



## **FINAL REPORT**

### **A SHARED VISION:**

**Ensuring quality of life for adults and children with asthma and allergies  
in First Nations and Inuit communities in Canada**

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### **To:**

Assembly of First Nations/National Indian Brotherhood

### **By:**

Asthma Society of Canada

## Table of Contents

<b>Table of Contents</b> .....	<b>1</b>
<b>Acknowledgements</b> .....	<b>2</b>
<b>Executive Summary</b> .....	<b>3</b>
<b>Introduction and Background</b> .....	<b>4</b>
<b>Organization of the Report</b> .....	<b>5</b>
<b>Section 1: Research Design and Methods</b> .....	<b>5</b>
<b>Section 2: Environmental Scan</b> .....	<b>6</b>
<i>Population Characteristics</i> .....	6
<i>Population Distribution</i> .....	7
<i>Living Situation</i> .....	7
<i>Burden of Illness</i> .....	8
<i>Summary</i> .....	12
<b>Section 3: Results from Interview Data Analysis</b> .....	<b>12</b>
<i>Community Health</i> .....	12
<i>Community Resources</i> .....	15
<i>Burden of Illness</i> .....	17
<i>Community Expertise</i> .....	18
<b>Section 4: Results of Focus Group Analysis</b> .....	<b>20</b>
<i>Methods</i> .....	20
<b>Key Themes</b> .....	20
Theme 1- <i>Lack of Access to Culturally Appropriate Asthma/Allergy Care and Education</i> .....	20
Theme 2- <i>Acknowledging the Risk</i> .....	23
Theme 3- <i>Lack of Community Empowerment</i> .....	25
<b>Section 5: Conclusions and Recommendations</b> .....	<b>26</b>
References.....	30
APPENDICES .....	35
Appendix 1: Survey Questions .....	35
Appendix 2: Focus Group Questions .....	37

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## **Executive Summary**

The prevalence of asthma and related allergies in Canada and much of the western industrialized world has increased substantially in the last few decades. In the development of a National Lung Health Framework for Canada, key stakeholders are concerned that the health needs of Canada's First Nations and Inuit peoples are addressed. These concerns relate specifically to the prevalence of asthma and related allergies in these populations. While the data are not as robust as we would like them to be, there are preliminary indications that the overall prevalence may be higher. Even if the prevalence of allergies among First Nations children is similar to that of children in the general population in Canada (12.2% and 16.4%, respectively), less than one third of First Nations children with allergies are receiving treatment. Issues of access to health care therefore may complicate the situation further as First Nations children and families try to cope with and seek treatment for asthma and related allergies. It is difficult to assess the extent of the circumstances because there is a lack of Inuit data in general, and specifically related to asthma and related-allergies. This exploratory study has examined the perceptions and experiences of asthma and related allergies in First Nations and Inuit communities in Canada.

Three sources of data were used to compile the findings in this report. First, an environmental scan was conducted of relevant public documents that would allow for a comprehensive description of the populations of interest. Second, focus groups were conducted in 3 First Nations and 3 Inuit communities to explore the impacts and experiences of asthma and related allergies, as well as gaps in existing services. Third, telephone interviews (n=30) were conducted with relevant community health personnel (2 per each First Nations and Inuit region). Important findings resulting from this report include prevalence, impacts and the need for management strategies tailored to these communities. These data have shown us that there are major gaps in family and community resources for coping with and managing asthma and related allergies. Further, there appears a lack of health care resources, opportunities and training; not surprising due to a range of access issues, including geographic access.

The findings from this analysis support five key recommendations, providing the ground work for further research in the area of First Nations and Inuit asthma and related allergies. In the context of the National Lung Health Framework, the development of culturally appropriate education and community asthma/allergy awareness is integral for improving access to asthma/allergy-related health services. Secondly, there is an acute need for a federal framework of asthma and allergy care for health care providers. In order to improve the level of diagnosis, care and management, physicians, nurses and community health workers should be encouraged to apply government asthma/allergy guidelines specific to Inuit and First Nations communities. Thirdly, key stakeholders must work together to develop a new health care delivery model for First Nation and Inuit people living with chronic conditions. A fourth recommendation involves addressing major gaps in family and community resources. Such a recommendation would encompass the implementation of programs for chronic disease prevention, health

promotion, injury prevention, infectious disease control, tobacco control and prevention, prenatal care, nutrition and obesity, and programs for asthma, lung health and related-allergies. Finally, it is essential that we begin to address the link between obesity and asthma and related-allergies by way of school-based programming.

While these recommendations are based on the evidence gathered to undertake this report, a clear take home message is the need for more research, better data, increased monitoring and surveillance, and enhanced access to care.

## **Introduction and Background**

This report is based on the findings of a research project sponsored by the Asthma Society of Canada, in collaboration with the Assembly of First Nations and the Inuit Tapiriit Kanatami. It is intended to provide recommendations for a strategy to address the burden of illness that asthma and associated allergies represent for First Nations and Inuit communities in Canada, given that there is widespread concern that they experience respiratory illness at rates higher than the Canadian population. While it may seem straightforward to report prevalence rates for asthma, it is actually rather difficult due to issues around diagnosis, lack of monitoring and surveillance, etc. It is even more difficult to provide accurate prevalence data for Canada's First Nations and Inuit peoples' issues in some cases of isolation and access to care. As a result, reported prevalence rates vary. For example, according to the Canadian Community Health Survey, asthma prevalence for the Canadian population hovers around 8%, with a rate of 13% among children 11 years and younger. However, a composite measure reported by key researchers in the area puts the range closer to 15 – 20% (Subbarao et al, 2009). While the Aboriginal Peoples Survey (2001, which includes both on and off reserve First Nations, Inuit and Metis) reports asthma levels at around 12% overall, the First Nations Regional Health Survey, 2002-03 (for on reserve only) reports an overall rate of around 11%; 15% for youth and 14% for children under 12. Finally, Statistics Canada (2007) puts the rate among our Inuit population at approximately 6% overall and levels in children similar to the Canadian population as a whole however issues of access to health care in the Arctic may be impacting these prevalence rates. Indeed, approximately 28% of Inuit children (aged 0 – 14) have contact with a family doctor at least once per year compared to 67% of children in the general population in Canada. Comparing these data across groups becomes even more difficult when we examine the wording of the question asked to elicit the response. For example, while the Canadian Community Health Survey asks about physician diagnosed asthma, the First Nations Regional Health Survey asks if a respondent has ever been told they have asthma, with no attribution specified. In summary, rates vary but the take home message remains the same: rates are concerning and potentially on the rise; further, these populations may be more at risk than others due to their exposure to well known determinants of respiratory illness, as well as documented access to care issues.

In April 2006, the Canadian Lung Association initiated the development of a National Lung Health Framework. This is in the context of the burden of illness that respiratory disease represents to Canadians. Indeed, the World Health Organization estimates that by

the year 2020, lung disease will be the third leading cause of death in the world. For Canada to respond to this impending health crisis, a comprehensive and coordinated national plan was required that could attempt to manage the social, economic, cultural and health implications of this burden. The resulting framework represents a coordinated approach to prevention and management of respiratory disease and is intended to inform policy, research, innovation, education and leadership in the area of Canadian lung health.

