre à un court questionnaire servant à déterminer si vous êtes admissible à une brève entrevue de 30 minutes.

Les personnes retenues qui se soumettent à l'entrevue recevront une indemnité de 50 \$.

Si vous souhaitez participer à l'étude, veuillez répondre au questionnaire d'admissibilité en cliquant sur le lien suivant: www.asthma.ca/etude2013

Une fois la première étape de l'étude terminée, la SCA procédera à un sondage en ligne auprès de Canadiens adultes souffrant d'asthme aigu ou non maîtrisé.

Asthma Society of Canada - 124 Merton Street - Suite 401 - Toronto - Ontario - M4S 2Z2

(T) 416-787-4050 (F) 416-787-5807 (E) info@asthma.ca

Charitable Registration No. 89853 7048 RR0001

F. National Asthma Patient Alliance and Twitter Alert

NAPA Alert/Twitter Alert:

The Asthma Society of Canada (ASC) is conducting a study to learn more about adult Canadians, aged 18 and over, living with severe and/or uncontrolled asthma. The ASC would like to hear your experiences about your journey with asthma, your treatment preferences and your experience with health care professionals and the healthcare system. You will be asked to complete a short survey to see if you qualify to participate in a brief 30 minute interview. You will be compensated for your time.

Please complete the short survey to see if you can be part of this study: *(provide link to online screener questionnaire)*



G. Telephone Script

Asthma clinics via phone and email

Hi my name is _____ I am calling from the Asthma Society of Canada we are conducting a study to learn more about Adult Canadians 18 and over living with severe and/or uncontrolled asthma. We are asking individuals to complete a short online survey to see if they qualify to participate in a brief 30 minute interview. Individuals who qualify and complete the interview will be compensated \$50. We will be mailing out few copies of a promotional flyer with all the information about the study and was also wondering if we could email it to you as well. (Ask for email address)

H. Email Script

Hi, my name is (name of research lead), I am working as a research investigator at the Asthma Society of Canada (ASC). The ASC is conducting a comprehensive study entitled: "Asthma Matters: A Study of Adult Canadians Living with Severe Asthma", targeting adult Canadians, aged 18 and over, living with severe asthma. This current study will provide an up-to-date understanding of severe asthma in Canada looking at the prevalence, burden, and needs and expectations of patients with asthma further asking questions on motivation, or lack thereof, for compliance and adherence to asthma management plans.

We have developed and launched a short eligibility questionnaire to see which individuals qualify to participate in a brief, 30 minute interview. Participants who qualify and complete the interview will be compensated.

I have attached the following documents to this email: "Project Outline" for more details on the project and a "Promotional Flyer" to be placed up in the clinic or office for participants to see. Please note that the Promotional Flyer does have tear offs at the bottom of the flyer. We will also be mailing out the above documents to your location.

If you have any questions or concerns, please do not hesitate to contact the Project Manager (name of Project Manager) and contact information (email and/or phone number).

Thank you for your time.

I. Consent Form for In-Person Interview

Insert Organization Logo

*“Asthma Matters: A Study of Adult Canadians
Living with Severe Asthma”*

Letter of Information

- The Asthma Society of Canada (ASC) has a special interest in helping adults and children with asthma.
- You are being asked to participate voluntarily in the completion of an individual interview for the project entitled “Asthma Matters: A Study of Adult Canadians Living with Severe Asthma.”

Purpose of the project

- The aim of the individual interview is to gain a better understanding about your personal experiences, your journey with severe asthma and your needs and priorities in asthma management.
- What we learn from the individual interviews will help the ASC provide an up-to-date understanding of severe asthma in Canada and be the first step towards establishing national and provincial/territorial perspectives on the social and economic impact of severe asthma in Canada that can be used by the governments and policy makers in Canada to address asthma.

Procedures involved in the project

- You will be asked to participate in an individual interview where the ASC will ask you to provide your voice and experiences on your journey with severe asthma.
- The individual interview will be held in a meeting room in a central location in your region for approximately half an-hour duration.
- The interviews will be audio or video recorded in order to accurately capture what is said. The recordings will be transcribed, but your name will not be included in the transcriptions. The recording and transcription will be kept on a password-protected computer. Reports of study findings will not include any identifying information.
- Participants will be asked for express consent before any pictures, names and/or quotes are used in the public materials.

Potential Harms, Risks or Discomforts:

- There is the remote chance that discussing your personal journey about living with severe asthma may be emotional, difficult, frustrating or upsetting in an individual interview. We believe that the risk of emotional upset is no greater than in everyday life.

Potential Benefits:

- There are several possible benefits to individuals participating in the project as well as individuals with similar conditions who might also benefit from the results from this project.
- The benefits include having ASC resources and National Asthma Patient Alliance (NAPA) programs available to patients to educate asthma patients on the importance of proper asthma control and to raise public awareness about the burden of severe asthma.

Confidentiality:

- During the interview the ASC will be recording the interview. The recordings will include audio or video recordings.

- Participant confidentiality (privacy) will be respected and no information that directly identifies the participant will be given out or published unless required by law.
- Confidentiality (privacy) will be ensured by the use of pseudonyms (made up names). Data (transcripts) will be coded and stored in a secure location in the office of the project staff. The recordings will include audio or video recordings and no names will be attached to the recordings. There will be no identifying information or names used in any written reports. The recordings will be downloaded in an MP3 folder and saved on a secure drive on a password-protected computer of the project staff directly involved.
- Confidentiality regarding the information that you provide will be assured by the ASC and your name will not be shared or presented in any way that would identify you as the source.
- Any potential identifying information such as pictures, quotes and names used will only be drawn from the pool of individuals who have expressly given consent.
- All data related to this project will be for the sole use of the Asthma Society of Canada and will be retained only as long as necessary for the completion of this project.
- Participants may withdraw from this study at any time and only information gathered prior to the withdrawal will be used for the purposes of the study.