The findings presented in this report will feed into the Lung Health Framework, as well as inform health care providers, asthma educators and the general public about issues of illness and access with respect to asthma and associated allergies among Canada's First Nations and Inuit peoples in order to actualize a radical improvement in the quality of life of those impacted.

## **Organization of the Report**

The report is divided into five sections. Section one briefly describes the methods used to undertake the collection of data and information reported on in the document. Section two describes the results of an environmental scan of key documents that allow a comprehensive description of the populations of interest (i.e., demographics, geographic distribution, living situation, burden of illness). Section three links determinants with the populations of interest while section four presents the results of focus groups and interviews with key informants in both First Nations and Inuit communities about the experiences and burdens associated with asthma and allergies. Section five concludes the report with recommendations linking back to the National Lung Health Framework.

### **Section 1: Research Design and Methods**

The Asthma Society of Canada worked with the project Steering Committee to identify a researcher that had both the network and the skills to undertake the study as described. Kim Bulger was recommended and thus chosen as the lead on the project, and mandated with the task of collecting the data.

Three sources of data were used to compile the findings in this report. First, an environmental scan was conducted of relevant public documents that would allow for a comprehensive description of the populations of interest. This information includes demographics, geography, living situation, and burden of illness. Second, 6 focus groups were undertaken in the spring of 2008 in 3 First Nations and 3 Inuit communities in order to explore the impacts and experiences of asthma and related allergies, as well as gaps in existing services. Focus group participants included members of advisory committees, health care providers, parents and school principals. Third, telephone interviews (n=30) were conducted with relevant community health personnel (2 per each First Nations and Inuit region). This sample list was provided by the Assembly of First Nations (AFN) and Inuit Tapiriit Kanatami (ITK) representatives. If someone had left the organization, the

organization suggested an alternative. All interviews were conducted in the spring of 2008 by a single researcher and lasted approximately 30 minutes. All questions were open-ended.

Descriptive analyses of the quantitative survey data and qualitative analyses of the qualitative data were undertaken by researchers at McMaster University. Oral presentations of preliminary results were made to both the AFN and ITK in order to assess their sense of whether or not the results resonated with their understanding of how these issues were perceived and experienced in their relative communities. On the whole, their view was that the results ‘made sense’, with a couple of caveats. There was a sense among the ITK that asthma and related allergies would have emerged as a health issue of higher priority if the question has been targeted to children and youth. Second, the AFN felt strongly that results had to reflect the importance of cultural practices; for example, the reliance on wood burning as a source of home heating.

The research has been overseen by a working group made up of staff from the Asthma Society of Canada, representatives of the Assembly of First Nations, Inuit Tapiriit Kanatami, the Public Health Agency of Canada (PHAC) and the First Nations and Inuit Health Branch – Health Canada (FNIHB) and the AllerGen National Centre of Excellence.

It is important to note that, while informative, the study sample is not large and therefore can not represent the views of all relevant stakeholders. Having said that, the breadth and representativeness of the sample group provides a solid foundation for thinking about issues of respiratory health among First Nations and Inuit communities in Canada, as well as a way forward.

## **Section 2: Environmental Scan**

### *Population Characteristics*

The growth rate among Aboriginal (First Nations, Inuit and Metis) Peoples in Canada (1.8% per annum) is much higher than that of the non-Aboriginal population (less than 1%). In 2001, the Aboriginal population (of approximately 1 million) represented 3.4% of Canada’s total population. By 2017, projections indicate Aboriginal Peoples in Canada will represent over 4% of the national population. The biggest contributing factor to population growth is fertility, given that the current Aboriginal birth rate is 1.5 times the overall Canadian rate. The majority (approximately two-thirds) of Aboriginal Peoples in Canada are First Nations with Metis representing about 27% and Inuit about 5% (Statistics Canada 2005). According to a medium growth scenario, the Inuit population will have the fastest rate of growth (approximately 2.3%).

In 2006, 2.2% of the Canadian population self-identified as First Nations (approximately 700,000 individuals) while approximately 50,000 identified as Inuit; this is an increase of 26% from 1996.

The mean age of the First Nations population at the time of the last census was 25 years, compared to 22 years for the Inuit population and 40 years for the general Canadian population. Life expectancy for the First Nations population in Canada in 2006 was 69 years for men and 77 years for women; life expectancy was 65 for men and 70 for women in the Inuit population. This is low, compared to the general Canadian population (77 and 82 years for men and women, respectively). Among Inuit –inhabited populations life expectancy has decreased by one year (68 vs 67) during the period 1991 to 2001; this figure parallels the overall life expectancy rates in Canada in 1946 (Wilkins et al. 2008).

The proportion of First Nations people who can speak a native language well enough to carry on a conversation is relatively low (29%) but has remained steady from 1996 to 2006. Very few First Nations people did not speak English (1% among total population; 5% among seniors). In 2006, 64% of Inuit reported Inuktitut as their mother tongue, down 4% from 1996.

The combination of high fertility rates and increasing life expectancies means that the First Nations and Inuit populations will continue to have increasing numbers of young people, but these young people will have a larger cohort of ‘dependents’ to look after (infants and children; seniors). Prevalence of asthma and allergies will likely increase in these populations under this scenario, while related respiratory illness (e.g., Chronic Obstructive Pulmonary Disease) may increase among the older segment of the population, particularly smokers.

### *Population Distribution*

83% of the First Nations population in Canada lives in Ontario, Manitoba, Saskatchewan, Alberta and BC. Less than half the First Nations population lives on reserve; 98% of these are Status Indians. The diffuse nature of the distribution of this population may affect access to appropriate health care, as well as educational and other services related to asthma and related allergies, in addition to other health outcomes.

78% of the Inuit population in Canada is spread across four regions within Inuit Nunaat which stretches from Labrador to the Northwest Territories: Territory of Nunavut (49%), Nunavik (19%), Inuvialuit region (6 %) and Nunatsiavut (4%). The dispersed nature of this population in remote areas affected by severe weather for much of the calendar year has obvious implications for access to health care services.

### *Living Situation*

Most First Nations children live with a relative, but are much more likely to live with a lone parent, grandparent or other relative (45%) than is the case in the general Canadian population (18%). 69% of Inuit children are living with both parents, compared with 54% of the First Nations population and 82% in the rest of Canada. A partial explanation

may stem from the unique cultural practices in Inuit communities whereby informal adoption is common.

15% of the First Nations population resides in a crowded dwelling according to the 2006 census compared to 3% of the general Canadian population. A *crowded dwelling*, according to Statistics Canada, is defined as more than one person per room. Overcrowding is more common on reserve, where 26% of the population lives in overcrowded conditions (down from the 33% reported in the 1996 census). Off-reserve, 7% of First Nations live in overcrowded conditions and 31% of Inuit live in overcrowded dwellings according to the 2006 census. However, it is important to note that Inuit are four times more likely to share a dwelling with one or more families.

The census asks Canadians to report whether or not they feel their home is in need of major repairs. According to the 2006 census, the rate of homes in need of major repairs in the non-Aboriginal population was 7%. The comparable rate for First Nations was 44% (on reserve, up from 36% in 1996) and 17% (off reserve). 28% of Inuit peoples reported their home was in need of major repairs, an overall increase from 1996.

Additional data on living situation comes from the 2002/2003 Regional Health Survey undertaken among First Nations communities in Canada. Herein we learn that 22% of First Nations report no access to garbage collection, while another 9% report no access to septic or sewage services in the home. Only two-thirds of respondents to this survey felt their water was safe to drink.

All of these living situations have been shown to be determinants of health in some contexts and populations. Lone parenting can be stressful and that can impact health; so too can the conditions of overcrowding which can also affect the transmission of infectious diseases. Overcrowding can lead to the transmission of respiratory tract infections in children, resulting in the increased likelihood of developing chronic respiratory tract diseases (e.g., asthma). These situations may lead to increased allergic sensitization, increased incidence of asthma, and increased incidence of the exacerbation of asthma. Obviously, poorly maintained dwellings can lead to several health situations, both physiological and psychosocial. Older dwellings and those with dust, damp and mould have been shown to be associated with asthma and related allergies.

### *Burden of Illness*

**Asthma** is a chronic inflammatory condition of the airways characterized by recurrent symptoms of variable airflow limitation. Allergy is an important factor in lung health. Allergic rhinitis (ie. hay fever) and asthma very often occur together. Atopic dermatitis is often seen in young children who later develop asthma (Leung 2004). The risk factors for, or determinants of, asthma and related allergies (e.g., chronic rhinitis) have become the subject of much attention by researchers given substantial increases in disease prevalence over the past few decades. This research has shown firstly that there is substantial geographic variation in asthma prevalence; for example, rates in some parts of the world (e.g., Asian countries) are much lower (2 – 4%) than in other parts of the world

where rates are in the range of 15 – 20 % (e.g., UK, Canada, Australia, New Zealand). Secondly, no clear risk pattern emerges for asthma causation, although a wide range of factors have been shown to be either a determinant of or a protective mechanism for asthma and allergies. Sometimes this literature can be very confusing because of conflicting reports. For example, for many years, researchers suggested that breastfeeding of infants had a protective effect for asthma and allergies. Recent studies have shown that in fact this may not be the case. The same is true for the presence of pets in the household; some studies show that pets can exacerbate lung diseases, while others indicate they may have a protective effect. Thirdly, there is extensive discussion in the literature about the relative contribution to the ‘asthma epidemic’ of genes versus environment. The current state of thinking indicates quite rightly that the relative recency of the asthma epidemic would rule out ‘genes’ as the primary contributing factor; in brief, human genes just don’t change that fast. This conclusion leads us to point the finger at environment; indeed, it plays a major role, but given that genetics does play some role (i.e., asthma and allergies are much more prevalent in children of parents with asthma or allergy), researchers now suggest that genes and environment are working together to affect respiratory health, mediated by both innate and adaptive immunity in humans. This relationship is further complicated by the fact that environmental triggers may impact the development of asthma and related allergies at different times in life and the relevant risk factors may change over time (Subbarao et al., 2009).

In short, there is a lot we do not know about the major risk factors for asthma and allergies, but there are some important aspects of the etiology of these illnesses that we are clear on:

- Substantial evidence suggests that the early periods of one’s life (in *utero*, early infancy, pre-school years) are the primary developmental periods for asthma and related allergies.
- While heredity plays a very important role in the determination of asthma and allergies, so too does the environment (i.e., indoor and outdoor air, including both air pollution and especially environmental tobacco smoke).
- Some groups have been shown to be more vulnerable to asthma and related allergies, typically those with lower levels of socioeconomic status.

Gender also plays an important role. For example, while rates of asthma – particularly severe asthma – are higher in boy children than girl children, boys are much more likely to ‘out grow’ their asthma, and girls much more likely to develop asthma at the onset of puberty. Some researchers suspect a link with obesity.

Typically, asthma and related allergies can be managed with medication, good lifestyle choices, and the avoidance of triggers (e.g., environmental tobacco smoke, dust, moulds). However, according to the Asthma Society of Canada website ([www.asthma.ca](http://www.asthma.ca)), about 500 Canadians die each year from asthma. Further, this burden of illness has substantial economic impacts on Canadian society; the Canadian Lung Association ([www.lung.ca](http://www.lung.ca)) estimates that respiratory diseases cost the Canadian economy approximately \$154 billion dollars annually.

A problem arises in the attempt to characterize the burden of illness for First Nations and Inuit communities in Canada, and this relates to a lack of data. Using what data we do have, as well as research literature characterizing similar populations, and extrapolating (cautiously) from what we know of the determinants of asthma and related allergies, we see a picture emerging that galvanizes the need for further investigation.

Worldwide, indigenous groups have been shown to be disproportionately represented at the severe end of the asthma spectrum (Chang 2007). In a study of emergency room visits for asthma and COPD, Sin et al (2002) found that Aboriginal Peoples are 2.1 times more likely to have an emergency room visit for asthma or COPD than their non-Aboriginal counterparts. Given what we know about the demographics and living situations of First Nations and Inuit communities in Canada, this may not be surprising. For example, we know that there are high rates of *tobacco use* among these communities; recent statistics indicate that the rate of smoking among First Nations people in Canada is 59%, approximately three times the rate of the general Canadian population. Smoking rates are even higher in the Inuit population with approximately 70% of both men and women reporting that they smoke on a daily basis; 62% of Inuit women who were pregnant in 2001 reported smoking on a daily basis (Inuit Statistical Profile 2007). Smoking while pregnant and early childhood exposure to environmental tobacco smoke, have been shown to be key risk factors for asthma and related allergies.

*Socioeconomic status* has consistently been shown to be related to asthma and related allergies. We know that the median income for Aboriginal Peoples in Canada ranges widely but is typically less than \$40,000 per year (compared to \$55,000 for the rest of Canada in the same year). This would lead us to suspect that rates of asthma and related allergies may be higher in First Nations and Inuit communities. While affecting access to the determinants of health (e.g., adequate housing and nutrition, etc), lower income can also affect access to care. Despite access to universal health care in Canada, Ungar and Ariely (2005) have shown that 10% of Canadian children diagnosed with asthma do not receive medication (see also Subbarao et al., 2009). Further, an investigation by Anita Kozyrskyj (2001) of access to inhaled corticosteroids (a primary treatment for asthma) revealed that children covered by the First Nations benefits programs were only 82% as likely as children from a higher socioeconomic group to receive a prescription.

We have already seen that individuals in First Nations and Inuit communities are more likely to report living in *over crowded* or *substandard housing*. Both of these may be risk factors for asthma and related allergies in these populations (see for example Lawrence and Martin 2001). For example, respiratory infections are more likely to occur when children live in substandard housing (dusty, damp, poorly heated) and more likely to pass these infections on when living in overcrowded conditions. It is well known that frequent respiratory infections in early life are a key risk factor for asthma and related allergies. However, it is important to note that there is conflicting evidence in the literature on the role of crowding and, to be blunt, dirt. That is, there is a substantial and growing literature around what is known as the 'hygiene hypothesis'. This stems from the fact that the highest rates of asthma in the world are in the western/developed nations

where we have done away with most infectious diseases, rely heavily on antibiotics, and essentially sterilize the environments in which we raise our children. There is some evidence to suggest firstly that living with many siblings has a protective factor against asthma given that exposure to microbes helps young bodies build strong immune systems. The same argument is put forth around exposure to dirt, more generally. It must be noted that this is simply a hypothesis gaining increasing recognition but it has yet to be empirically substantiated.