Payment or Reimbursement

- Participants participating in the individual interviews will receive a reimbursement in the form of a cheque for \$50. This cheque will be mailed to you a week after the completion of the interview.

Participation:

Your participation in the interview is completely voluntary. It is your choice to be part of the study or not. There will be no negative consequences if you decide not to take part, stop part way through the study or decide to skip questions. If you choose to withdraw, your compensation will be fully provided.

This study has been reviewed by (Name of Ethics Board), which is not affiliated with the research or research team, if you have any questions about your role and rights as a research participant, or have concerns, complaints or general questions about the research, please contact:

(Insert contact information for Ethics Board)

Contact for more information:

If you have any questions or concerns about the interview and how it is being used, please free to contact the Research Lead *(insert name)* by email: *(insert email)* or telephone number: *(insert phone number)*

Statement of Consent

I have read the above information and have received answers to all my questions. I am 18 years and older.

I voluntarily consent to take part in this research study and to have this interview:

- Video recorded
- Audio recorded only

I voluntarily consent to the following:

- I agree to be quoted and to be identified by name in report publications
- I agree to be quoted but all personally identifying information shall be removed or altered and contents of the quote shall not be revelatory of my identity
- I do not wish to be quoted
- I do provide my permission to share personal images in the report publications

I do not provide my permission to share personal images in the report publications

Participant's Name (Printed): _____

Participant's Signature: _____ Date: _____

Please provide personal contact information: *(will be used only for the purpose of sending out a payment for your participation in the individual interview)*

Name

(First): _____ (Last): _____

Address

(Street Name): _____

(City): _____ (Province): _____ (Postal Code): _____

(Phone Number: *optional*): (____) _____

(Email Address: *optional*): _____

Insert Organization Logo

**Asthma Matters:
A Study of Adult Canadians Living with Severe Asthma
Interview Discussion Guide
August 1st, 2013**

Project Overview

Objectives of the Project

The goal of the proposed study is to gain a better understanding about the experiences of Canadian adults affected by severe asthma and their needs and priorities in asthma management.

The first objective of the proposed study is to undertake a qualitative study involving Canadians with severe asthma, mapping out their journey with asthma, to ultimately ensure that the patient voice and patient experience is heard by:

- The Canadian public to educate them on the personal, social and economic cost of severe asthma in Canada;
- Public policy makers through a call to action to governments in Canada to create provincial, territorial and national asthma strategies and meet the needs of Canadians with severe asthma;
- The pharmaceutical and medical device industries to promote innovation and better therapeutic treatments to provide greater options and alleviate the suffering of people with severe asthma;
- Health care professionals to draw attention to patient needs, desires and priorities;
- Canadian asthma researchers to focus research efforts on stated patient concerns;
- ASC stakeholders, funders and partners to focus attention on the severity and the burden of illness faced by people with severe asthma in Canada.

The second objective is to provide the foundation for a quantitative study to verify the qualitative study, assess regional and demographic differences, and identify further key issues and areas of concern, from the patient perspective, regarding the treatment and management of severe asthma in the Canadian Healthcare system.

Design of the Project

This project has been designed to gain insight from adult Canadians, 18 years and older, living with severe controlled or uncontrolled asthma. The first phase consists of a series of 30-minute, one on one journey mapping interviews to be held in Toronto, Hamilton, Montreal and Edmonton with a maximum of 36 interviews (12 interviews from each of provincial centre). Some interviews may be conducted by telephone with on-line assistance and may last for 45 minutes. The second phase will include a quantitative survey to verify results and establish regional or demographic differences.

Session Details

Objectives of the Interview Session

1. To hear the patient's journey with severe asthma;
2. To record the impact of the chronic disease state on the patient's quality of life;
3. To explore patient's compliance with medication regimes, asthma management plan, and knowledge of treatment options and usage;
4. To explore the doctor-patient relationship and how involved the patient is in decisions about their own asthma care and treatment;
5. To understand the barriers and challenges patients experience in obtaining information and accessing the healthcare system for asthma.

Interview Schedule

City	Facility	Date/Session Time

Introduction and Preparatory Homework

Objectives of the Project

Introduce the participant to the session objectives and details. Also, gain insight into the participant's emotions and how they feel about their asthma.

Targeted Insights

- Understand how the patient feels about their asthma
- Understand how this feeling impacts their quality of life
- Identify how they would feel if they did not have asthma

Exercise Details: Time Allocation: 5 minutes

Tools: Participants will have been asked to bring one picture (clipped from a magazine, from the Internet or other source) that portrays how they felt when they first found out through diagnosis that they had severe asthma. Additionally, the Moderator will have photos to supplement and to offer for other touch points in the life map with asthma. These will be available electronically for telephone interviews.

Moderator Guide

The moderator will explain the objective of the exercise. The start of the asthma journey, explained by the participant, will be captured on the brown paper and the moderator will probe selected key phases to gain the required insights.

Step 1: Introduction

1. Session Objective:

To gain a better understanding about the patient's experience through their voicing a personal description of their journey with severe asthma and how they are affected by severe asthma and their needs and priorities in asthma management.

2. Outline Logistics:

- Collect Consent Forms (given at the beginning of their interview);
- Confidentiality principles outlined;
- Taping of the session: The interview will be video/audio recorded (unless participant agrees only to audio taping as indicated in the completed consent form). Taping will be done to ensure accuracy and reduce the chance of misinterpreting the conversation;
- Duration of Session (30 minutes).