In addition to environmental tobacco smoke, dust and moulds, *indoor air quality* in northern First Nations and Inuit communities can also be impacted by the use of wood burning stoves for heating, as well as activities related to curing and tanning. Guggisberg (2003) undertook a study of 400 households in Deline, NWT in order to examine the relationship between wood smoke and respiratory symptoms. He found that women who smoked, were exposed to wood smoke, and engaged in curing and tanning activities reported statistically significantly higher rates of respiratory symptoms than the comparison group. No significant relationships were found for males.

*Life stress* may also contribute to the development and expression of asthma and related allergies. This can be brought on by many factors – personal, emotional, economic. A growing body of evidence also links maternal stress with childhood asthma. We know that many First Nations and Inuit children are much more likely to live with a lone parent, grandparent or other relative (45%) than is the case in the general Canadian population (18%). Recent studies show that children whose caregivers report high levels of stress and have difficulties parenting are at greatest risk for asthma (Klinnert et al., 1994). Further, prolonged exposure to maternal distress during the first seven years of life has been shown to be associated with a 1.3-fold increased risk of asthma diagnosis (Kozyrskyj et al., 2008).

While the links with asthma and *obesity* are not yet well understood, there is an emerging literature which points to a clear association (see Ford 2005). In 2005, 35% of Canadian adults were overweight; 24% were obese. In 2002-03, 36% of First Nations people living on reserve were overweight; 36% were obese. These higher rates of obesity among First Nations translate down to children and youth, with rates two to three times higher than children and youth in the general Canadian population. There is also evidence of an association between GERD (gastroesophageal reflux disease) and asthma; asthma treatment has been shown to also treat symptoms of GERD (Harding, 2005). There is also evidence to support the link between asthma and allergies and sleep disorders (Léger, 2006)

### *Health Care Services*

Inuit receive most of their health care services from provincial or territorial governments either directly or through transfer or land claim agreements. For specific initiatives, Health Canada's First Nations and Inuit Health Branch allocates funding to health programs and services for on-reserve and northern Inuit peoples, including: children and

youth; chronic disease and injury prevention; communicable disease control; environmental public health and research; health governance and infrastructure support; mental health and addictions; primary care and supplementary health benefits.

*Summary*

While there is a clear need to collect more information, and have access to better quality, more timely and reliable data, this background discussion of asthma and related allergies and its associated risk factors indicates that First Nations and Inuit communities may indeed be at substantial risk. While some of the prevalence data may indicate otherwise, it is important to note that this may be the result of low levels of diagnosis and reporting, due to inadequate access to care, as opposed to actual levels of illness burden. In general, First Nations and Inuit communities are reporting inadequate access to care. For example, a Statistics Canada survey indicated that over one-third of the on-reserve First Nations population felt they had poorer access to health care services than the Canadian population. Barriers to access reported by the respondent group included: no doctor/nurse available in the area; inadequate care provided; and wait lists. With respect to asthma, Sin et al (2002) reports that Aboriginal Peoples with asthma were 55% less likely to see a specialist and 66% less likely to undergo spirometry than their non-Aboriginal counterparts.

The primary data collected from the focus groups and interviews, reported on in the next section, will help us to be able to start filling in some of these gaps.

**Section 3: Results from Interview Data Analysis**

Interview data were collected through telephone interviews (n=30) with relevant community health personnel (2 per each First Nations and Inuit region) in order to better understand the burden of illness and potential mechanisms for alleviating this burden in First Nation and Inuit communities. Tables are utilized to display frequencies in the data set; data is partial and reflects only the top three most mentioned responses.

*Community Health*

In order to get a sense of whether asthma and associated-allergies is considered a community priority, respondents were asked to describe what they perceived to be the most urgent health priorities in their communities. Both First Nation and Inuit communities identified suicide as the number one priority (50%), followed closely by chronic disease (40%), including prevalence of diabetes and cancer (see Table 1). Other health priorities (7%) included asthma and related respiratory illness.

**Table 1**

<b>Top 3 Health Priorities</b> (n=30)		
<b>First Nations</b> (n=15)	<b>Inuit</b> (n=15)	<b>Total</b> (n=30)
1. Suicide (60%)	1. Suicide (40%)	1. Suicide (50%)

2. Chronic disease (33%)	2. Chronic disease (47%)	2. Chronic disease (40%)
3. Other (7%)	3. Other (7%)	3. Other (7%)

In the context of asthma itself, respondents were undivided in what they perceived to contribute to high rates of asthma (as described in the environmental scan) in their community (see Table 2). 40% of respondents in both First Nation and Inuit communities identified air quality as the most central factor leading to high rates of asthma. Overall, 30% of respondents indicated the prevalence of both poor housing conditions and tobacco use. Taken together, these three factors were thought to account for the high rates of asthma in these communities.

**Table 2**

<b>Factors contributing to high rates of asthma</b> (n=30)		
<b>First Nations</b> (n=15)	<b>Inuit</b> (n=15)	<b>Total</b> (n=30)
Air quality (40%)	Air quality (40%)	Air quality (40%)
Tobacco use (40%)	Housing (40%)	Housing (30%)
Housing (20%)	Tobacco use (20%)	Tobacco use (30%)

Mechanisms linked to reducing rates of asthma correspond to factors contributing to high rates of asthma in Table 2. Addressing potential triggers of asthma in the home (57% in both communities) was seen as a strategy to mediate poor air quality shaped by dust, mold, pollen and smoking. Overcrowding and substandard housing conditions act to exacerbate situations in which families are dealing with asthma and associated-allergies. A second strategy to reduce rates of asthma was the implementation of public awareness and education, noted by 20% of respondents in First Nations and 33% in Inuit communities. Additionally, First Nations and Inuit respondents (13% in each community) acknowledged that improvement to air quality and the introduction of smoking cessation programs, respectively, would help to alleviate current rates of asthma.

**Table 3**

<b>What would help to reduce rates of asthma?</b> (n=30)		
<b>First Nations</b> (n=15)	<b>Inuit</b> (n=15)	<b>Total</b> (n=30)
Presence of potential triggers in the	Presence of potential triggers in the	Presence of potential triggers in

home (67%)	home (47%)	the home (57%)
Public awareness/education (20%)	Public awareness/education (33%)	Public awareness/education (27%)
Air quality improvement (13%)	Smoking cessation (13%)	Air quality improvement (10%)

Although asthma is considered a community-based problem, some groups of individuals are impacted more than others (as shown in Table 4). Participants from both communities (80% overall) agreed that children were most affected by asthma, and that the elderly (7%) were also significantly affected; both groups were thought to be most vulnerable to asthma and associated-allergies.

**Table 4**

<b>Who is most affected by asthma?</b> (n=30)		
<b>First Nations</b> (n=15)	<b>Inuit</b> (n=15)	<b>Total</b> (n=30)
Children (73%)	Children (87%)	Children (80%)
Elderly (7%)	Elderly (7%)	Elderly (7%)
Other (13%)	Don't know (6%)	Other (7%)

When respondents were asked to describe existing barriers to accessing community resources, it was obvious there is a lack of culturally appropriate materials to increase public awareness and education (see Table 5). While 60% of First Nations and 40% of Inuit participants noted this barrier, another 20% (overall) felt that the overburdened health care system hindered access to asthma and allergy-related resources. 17% (overall) of respondents indicated that a transportation and jurisdiction policy also acted as an obstacle to pertinent resources.