Step 2: Preparatory Homework Review

Exercise:

Moderator will ask the participant to show their picture (or choose one) and share one word that describes how they felt when they first found out that they had severe asthma.

Probe Questions:

- Why this particular picture?
- How does this picture express what you felt when you were diagnosed?

Journey Mapping

Exercise objective

To understand the participant's journey of living with severe asthma. Identify the steps taken along the journey since diagnosis and the participant's various experiences through their personal description of their journey with severe asthma. This will include the impact of severe asthma on the quality of their life, current treatment and their compliance of medication, doctor-patient relationship and the barriers/challenges to care encountered along their journey.

Exercise Details: Time allocated: 25 minutes

Tools: Brown paper to capture the journey, coloured markers

Targeted Insights

Identify:

1. When was the patient first diagnosed with asthma? When were they told they had severe asthma? How long did diagnosis take?
2. Who diagnosed them? What tests were done? Have they ever had access to a certified asthma/respiratory educator?
3. How has their asthma impacted the quality of their life – family life, working life, recreational life?
4. How compliant are they with their medication? Do they have a written Asthma Management Plan? How closely do they follow it?
5. How often do they have asthma attacks? How many times have they been hospitalized?
6. What is their relationship with health-care professionals like? Who is the most helpful?
7. What do they perceive the barriers/challenges they face in managing their asthma?

Exercise Description

The moderator will explain the objective of the exercise. Particular focus should be on the key objectives outlined and identify the targeted insights. The journey explained by the participant will be captured on the brown paper and the moderator will probe into each key phase to gain the required insights.

Moderator Guide

Exercise: participants will be asked to describe their journey with severe asthma from the 1st time they were diagnosed. The moderator will capture key steps along the journey and use the key objectives and probing questions below to capture the targeted insights

1. Moderator will introduce exercise.

2. Participant will describe their journey and identify key incidents, steps, changes experienced.

Key Objectives	Probing Questions
Asthma History	<ul style="list-style-type: none">• At what age were you first diagnosed with asthma?• When were you told you have severe asthma? Who diagnosed you?• When was your last asthma attack/incident/exacerbation?• Last hospital stay because of your asthma?• Last medical doctor appointment?• Who is your primary source of care: family doctor, specialist (what type), hospital, community clinic, Asthma Educator, pharmacist? Your secondary source of care?
Impact on their Quality of Life	<ul style="list-style-type: none">• Can you describe your quality of life? Is there a picture or image here that helps you describe it?• How has your asthma impacted your family life, social life, work life, financial life, etc.?• Do you consider your asthma controlled or uncontrolled?• Thinking about life right now, how does having severe asthma affect your life style? Are there things that you can no longer do/are restricted in doing because of asthma? How do you feel about this?• Has having asthma impacted relationships and, if so, how?

Key Objectives	Probing Questions
Current Treatment/ Medication Compliance	<ul style="list-style-type: none"> • What is your primary information source about treatments for severe asthma? • How satisfied are you with your current medications or therapies? • What tests have you had done lately regarding your asthma? • What impact does the medicine you take have on your asthma symptoms i.e., complete or only partial relief/control? How do you feel about this? • Are you taking your medication as prescribed? • What is stopping you from taking your medications in the agreed way (i.e., amount of medicine, embarrassed about taking it, simply forget to take it, don't think it helps, worried about side effects, interferes with other activities)? • Do you have any concerns about the side effects of these medicines? Which side effects are most bothersome and why? • Do those concerns affect how/when you take your medicine? • How well do you control your asthma triggers: exposure to allergens? Exercise? Stress? Weight? • Who have you discussed these concerns with? How much did this help? • Are you seeking alternative treatments? Which ones? • Are you aware of newer treatments for asthma? Biologics? Bronchial Thermoplasty? • Have you asked about them and found them to be unavailable in your area or not known about by your physician?
Doctor – Patient relationship	<ul style="list-style-type: none"> • Are you able to ask him/her questions about your asthma? • Does your physician provide you with enough information to the point where you can control your asthma? • Have you ever seen a specialist (Respirologist or Allergist)? Are you regularly treated by a specialist? Do you attend an asthma clinic? • Do you consider your pharmacist to be a key asthma health care professional? If yes, how do they support you? • What would you like to see more of from their primary care doctor? Your specialist? Your pharmacist? • Have you met with a Certified Asthma Educator or a Certified Respiratory Educator? Were they helpful? • Do you feel that you have all the support they need to manage your asthma (i.e., from health professionals/family/work)? • Do you feel involved in decisions about your asthma care and treatment?
Barriers/Challenges to care: <ul style="list-style-type: none"> • Obtaining information • Access to the system 	<ul style="list-style-type: none"> • How would you describe your healthcare experience with respect to your asthma? • Do you experience financial difficulties as a result of your asthma? • Have you experienced or do you feel there are any barriers to accessing the healthcare system for managing your asthma? • Does it take you a long time to see a specialist? How long? • Is the cost of your medication impacting how your asthma is controlled?

Wrap up and Close

Moderator Guide

The moderator will wrap up and close the session by asking the following questions if time is remaining:

- Is there anything else that you would like to say about living with severe asthma?
- Is there anything the Asthma Society of Canada could be doing better, or doing to help individuals like you?
- If you could ask for one thing that would make living with severe asthma easier what would it be?

The moderator will thank the participants for their time and direct any questions and/or concerns about the interview and how it is being used to the Research Lead, (*insert name*).

K. Facilitator Guide for In-Person Interview

Insert Organization Logo

*Asthma Matters: A Study of Adult Canadians Living
With Severe Asthma*

Oath of Confidentiality

I understand that as a moderator / transcriber / audio/ video assistant/ or research assistant (circle one) for a study being conducted by _____ under the supervision of _____, confidential information will be made known to me.

I agree to keep all information collected during this study confidential and will not reveal by speaking, communicating or transmitting this information in written, electronic (disks, tapes, transcripts, email) or any other way to anyone outside the research team.

Name (Print): _____ Signature: _____

Date: _____ Witness Signature: _____

L. Small online quantitative Survey

Asthma Matters: A Study of Adult Canadians Living With Severe Asthma

This first section will be included in the introduction email

Purpose of the study

The goal of this study is to gain a better understanding about the experiences of Canadian adults affected by severe asthma and their needs and priorities in asthma management. During the previous phase of this study, the Asthma Society of Canada conducted a series of interviews with Canadian Adults living with severe asthma, listening to their stories and mapping out their journeys with asthma. This online survey is designed to build on those stories, verify what we have heard and to identify further issues and areas of concern, from the patient perspective, regarding the treatment and management of severe asthma in the Canadian Healthcare system.

Procedures involved in the study

- We are asking Canadians over 18, who believe they are living with severe asthma, to complete an online survey identifying their experiences.
- The survey will take approximately 20 minutes to complete and you have a choice of not answering any questions or withdrawing at any time.

Potential Harms, Risks or Discomforts:

- There is the remote chance that identifying your personal journey about living with severe asthma may be emotional, difficult, frustrating or upsetting as you complete the survey.
- We believe that the risk of emotional upset is no greater than in everyday life.

Potential Benefits:

- There are several benefits to individuals participating in the project as well as individuals with similar conditions who might also benefit from the results of this project.
- The benefits include having Asthma Society of Canada resources and National Asthma Patient Alliance (NAPA) programs available to patients to educate them about the importance of proper asthma control and to raise public awareness about the burden of severe asthma.

Confidentiality:

- Confidentiality will be respected and no information that discloses the identity of the participant will be released or published unless required by law.
- The personal information obtained in this survey will be kept anonymous and will not be revealed or used for any other purposes except for the purpose of this project.
- The ASC assures that the information that you provide will be kept confidential and your individual answers will not be shared or presented in any way that would identify you as the source.

Participation:

Your participation in this survey is entirely voluntary and there will be no negative consequences if you refuse to participate, withdraw from it, or refuse to answer certain questions in the survey.

This study has been reviewed by (name of Ethics Board), which is not affiliated with the research or research team, if you have any questions about your role and rights as a research participant, or have concerns, complaints or general questions about the research, please contact:

(Insert contact information for Ethics Board)

Contact for more information:

If you have any questions or concerns about the survey or how it is being used, please free to contact *(name of Project Manager)* and *(insert contact information)*.

Opening section of the online survey

The goal of this study is to gain a better understanding about the experiences of Canadian adults affected by severe asthma and their needs and priorities in asthma management. During the previous phase of this study, the Asthma Society of Canada conducted a series of interviews with Canadian Adults living with severe asthma, listening to their stories and mapping out their journeys with asthma. This online survey is designed to build on those stories, verify what we have heard and to identify further issues and areas of concern, from the patient perspective, regarding the treatment and management of severe asthma in the Canadian Healthcare system.

Please note that while there is the remote chance that identifying your personal journey about living with severe asthma may be emotional, difficult, frustrating or upsetting as you complete the survey, we believe that the risk of emotional upset is no greater than in everyday life.

By participating in this survey, you are helping inform the development of resources and programs of the Asthma Society of Canada and National Asthma Patient Alliance (NAPA) programs which are available to patients to educate them about the importance of proper asthma control and to raise public awareness about the burden of severe asthma.

Confidentiality:

Confidentiality will be respected and no information that discloses the identity of the participant will be released or published unless required by law. The personal information obtained in this survey will be kept anonymous and will not be revealed or used for any other purposes except for the purpose of this project. The ASC assures that the information that you provide will be kept confidential and your individual answers will not be shared or presented in any way that would identify you as the source.

Your participation in this survey is entirely voluntary and there will be no negative consequences if you refuse to participate, withdraw from it, or refuse to answer certain questions in the survey.

Survey questions

This first section will help us identify if you fit the parameters of this study.

1. Are you or is any member of your family employed by or in any way affiliated with? (Please check all that apply)
 - An ad agency/public relations firm/marketing research firm
 - Any government agencies involved with food, drug, environmental or trade regulation
 - A manufacturer/retailer or wholesale distributor of pharmaceuticals
 - None of the above

Terminate if check any option other than “None of the above”
2. How many years have you been living in Canada
 - Less than 5 years – **Terminate**
 - 5 plus years
3. In which age group are you?