**Table 5**

<b>Existing barriers to accessing resources</b> (n=30)		
<b>First Nations</b> (n=15)	<b>Inuit</b> (n=15)	<b>Total</b> (n=30)
Lack of culturally appropriate public awareness/education	Lack of culturally appropriate public awareness/education	Lack of culturally appropriate public awareness/education

(60%)	(40%)	(50%)
Jurisdictions/Transportation policy (20%)	Overburdened health care system (27%)	Overburdened health care system (20%)
Overburdened health care system (13%)	Jurisdictions/Transportation policy (13%)	Jurisdictions/Transportation policy (17%)

### *Community Resources*

Although respondents seemed fairly unanimous in relationship to barriers that inhibit access to asthma and allergy-related resources, they also identified some resources that *were* available in their communities. In Table 6, we can see that in both communities respondents (57% overall) suggest that hospitals, public health nurses, and community health workers were considered the number one resource for individuals and families dealing with asthma and related-allergies. Programming for pregnant women and babies was considered by 17% (overall) of respondents, while free puffers and asthma medication was also noted (by 10% of all respondents).

**Table 6**

<b>What resources exist in your community to address asthma?</b> (n=30)		
<b>First Nations</b> (n=15)	<b>Inuit</b> (n=15)	<b>Total</b> (n=30)
Hospital/Public health nurse /Community health worker (60%)	Hospital/Public health nurse /Community health worker (53%)	Hospital/Public health nurse /Community health worker (57%)
Free puffers/Medication (13%)	Programming for pregnant women/babies (20%)	Programming for pregnant women/babies (17%)
Programming for pregnant women/babies (13%)	None (13%)	Free puffers/Medication (10%)

The types of resources illustrated by respondents to help children and families identify and manage their asthma largely reflect the documented barriers to accessing resources (see Table 5). In Table 7, 67% of respondents from First Nation communities and 60% from Inuit communities indicated that culturally appropriate asthma education and awareness would help children and families to identify and manage their asthma. Another 27% (overall) suggested that the services of primary health care providers and specialists would encourage the identification and management of asthma.

**Table 7**

<b>What types of resources would help children/families identify and manage their asthma?</b> (n=30)		
<b>First Nations</b>	<b>Inuit</b>	<b>Total</b>

(n=15)	(n=15)	(n=30)
Culturally appropriate asthma education/awareness (67%)	Culturally appropriate asthma education/awareness (60%)	Culturally appropriate asthma education/awareness (63%)
Primary health care provider/Specialist (20%)	Primary health care provider/Specialist (33%)	Primary health care provider/Specialist (27%)
Don't know (13%)	Don't know (7%)	Don't know (10%)

When respondents were asked about whether families receive an asthma action plan when their children are diagnosed with asthma (Table 8), most (70% overall) indicated that they did not. Another 20% did not know whether this practice was offered; a very small proportion (7%) of respondents in First Nations communities was aware of the provision of asthma action plans upon diagnosis.

**Table 8**

<b>Are you aware if families receive an asthma action plan when their children are diagnosed?</b> (n=30)		
<b>First Nations (n=15)</b>	<b>Inuit (n=15)</b>	<b>Total (n=30)</b>
No (73%)	No (67%)	No (70%)
Don't know (20%)	Don't know (20%)	Don't know (20%)
Yes (7%)	Sometimes (13%)	Sometimes (7%)

In line with what respondents identified as barriers to accessing resources (see Table 5), in Table 9 respondents confirmed this assertion as 80% (in each community) believed that written materials for asthma are not tailored to address cultural sensitivities of communities. Another 10% (overall) felt that these materials were only somewhat tailored to cultural sensitivities, while 7% simply did not know.

**Table 9**

<b>Are written materials for asthma tailored to address cultural sensitivities of your community?</b> (n=30)		
<b>First Nations (n=15)</b>	<b>Inuit (n=15)</b>	<b>Total (n=30)</b>
No (80%)	No (80%)	No (80%)
Somewhat (13%)	Yes (7%)	Somewhat (10%)
Don't know (7%)	Somewhat (7%)	Don't know (7%)

In addition to written materials, respondents were asked to describe their knowledge of clinical guidelines of community health professionals. Nearly half (47% overall) of all respondents acknowledged that health professionals in the community were *unaware* of clinical guidelines for

asthma. 27% of the sample indicated that health professionals were only somewhat aware of clinical asthma guidelines, while another 16% simply did not know.

**Table 10**

<b>Are health professionals in your community aware of clinical guidelines for asthma?</b> (n=30)		
<b>First Nations (n=15)</b>	<b>Inuit (n=15)</b>	<b>Total (n=30)</b>
No (60%)	Somewhat (40%)	No (47%)
Don't know (20%)	No (33%)	Somewhat (27%)
Somewhat (13%)	Yes (13%)	Don't know (16%)

*Burden of Illness*

While respondents were acutely aware of the paucity of available and appropriate community resources, most did not know the scale of the burden of illness (see Table 11). 77% (between both communities) of respondents indicated that they were unaware of the number of hospitalizations in their community from asthma. Others (17% overall) did not know, while a smaller 6% (between both communities) indicated that they *were* aware of the number of community-hospitalizations.

**Table 11**

<b>Are you aware of the number of hospitalizations from your community due to asthma?</b> (n=30)		
<b>First Nations (n=15)</b>	<b>Inuit (n=15)</b>	<b>Total (n=30)</b>
No (87%)	No (67%)	No (77%)
Yes (7%)	Don't know (27%)	Don't know (17%)
Don't know (6%)	Yes (6%)	Yes (6%)

Further to Table 11, when asked whether or not a practice of tracking or collecting information of clients with asthma existed in their community, most respondents (70% overall) indicated that this process was not available (see Table 12). Another 27% of all respondents did not actually know if this practice existed, while only 3% (overall) knew of this practice.

**Table 12**

<b>Is there any practice of tracking or collecting information of clients with asthma in your community?</b> (n=30)
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<b>First Nations (n=15)</b>	<b>Inuit (n=15)</b>	<b>Total (n=30)</b>
No (73%)	No (67%)	No (70%)
Don't know (27%)	Don't know (27%)	Don't know (27%)
	Yes (6%)	Yes (3%)

### *Community Expertise*

In addition to resources (see Tables 6-10), respondents were asked to describe available community asthma expertise. More than half (60%) of all respondents indicated that there was actually no expertise available in their community, while 33% (overall) noted the availability of health care providers and ambulance personnel to address community asthma problems. A smaller 3% of respondents referred to the availability of community health/resource centres to address these types of problems in the community. Overall, only about a third of all respondents believed that there was actually expertise available to address asthma-associated problems in their community.