Under 18 - Terminate

<input type="checkbox"/> 19 to 24	<input type="checkbox"/> 40 to 49	<input type="checkbox"/> 65 to 79
<input type="checkbox"/> 25 to 29	<input type="checkbox"/> 50 to 59	<input type="checkbox"/> Over 80 - Terminate
<input type="checkbox"/> 30 to 39	<input type="checkbox"/> 60 to 64	<input type="checkbox"/> Refused
4. Have you ever been told by a health care professional that you have asthma?
 - Yes
 - No - **Terminate**
5. Are you currently prescribed medication for your asthma?
 - Yes
 - No – **Terminate**
6. What is the name of the medications you are taking for your asthma? (Please check all that apply)

<input type="checkbox"/> Pulmicort® (Budesonide)	<input type="checkbox"/> Spiriva® (Tiotropium bromide)
<input type="checkbox"/> Flovent® (Fluticasone)	<input type="checkbox"/> Onbrez® (Indacaterol)
<input type="checkbox"/> Serevent® (Salmeterol)	<input type="checkbox"/> Seebri® (Glycopyrronium)
<input type="checkbox"/> Foradil®, Oxeze® (Formoterol)	<input type="checkbox"/> Accolate® (Zafirlukast)
<input type="checkbox"/> Symbicort® (Budesonide/formoterol)	<input type="checkbox"/> Singulair® (Montelukast)
<input type="checkbox"/> Advair® (Salmeterol/Fluticasone)	<input type="checkbox"/> Prednisone
<input type="checkbox"/> Ventolin®, Apo-Salvent®, Novo Salmol®, Gen-salbutamol®, Alti-Salbutamol®, Airomir® (Salbutamol)	<input type="checkbox"/> Prednisolone (PediaPred®)
<input type="checkbox"/> Berte®, ipratropium bromide, Atrovent® (Venoterol hydrobromide)	<input type="checkbox"/> Dexamethasone (Decadron®)
<input type="checkbox"/> Bricanyl® (Terbutaline sulfate)	<input type="checkbox"/> Xolair® (Omalizumab)
<input type="checkbox"/> Alvesco® (Ciclesonide)	<input type="checkbox"/> TheoDur®
<input type="checkbox"/> QVAR® (Beclomethasone dipropionate)	<input type="checkbox"/> Uniphyll®
<input type="checkbox"/> Zenhale® (Mometasone furoate/formoterol)	<input type="checkbox"/> Phyllocontin®
<input type="checkbox"/> Asmanex® (Mometasone Furoate)	<input type="checkbox"/> TheoLair®
	<input type="checkbox"/> Other
	<input type="checkbox"/> None of the above – Terminate
7. In the past 4 weeks, how often have you used your reliever or your rescue medication because of your asthma?
 - Less than 4 days/week – **Terminate**
 - Several times a day
 - More than 4 days/week

8. How often have you used or required an oral or systemic corticosteroid because of your asthma exacerbations?

Never – Terminate

Once or more per year

One a month

Once a week

Please tell us a bit about yourself

9. What is your Gender?

Male

Female

10. Please specify which Province or Territory you reside in:

Alberta

Labrador

Prince Edward Island

British Columbia

Northwest Territories

Quebec

Manitoba

Nova Scotia

Saskatchewan

New Brunswick

Nunavut Territories

Yukon Territories

Newfoundland and

Ontario

11. What are the first 3 digits of your postal code?

12. Please tell us about your city or community.

Small population centre, with a population of between 1,000 and 29,999

Medium population centre, with a population of between 30,000 and 99,999

Large urban population centre, consisting of a population of 100,000 and over

13. How would you describe your community?

Urban

Suburban

Rural

Remote

14. What is your highest educational level achieved?

Elementary School

College degree

Post-Graduate degree

High school diploma

University degree

Rather not say

15. Which one of the following best describes your employment situation?

Employed full-time

Unemployed

Stay at home parent

Employed part-time

Not working due to
disability

Student

Retired

Rather not say

16. Which of the following income groups would best describe your annual household income?

Less than \$19,999

\$50,000 – 69,999

150,000 or more

\$20,000 – 29,999

\$70,000 – 89,999

Rather not say

\$30,000 – 39,999

\$90,000 – 119,999

\$40,000 – 49,999

\$120,000 – 149,999\$

Now we'd like to talk a bit about your experience of living with asthma

17. When were you diagnosed with asthma?

- More than 1 year Less than 1 year

If Less than 1 year, for how many months have you been diagnosed with asthma?

- | | | |
|-----------------------------------|-----------------------------------|-------------------------------------|
| <input type="checkbox"/> 1 month | <input type="checkbox"/> 5 months | <input type="checkbox"/> 9 months |
| <input type="checkbox"/> 2 months | <input type="checkbox"/> 6 months | <input type="checkbox"/> 10 months |
| <input type="checkbox"/> 3 months | <input type="checkbox"/> 7 months | <input type="checkbox"/> 11 months |
| <input type="checkbox"/> 4 months | <input type="checkbox"/> 8 months | <input type="checkbox"/> Don't know |

If More than 1 year, for how many years have you been diagnosed with asthma?

- | | |
|----------------------------------------------|----------------------------------------------|
| <input type="checkbox"/> Less than 10 years | <input type="checkbox"/> From 20 to 34 years |
| <input type="checkbox"/> From 10 to 15 years | <input type="checkbox"/> More than 34 years |
| <input type="checkbox"/> From 15 to 20 years | <input type="checkbox"/> Don't Know |

18. At what age were you first diagnosed with asthma?

- | | |
|--------------------------------------------------------------|--------------------------------------------------------------|
| <input type="checkbox"/> Before I was 12 years old | <input type="checkbox"/> Between the ages of 30 and 50 years |
| <input type="checkbox"/> Between the ages of 12 and 20 years | <input type="checkbox"/> After the age of 50 years |
| <input type="checkbox"/> Between the ages of 21 and 30 years | |

19. Who initially or first diagnosed your asthma?

- | | | |
|-----------------------------------------------------------------------------|--------------------------------------------------|--------------------------------------------------|
| <input type="checkbox"/> General Practitioner/
Family Medicine Physician | <input type="checkbox"/> Respiriologist | <input type="checkbox"/> Intern/Medical Resident |
| <input type="checkbox"/> Allergist | <input type="checkbox"/> Cardiologist | <input type="checkbox"/> Technician at clinic |
| <input type="checkbox"/> Respiratory Specialist | <input type="checkbox"/> Myself (self-diagnosis) | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Pediatrician | <input type="checkbox"/> Obstetrician | <input type="checkbox"/> Other? |

20. Prior to your diagnosis of asthma, were you referred for any breathing testing (pulmonary functions, Spirometry, Methacholine Challenge)?

- Yes No Don't Know

21. Has the healthcare professional who treats you for your asthma, ever referred you to a pulmonary function lab for a breathing test (spirometry, bronchodilator, Methacholine Challenge Test)?

- Yes No

22. How strongly do you agree or disagree with the following statements? Please use a scale of 1 to 5 where 1 means you totally disagree and 5 means you totally agree with the statement. [1- Totally disagree, 2- somewhat disagree, 3 neither disagree nor agree, 4 somewhat agree, 5 – Totally agree]

- a. Asthma is a chronic disease
- b. Asthma symptoms come on suddenly, with little warning
- c. Asthma, if not controlled, will lead to permanent lung damage
- d. Asthma treatment should [can] be stopped when the symptoms go away
- e. Exercise is an asthma trigger, so one should not exercise (strenuously)
- f. Asthma symptoms come on gradually over time and get worse, if not treated

33. In the past 12 months, have you had to miss work or school because of asthma?
 Yes No
If YES, approximately how many days did you miss in the past year?
 1 4 7 10
 2 5 8
 3 6 9
34. Has your asthma affected your work or school performance over the past year?
 Yes No
If YES, would you say your asthma affected your work or school performance
 A great deal Not at all
 Somewhat Don't Know
 Just a little
35. In the last 3 months, have you or a family member missed social engagements, been absent from school or work, or avoided participating in activities or sports because of your asthma symptoms?
 Yes No Don't Know
36. In the last 3 months, have you or a family member ever experienced trouble sleeping because of your asthma symptoms such as wheezing, persistent cough, shortness of breath or tightness of the chest?
 Yes No Don't Know
37. How often do you feel that your asthma prevents you from participating in outdoor and/or physical activities?
 Very often Occasionally Not very often Not at all
38. Has your asthma ever caused you to feel stigmatized or isolated?
 No Sometimes Yes quite often
39. Do you feel living with asthma interferes with the quality of your social interactions with others?
 No Sometimes Yes quite often
40. How many asthma attacks have you had in the past 6 months?
 0 3 More than 5
 1 4 More than 10
 2 5 Don't know
41. How many asthma attacks have you had in the past 12 months?
 0 3 More than 5
 1 4 More than 10
 2 5 Don't know
42. For the most recent asthma attack you had, what action was taken?
 I took my rescue medication I was taken/went to an Emergency room
 I went to see a general practitioner (doctor) I was admitted to the hospital

43. In the last 3 months did you/your family member have to go to an emergency clinic or seek an appointment with your doctor because of your asthma symptoms?
- Yes No Don't Know

This section will tell us some more about your experience with asthma medications and treatment

44. On average, how often do you use your asthma reliever medication (used to quickly alleviate asthma symptoms)?
- Once a day Once a week Don't know
 Twice a day Twice a week
 Three times a day Three times a week
45. What is the name of the medications you are taking for your reliever medication? (Please check all that apply)
- | | |
|--------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------|
| <input type="checkbox"/> Pulmicort® (Budesonide) | <input type="checkbox"/> Spiriva® (Tiotropium bromide) |
| <input type="checkbox"/> Flovent® (Fluticasone) | <input type="checkbox"/> Onbrez® (Indacaterol) |
| <input type="checkbox"/> Serevent® (Salmeterol) | <input type="checkbox"/> Seebri® (Glycopyrronium) |
| <input type="checkbox"/> Foradil®, Oxeze® (Formoterol) | <input type="checkbox"/> Accolate® (Zafirlukast) |
| <input type="checkbox"/> Symbicort® (Budesonide/formoterol) | <input type="checkbox"/> Singulair® (Montelukast) |
| <input type="checkbox"/> Advair® (Salmeterol/Fluticasone) | <input type="checkbox"/> Prednisone |
| <input type="checkbox"/> Ventolin®, Apo-Salvent®, Novo Salmol®, Gen-salbutamol®, Alti-Salbutamol®, Airomir® (Salbutamol) | <input type="checkbox"/> Prednisolone (PediaPred®) |
| <input type="checkbox"/> Berotec®, ipratropium bromide, Atrovent® (Venoterol hydrobromide) | <input type="checkbox"/> Dexamethasone (Decadron®) |
| <input type="checkbox"/> Bricanyl® (Terbutaline sulfate) | <input type="checkbox"/> Xolair® (Omalizumab) |
| <input type="checkbox"/> Alvesco® (Ciclesonide) | <input type="checkbox"/> TheoDur® |
| <input type="checkbox"/> QVAR® (Beclomethasone dipropionate) | <input type="checkbox"/> Uniphyll® |
| <input type="checkbox"/> Zenhale® (Mometasone furoate/formoterol) | <input type="checkbox"/> Phyllocontin® |
| <input type="checkbox"/> Asmanex® (Mometasone Furoate) | <input type="checkbox"/> TheoLair® |
| | <input type="checkbox"/> Other |
| | <input type="checkbox"/> None of the above |
46. During the past week, how many times did you need to take your reliever medications for relief of coughing, wheezing, chest tightness or shortness of breath?
47. On average, how often do you use your asthma controller medication (medications which help to treat the underlying inflammation of the airways)?
- Once a day Once a week Don't know
 Twice a day Twice a week
 Three times a day Three times a week
48. What is the name of the medications you are taking for your controller medication? (Please check all that apply)
- | | |
|--------------------------------------------------|--------------------------------------------------------|
| <input type="checkbox"/> Pulmicort® (Budesonide) | <input type="checkbox"/> Serevent® (Salmeterol) |
| <input type="checkbox"/> Flovent® (Fluticasone) | <input type="checkbox"/> Foradil®, Oxeze® (Formoterol) |