**Table 13**

<b>Expertise available to address asthma problems in your community?</b> (n=30)		
<b>First Nations (n=15)</b>	<b>Inuit (n=15)</b>	<b>Total (n=30)</b>
None (73%)	Health care providers/Ambulance (47%)	None (60%)
Health care providers/Ambulance (20%)	None (46%)	Health care provider/Ambulance (33%)
Community health/Resource centres (7%)	Don't know (7%)	Community health/Resource centres (3%)

An important predictor of asthma and allergy management and maintenance is the presence of family skills. Unfortunately, more than half (57% overall) of all respondents indicated that these types of skills were not present in family units. 16% (overall) of community members denoted the availability of education and information from health care providers, as well as the initial response (16%) to symptoms and asthma attacks (offered by ambulance personnel).

**Table 14**

<b>Family skills to address asthma</b> (n=30)		
<b>First Nations (n=15)</b>	<b>Inuit (n=15)</b>	<b>Total (n=30)</b>
None (47%)	None (67%)	None (57%)

Initial response to symptoms/attack (26%)	Education/Information from health care provider (20%)	Education/Information from health care provider (16%)
Education/Information from health care provider (13%)	Initial response to symptoms /attack (7%)	Initial response to symptoms /attack (16%)

Another important indicator of community resources, knowledge and education is the effective response of communities to other serious health problems. 50% of all respondents noted an effective community response to chronic disease (i.e. diabetes, cancer, etc.). In addition, another 40% (overall) felt that infectious disease was handled appropriately, while overall, a smaller 7% were unsure about the extent of how other health problems had been dealt with in their community.

**Table 15**

<b>Other serious health problems that were addressed effectively</b> (n=30)		
<b>First Nations</b> (n=15)	<b>Inuit</b> (n=15)	<b>Total</b> (n=30)
Chronic disease (60%)	Infectious disease (47%)	Chronic disease (50%)
Infectious disease (33%)	Chronic disease (40%)	Infectious disease (40%)
Don't know (7%)	Housing conditions (7%)	Don't know (7%)

In a final query, participants were asked to brainstorm about ideas that would help communities to address asthma in the future. Consistent with the sentiments of Tables 5 and 7, the majority of respondents (60%) indicated that culturally appropriate educational materials would be most effective in this capacity. In addition, regular check-ups and preventative programming was mentioned by 20% of all respondents to improve community responses to asthma. Another 10% indicated the need for relevant tobacco control by-laws to cope with circumstances related to asthma management and maintenance.

**Table 16**

<b>Ideas to help address asthma in your community</b> (n=30)		
<b>First Nations</b> (n=15)	<b>Inuit</b> (n=15)	<b>Total</b> (n=30)
Culturally appropriate educational materials (60%)	Culturally appropriate educational materials (60%)	Culturally appropriate educational materials (60%)

Regular check-ups /Preventative programming (20%)	Regular check-ups /Preventative programming (20%)	Regular check-ups /Preventative programming (20%)
Asthma workshops/Taskforce (7%)	Tobacco control by-laws (13%)	Tobacco control by-laws (10%)

## Section 4: Results of Focus Group Analysis

### *Methods*

Qualitative focus groups were conducted to elicit the perspectives of health care providers and community members on access to asthma and allergy care. Focus group data were coded according on the basis of key themes. Themes were generated both deductively from objectives outlined in the research proposal, and inductively as they emerged organically through focus groups. The key objective of the thematic analysis was to elaborate on and explore phenomena and processes at the individual level.

### **Key Themes**

The results of focus group sessions are organized into key themes; lack of access to culturally appropriate asthma/allergy care and education, acknowledging the risk, and lack of community empowerment emerged from the thematic analysis. Community results are analyzed in order to describe Inuit and First Nation community’s experiences of asthma and related allergies in the context of their surroundings and unique circumstances.

#### *Theme 1- Lack of Access to Culturally Appropriate Asthma/Allergy Care and Education*

Access to and uptake of asthma and allergy education and information varied among First Nations and Inuit communities. Levels of resources and knowledge of health care providers and community health workers was contextual and inconsistent. Families dealing with asthmatic children expressed frustration surrounding a lack of community resources and screening. In addition, respondents acknowledged the lack of culturally appropriate educational materials. In expressing concern regarding issues of language, many felt that interpretive services would allow them to become more informed about their child’s asthma/allergy management.

In an effort to augment available community asthma/allergy resources, respondents illustrated the need for the implementation of community workshops and discussion forums as ways to engage community members in asthma/allergy education and consultation. Printed materials were also presented as ways “to help children to manage their asthma.” Having access to reliable information was seen as key in providing parents and children with coping strategies at the onset of asthma attacks and allergy

symptoms. The internet was seen as a potential source of uncertainty: *“Internet is used a lot; you can pick up bad information, unreliable resources.”* Community workshops and education fairs would offer parents and children the opportunity to ask questions and to voice their concerns about dealing with asthma and allergies.

Respondents highlighted the need for hands-on education by having resources readily accessible in the community. Accessibility issues were paramount as parents felt that geography and weather often hindered their access to resources. They felt that parents and children:

*Need to live with it; needs to be hands on education; if people don't really see and live with something they don't really understand it, so teaching needs to be hands on.*

*People want a reward or to be paid to participate in education; hard to get people together; distances make it hard too.*

Concern surrounding the level of asthma/allergy knowledge of health care providers and asthma patients extended beyond asthma care, and intersected issues of geography.

*I think the nurses need to be better educated as well. In a clinic in an isolated place they need to know what to do. My son had an allergic reaction and she (nurse) gave me an epipen and she didn't know how to use it.*

*This health centre is it- this is the only place that has the expertise; distant resources.*

Respondents considered the relevance of the link between the dearth of culturally appropriate asthma/allergy education and the low levels of community diagnoses and underreporting. Low levels of diagnoses were common, and created uncertainty and worry in parents. Community perceptions of free medication were two-fold; free medication was considered positive for Inuit and First Nations people who were diagnosed with asthma and allergies, but was also considered negative when it was prescribed without a diagnosis.

*Loose prescribing of asthma medications contributes to problems; everyone gets inhalers, even if no diagnosis of asthma.*

*This underreporting of allergies may be linked to the Doctor shortage; people are less likely to report as these are seen as less serious, not life threatening.*

Respondents viewed this breakdown between education and diagnoses as evidence of inadequate access to health care services and medication.

*People get the puffer prescribed and then discontinue use; don't use the medications properly, not being educated, don't understand the importance of taking the medication properly.*

The potential consequence of improper medication-use was an additional worry of community members. Asthma-related policy development was identified as a means by which patients could access timely and appropriate care and instruction. Asthma and allergy screening was viewed as one method that might help to reduce symptoms before they become exacerbated. A framework of understanding was seen as necessary for proper asthma management; this framework was seen as being primary to encouraging asthma control and management in the community.

*Education and protocols should be in place similar to protocols for TB so health professionals have a map to follow.*

*The only natural champions in the community are the community health reps, but this federal Health Canada program is ending and these roles are being lost.*

School-related asthma and allergy policies were considered to be problematic from the stand-point of parents with asthmatic or allergic children. Inadequate asthma education for teachers has meant that children are responsible for their own asthma and allergy medication administration, regardless of their age and ability. Parents are encouraged to keep children at home if they are experiencing symptoms of asthma and or allergies; parents also felt that they were responsible for advocating for their children. The lack of school-related asthma support also resulted in parents feeling powerless in the management of their child's asthma and allergies. This lack of support translates into higher school absences, which has the potential to generate long-term implications for learning.

*The policy requires that children sign papers, get medical forms filled out by doctor to allow medications to be kept at the school, but the staff cannot administer the medications.*

*There is a policy in the schools concerning asthma, but it doesn't encourage people to send their children to school when they are having active asthma symptoms; one woman described how she just keeps her children home when they are sick with asthma symptoms. The schools require the children to administer the medications themselves and her children are too young to do so.*

*Teachers aren't trained at all in asthma or allergy treatment.*

The notion that children were unable to participate in physical activities was a source of regret for some parents. This regret appeared to have stemmed from the positive implications of physical activity that their children might have been missing. On the contrary, some respondents sensed that their children sometimes took advantage of their asthma and, as such, opted out of or simply refused physical activity. Using their

diagnosis as an excuse not to participate in exercise was another example of how proper, accurate asthma education could help to enlighten parents and children of the health benefits of physical activity for asthmatics.

*One effect in eldest child; used asthma diagnosis not to be physically active; can be used as an excuse.*

## Theme 2- Acknowledging the Risk

Respondents viewed asthma/allergy risk as inherent within their community landscape; the most common triggers were: living/housing conditions; smoking; and chronic disease. Respondents felt that children and elders were most at risk for respiratory illness in their community. In addition, babies were also seen as facing risk due to the smoking habits of their mothers and other family members.

Housing conditions were consistently viewed as one of the most common variables contributing to rates of asthma and allergies in these communities. Dust, pollen, pets, mould and smoking were thought to both exacerbate existing symptoms, and to increase asthma incidences in both adults and children. Overcrowding was common among these communities, as evident in the literature above describing cultural cohabitation practices. Respiratory illness can become transmitted via crowded and unsanitary living conditions, which can lead to allergic sensitivities and increased rates of asthma and related respiratory conditions. Living conditions were viewed as a source of frustration, and respondents felt a sense of powerlessness in an effort to improve them.

One story told of how a brand new house developed mould because the insulation was allowed to get wet during the construction phase.

One respondent expressed that they: *“still have asbestos insulation in many homes on the community.”*

*Improper inspections of houses, built on swamps, landfill sites, water run through where people live.*

*Lots of mould in homes, in bathrooms, kitchens, as a result of leaks, improper insulation, construction defects.*

Respondents viewed home carpeting as a major contributor to allergy exacerbation. Cleanliness was linked to carpeting as it was difficult to rid the carpeting of smoke, dirt and dust. Dust from gravel roads contributed to this problem during construction when ground cover becomes destroyed by construction vehicles. Respondents indicated that exposure to strong scents within and outside of the home, such as perfumes, negatively impacted allergic sensitization.

As indicated, tobacco use in Inuit and First Nations communities is substantially higher than that of the general population; respondents were to some extent aware of the

impact of tobacco use (including second-hand smoke) and poor air quality on rates of asthma and allergies.

*I smoked 16 years ago, and after I quit smoking it was a big difference- you could never believe. I don't think people realize if you quit smoking or if you're smoking how much sicker you can get.*

Respondents differentiated between the consequences of indoor and outdoor smoking, noting that outdoor smoking lead to improvements in the respiratory health of children in the home.

*Early onset of smoking, and in non ventilated places, smoking near kids. Child with no puffers for 2 weeks in a house with smokers and wood fire had to be taken away from the home to have a chance to get better.*

*My two boys are asthmatic and I am as well. It was hard to figure out; one was diagnosed at 6 months and one at 3 months. The oldest outgrew it but the youngest one still – he's 15 now and still has it. I am a smoker. Yes, that is a problem but I quit when I was pregnant with my second child and his asthma is worse.*

Although there were smoking cessation programs in select communities, respondents were undivided in their support for improving and increasing community smoking cessation programming, especially targeted at pregnant women. They felt strongly that there was hope for improvement in respiratory health if parents and youth were informed about the direct implications of smoking for lung health, for example “talk with people that have quit, or visit with people with cancer patients.” In addition, implementing a blue-light initiative for smoke-free homes as well as limiting indoor smoking in office areas was suggested as ways to encourage smoking cessation.

Indoor wood stoves and outdoor environmental pollution were also seen as indicators of poor air quality, exacerbating existing asthma and allergy symptoms. The use of air exchangers was minimal; however, there was hope that air quality testing might facilitate a reduction in rates of asthma and allergies.

*Woodstoves are used in most homes, affecting breathing.*

*The fallout from the mill smoke has set off home fire alarms or carbon monoxide alarms, even up to 20 minutes away.*

*A small number, about 2% of homes use air exchangers, but they break down and people don't repair them, don't use them and leads to mould build up.*

The prevalence of chronic disease in Inuit and First Nations communities was manifested in perceived rates of cancer and diabetes, as “*cancer and diabetes seem to be a big thing here.*” Some respondents felt that these issues had been addressed appropriately: “it was

addressed effectively through Diabetes Prevention workers.” For others, the risk of chronic disease did not seem to be mediated by acceptable and timely health care and/or health promotion programming. Respondents expressed similar frustration for the paucity of education and programming surrounding community chronic disease.

*All other major health problems have the same history of not being dealt with appropriately. For example, diabetes and high blood pressure show the same kind of issues/problems.*

### Theme 3- Lack of Community Empowerment

Lack of community empowerment was broadly illustrated by respondents. A variety of obstacles prevent communities from feeling as though they are able to take control and manage their asthma, including funding, transportation, and subsequently, isolation. Respondents felt that their asthma was controlled by variables that operated as barriers in the context of asthma and allergy diagnosis, management and education and information.

Governmental funding was a source of tension as many respondents highlighted the funding disparities existing between their communities versus the general population.

*There are vast disparities in service being allotted to First Nation population versus the CCAC home care for the general population. First Nations are a population that has a much higher incidence of asthma and mortality rate than the average population. This could be addressed at a higher level to attain relative parity of funds and service. Should have an equal service to all First Nations people, not just the people who are status on reserve. A united health care program for all status clients would be the ideal (First Nation Home Care would deal with all First Nation people, on and off reserve).*

*Need is greater despite the population, yet same funds or less per capita for home care program.*

As outlined, the burden of illness in Inuit and First Nations communities is greater than that of the general population. Rates of asthma and allergy were attached to the lack of access to health care in general:

*Lack of money for nurses in the community.*

*Wait in emergency unit is long. If it is not life threatening, the reception is very surly, not welcoming.*

Respondents connected the lack of funding for asthma and allergy care to a sense of powerlessness. As treatment continues to be unavailable, the situation is perceived to be isolating and urgent. Uncertainty prevails as community members struggle to manage asthma and allergy symptoms, in addition to their living environment.

*Things are getting worse- 20 years ago medical concerns were not an issue.*

The nature of these remote communities makes transportation problematic and costly, and access to timely health care in emergency situations can become challenging. The distribution of the population is affected by weather for most of the year, which makes accessing primary and secondary health care difficult.