- Symbicort® (Budesonide/formoterol)
- Advair® (Salmeterol/Fluticasone)
- Ventolin®, Apo-Salvent®, Novo Salmol®, Gen-salbutamol®, Alti-Salbutamol®, Airomir® (Salbutamol)
- Berotec®, ipratropium bromide, Atrovent® (Venoterol hydrobromide)
- Bricanyl® (Terbutaline sulfate)
- Alvesco® (Ciclesonide)
- QVAR® (Beclomethasone dipropionate)
- Zenhale® (Mometasone furoate/formoterol)
- Asmanex® (Mometasone Furoate)
- Spiriva® (Tiotropium bromide)
- Onbrez® (Indacaterol)
- Seebri® (Glycopyrronium)
- Accolate® (Zafirlukast)
- Singulair® (Montelukast)
- Prednisone
- Prednisolone (PediaPred®)
- Dexamethasone (Decadron®)
- Xolair® (Omalizumab)
- TheoDur®
- Uniphyll®
- Phyllocontin®
- TheoLair®
- Other
- None of the above

49. Do you use a single maintenance and reliever therapy (SMART)?

- Yes No Unsure

50. On how many separate occasions in the last 12 months, if any, have you taken prednisone? (An occasion would be a single course of treatment)

51. When you take the medicines that your doctor currently prescribes, how important are each of the following to you? Please use a scale of 1 to 5 where 1 means not at all important and 5 means very important. [1- Not at all important, 2- not very important, 3 – neither unimportant nor important, 4 somewhat important, 5 – very important]

- a. How often you take it
- b. Taking it in private
- c. Convenience
- d. Cost
- e. Side effects that will come on slowly but last a long time
- f. Side effects that last a short time and then pass
- g. The way you take it (inhaler, pills etc.)
- h. How quickly it works
- i. How completely it stops your symptoms

52. Now thinking about how you take your medicines, in an ideal world how much would you like each of the following ways of taking your medicine. For the following options, please use a scale of 1 to 5 where 1 means you don't like it at all and 5 means you like it a lot? [1- Don't like it at all, 2- somewhat dislike it, 3 neither dislike nor like it, 4 somewhat like it, 5 – Like it a lot]

- a. A pill once a day
- b. An injection once a day
- c. An inhaler once a month
- d. A pill once a month
- e. An injection once a month

53. Which of the following methods would you prefer?

- a. A pill once a day
- b. An injection once a day
- c. An inhaler once a month
- d. A pill once a month
- e. An injection once a month

54. Do you use any asthma related equipment such as a spacer or peak flow meter?

- Yes No

If NO, why not?

- I don't think they are useful I find it difficult to find them
 I can't afford one I was never given/prescribed one
 I don't know anything about them

If YES, what type of related equipment do you use?

55. How important are the following outcomes to you as a result of successfully managing your asthma? Please use a scale of 1 to 5 where 1 means not at all important and 5 means very important. [1- Not at all important, 2- not very important, 3 – neither unimportant nor important, 4 somewhat important, 5 – very important]

- | | |
|-------------------------------------------------------|---------------------------------------|
| a. No hospital admissions or emergency room visits | e. No daytime symptoms |
| b. Able to do normal things (housework, walking, etc) | f. No nighttime symptoms |
| c. Do not need reliever treatment | g. Improved breathing test results |
| d. Able to exercise without symptoms | h. Able to go to work |
| | i. Reduce amount of asthma medication |

56. Please rate the following statements using a scale of 1 to 5 where 1 means do not agree at all and 5 means highly agree. [1- Do not agree at all, 2- somewhat disagree, 3 – neither disagree nor agree, 4 somewhat agree, 5 – highly agree]

- a. I would like to take asthma medication more often but it is too expensive
- b. I take my asthma medication exactly as instructed by my doctor
- c. I only take my asthma medication when I have an asthma attack
- d. My pharmacist suggests less costly alternatives compared to what is prescribed by my doctor for my asthma

57. Have you ever skipped filling a prescribed asthma medication because you were not able to afford it?

- Yes No

58. Have you ever experienced any of the following signs or symptoms in the last 6 months (Please check all that apply)

- Yes, thrush in the mouth or throat or white, sore patches
- Yes. Hoarseness/voice alteration
- Yes, Sore/irritated throat
- No never experienced anything that is mentioned above

If you have had any of the signs and symptoms listed above, what did you do?

- Start Gargling with water after taking inhaled steroid
- Visited my doctor to check out side effects
- Made no changes to my schedule of treatment
- Used my asthma medication less frequently
- Switched to another medication
- Stopped taking my asthma medication
- Other
- Nothing
- Don't know

59. Have you ever not taken your prescribed medications?

Yes

No

If yes, how many days a week have you missed?

I usually miss 2 days/week

I rarely miss a day

I miss 2-4 days/week

Don't know

I miss more than 4 days/week

60. What is the main reason you might stop or not take the correct dosage?

Forgot/Didn't have it with me

Doctor told me to stop

No reason

Only took as needed

Side effects/reactions

I was asleep/unconscious

Cost/couldn't afford it

Don't want to be dependent

Did not refill prescription/ran out

Other

Didn't work/had no effect

I did not need/feel better

Health reasons/sick

Don't know

No time/too busy

61. Who is your primary source of care?

Family doctor

Community clinic

Respiratory Specialist

Certified Asthma or Respiratory Educator

Respirologist

Pharmacist

Hospital

Other _____

62. Who do you feel is best suited to be your primary source of care?

Family doctor

Community clinic

Respiratory Specialist

Certified Asthma or Respiratory Educator

Respirologist

Pharmacist

Hospital

Other _____

63. How comfortable are you talking with a doctor, who treats your asthma, about the following topics?

For each topic, please use a scale of 1 to 5 where 1 means not at all comfortable and 5 means very comfortable. [1- Not at all comfortable, 2- not very comfortable, 3 – neither uncomfortable nor comfortable, 4 somewhat comfortable, 5 – very comfortable]

a. Talking about your medication concerns

b. Talking about making medication changes or taking other therapies that were prescribed by a naturopath or alternative practitioner

c. Talking about the cost of medications

d. That you need or want more information

e. That you need or want a referral to a specialist

64. Concerning the doctor who treats your asthma, how strongly do you agree or disagree with the following statements? Please use a scale of 1 to 5, where 1 means you totally disagree and 5 means you totally agree with the statement. [1- Totally disagree, 2- somewhat disagree, 3 – neither disagree nor agree, 4 somewhat agree, 5 – totally agree]

- a. The doctor knows a lot about asthma
- b. The doctor involves me in making the important decisions about my asthma
- c. The doctor gives me enough time to talk about my asthma
- d. The doctor takes time to make sure that my medicines are right for my life and my asthma
- e. The doctor makes sure I am using my medication properly

65. In the past year has any health care professional:

- a. Asked you to demonstrate how you take your inhaler medication?
 Yes No Unsure
- b. Discussed the benefits of a written asthma action plan?
 Yes No Unsure
- c. Asked what your concerns or fears are about taking asthma medication?
 Yes No Unsure
- d. Discussed the benefits and risks of an inhaled steroid medication?
 Yes No Unsure

66. Has the doctor who treats you for your asthma, ever referred you to the following?

- a. An allergist or immunologist for allergy testing?
 Yes No Unsure
- b. A respirologist or pulmonologist (lung specialist)?
 Yes No Unsure
- c. An asthma education program?
 Yes No Unsure
- d. A pulmonary function lab for a breathing test (spirometry)?
 Yes No Unsure

67. Do you have regular access to a health care worker when it comes to your asthma?

- Yes No
- If yes, which of the following health care workers do you have access to?
- Family doctor Hospital or Respiratory Educator
- Respiratory Specialist Community clinic Pharmacist
- Respirologist Certified Asthma Other _____

68. Do you have access to pulmonary physiology labs?

- Yes No

69. In obtaining asthma medication, would you prefer to buy brand name product or less costly alternative generic products?

- Less costly alternatives or generics No preference
- Brand name products Don't know

70. If your doctor suggested, a brand name and the pharmacist suggested an alternative generic, which would you prefer to take?
- Less costly alternatives or generics No preference
 Brand name products Don't know
71. How is the cost of your medication covered? (check all that apply)
- Provincial government drug plan
 Full private coverage provided by my employer
 Partial private coverage provided by my employer
 Private Health Insurance purchased by me
 I pay for my own asthma medications at the pharmacy as needed
72. Do you feel that your current method of covering your asthma drug costs provides you with sufficient drug treatments to control your asthma symptoms or do you feel you need more?
- Sufficiently covered Need more Don't know
73. Are government and/or private payer plans doing enough to provide patients with adequate coverage for medications to treat their asthma?
- Yes No Don't know
74. What else can government and/or private payer plans do to provide patients with adequate coverage for medications to treat their asthma? (check all that apply)
- Cover more of the cost/all of the cost Equal coverage for everyone
 Lower cost/price/deductible Improve the diagnosis
 Assist/Better coverage for low income families Access to brand names
 Cover more/better medication Offer more trials/samples
 Create awareness/more information Take money from smokers
 Need to invest more money into asthma More research/New medications
 Better care/coverage for seniors Other
 Coverage for children Nothing/doing nothing
 Prevention/cleaner environment Don't know
 Coverage for equipment
75. Are you exploring or taking alternative treatments?
- No Yes
 If yes, which ones?
76. Are you exploring or taking new treatments such as biologics or bronchial thermoplasty?
- No Yes
77. Do you feel you have access to information and services for newer treatments for severe asthma?
- Yes No Not sure
78. Have you ever been denied coverage for any new treatments for severe asthma by your insurance company or the exceptional access program?
- Yes No Not sure

79. What is your primary information source about treatments for severe asthma?

Thank you for completing this survey. Your participation will help us better understand the experience of living with asthma, identify further issues and areas of concern, from the patient perspective, regarding the treatment and management of severe asthma in the Canadian Healthcare system.

Disqualification message:

Thank you for your interest in this study, however at this time you did not meet the requirements to participate in this study. However, we often conduct market research studies and would like to keep your email address on file for future opportunities. If you are interested potentially participating in a future market research study please provide us with your email address below.



Asthma.caTM

Asthma Society of Canada

The Asthma Society of Canada is the only national, patient-driven charity, solely devoted to enhancing the quality of life for people living with asthma and respiratory allergies.

For more than 40 years, the Asthma Society of Canada has proudly served as the national voice for Canadians living with asthma. We empower patients with evidence-based information, education programs and support asthma research in Canada.