*3 out of 10 communities are so far away, it can take around 4 hours to get to the hospital after someone attends to your child.*

*You're in isolation and in order to get to a bigger centre you have to travel to a bigger centre, you have to go through your doctor to get tested for allergies. How many people with asthma ever saw a respiratory therapist in how to use a puffer correctly? You have allergies/asthma so you live with it.*

*Have to medivac people out; helicopter or land ambulance. Two staff members from the community have to meet the government helicopter.*

*Some communities are 75km just to the highway (remote for the land ambulance). If you have the ability to come into the clinic you can get the education, but you need the money to come in, vehicle, time.*

*You might have to go to St. John's or Goose Bay to get tested and if you don't get past your Doctor then you don't go. We can't afford to go to St. John's on our own.*

Uncertainty was prevalent as funding for asthma and allergy care continues to impact the everyday lives of participants and their families. Respondents felt that the circumstances surrounding asthma and allergies were much more than what they could cope with without assistance and screening from accredited health care providers. In the context of Inuit and First Nations communities, a framework for asthma and allergy care would be advantageous in that it would provide access to health care providers for increased diagnoses, information and education, and appropriate patient follow-up and monitoring.

## **Section 5: Conclusions and Recommendations**

This exploratory study of the perceptions and experiences of asthma and related allergies in First Nations and Inuit communities in Canada has only begun to scratch at the surface of the issues in prevalence, impacts, and the need for management strategies tailored to

these communities. However, the data reported herein provides a strong foundation for building a response, and for providing a way forward.

These data have shown us firstly that there are major gaps in family and community resources for coping with and managing asthma and related allergies. Further, there appears a lack of professional health care resources, opportunities and training as well; not surprising due to a range of access issues, including geographic access. Further, broad issues such as adequate housing and community support through the school system must be addressed in the face of this growing public health issue.

It is also important to point out the limitations of the study. Given its exploratory nature, perhaps there might have been additional questions we should have asked, or questions that could have/should have been asked in a different way. For example, the ITK felt strongly that asthma and related allergies would have emerged as a higher priority if the question had been targeted to children and youth. Further, the sample size employed in the study is small; while it is important to remember that the study was not meant to be representative, a larger sample size would have allowed for more sophisticated statistical analysis. Finally, it would have been useful to tape record the surveys as they were administered as well as the focus groups. This would have allowed a more comprehensive analysis of the data as collected. Regardless of these limitations, however, the data provide a useful snapshot of the issues related to asthma and related allergies in these communities and further allow us to make some informed recommendations.

The National Lung Health Framework recently released a draft action plan for consultation. This draft action plan acknowledges alarming rates of respiratory disease among First Nations, Inuit and Metis people in Canada and indicates that these communities are disproportionately affected by inequities in health outcomes as a result of poverty and social inequality. The action plan prescribes a number of key strategies and activities which should be implemented over the next five years. When implemented, all of these will result in improved respiratory health for all Canadians including First Nations and Inuit but several key activities relate specifically to these communities. Examples of these activities include: develop and implement awareness initiatives targeting chronic disease, with an emphasis on at-risk populations; promote collaborative community-based interventions that address local environmental exposure issues where everyone in Canada lives, learns, works and plays; expand evidence to identify and confirm the factors that place certain populations at increased risk and develop and implement early detection programs that reflect population-based risk factors that focus in these at-risk populations; identify at-risk populations and the barriers that are preventing their access to respiratory health and create/develop programs to address these barriers to access; and identify the impact that investments in community programs have on health outcomes with a focus on at-risk populations.

The findings from both phases of data collection and analyses support five key recommendations.

1. The development of culturally appropriate education and community asthma/allergy awareness is integral for improving access to asthma and associated-allergy related health services. Translating these types of knowledge to Inuit and First Nations communities would first require funding to initiate partnerships between policy makers and community working groups to ensure that materials are sensitive to a range of community needs in order to mobilize communities to better understand and manage their asthma, related-allergies and lung health. Translation of educational materials into appropriate languages would help ensure that resources are both culturally-sensitive and comprehensive. Access to asthma and allergy care and education would encourage community empowerment, and provide a knowledge-base for community members to be able to cope with and manage their symptoms for an improved quality of life. Targeting specific learning strategies for community health workers working in First Nation and Inuit communities would be valuable.
2. There is an acute need for a federal framework of asthma and allergy care for health care providers. In order to improve the level of diagnosis, care and management, physicians, nurses and community health workers should be mandated to follow government asthma/allergy guidelines specific to Inuit and First Nation communities. In consultation with the National Lung Health Framework, such a structure would be funded, guided and developed in partnership with policy makers and community working groups to make certain that the needs of the communities are the basis upon which it is designed and implemented. Strengthening partnerships at provincial and territorial (First Nation and Inuit organizations) levels between asthma and lung association organizations is an important component of ensuring understanding at the regional level. The quantitative data supports a lack of resources, opportunities and training available to health care professionals in the communities. It would be important to facilitate a discussion of whom the relevant health care professionals are in the community and in what ways they can be supported, in addition to assessing the availability of materials and educational strategies available to community health professionals.
3. There is a consensus around the need for the development of a new health care delivery model for First Nation and Inuit peoples with chronic conditions. This recommendation is supported by the identification of asthma-related policy development as a means by which patients and their families could access timely and appropriate care and instructions.
4. We must begin to address major gaps in family and community resources for managing and coping with asthma and related allergies. Integral to this finding is the implementation of programs for chronic disease prevention, health promotion, tobacco control and prevention, nutrition

and obesity, and programs for asthma, lung health and related-allergies. Asthma is unique as a chronic disease and managing and coping requires appropriate resource allocation at the family and community level. High smoking rates reported in the environmental scan support a need for a tobacco reduction strategy in First Nation and Inuit communities. For example, the interaction of various environmental risk factors makes children especially vulnerable to asthma and related- allergies as they experience high rates of acute respiratory infections, and exposure to environmental tobacco smoke and dust and molds. Housing issues are also linked to the National Lung Health Framework as the relationship between indoor air quality and respiratory health requires further exploration in the context of crowded dwellings, housing repairs, and access to garbage collection, septic and sewage services. In addition, as noted in the environmental scan, social groups that have lower levels of socioeconomic status tend to be more vulnerable to asthma and related-allergies, which makes these communities particularly at risk and, therefore, a top priority for asthma and related-allergy programming.

5. There must be more attention paid to the link between obesity and asthma and related-allergies. It would be valuable to provide information and educational programs that address asthma and obesity issues in the context of nutrition and physical activity. School-based programs for children with asthma and related allergies are one way to integrate education and awareness through resources and training at the local level. Given the findings of the current study, a key strategy would be to target school-aged children and teachers to increase their knowledge about lung health, asthma and allergies in health and physical education classes. A program of this nature would increase teacher understanding of lung health and offset the misconceptions of exercise as a danger to asthma and allergies, as well as place some of the responsibility of physical activity onto the school boards.

Cutting across these recommendations is a clear need for more research, better data, increased monitoring and surveillance, and enhanced access to care. Implicit across these recommendations is the recognition of the importance of the social determinants of health to the quality of life and well being of Canada's First Nations and Inuit peoples. There must be explicit recognition of these in any long-term research agenda.

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## APPENDICES

### Appendix 1: Survey Questions

#### **PRIORITIES**

1. Tell me about the health priorities in your community. What would you say are the top three?
2. What factors do you think contribute to that high rate of asthma in your community?  
Allergies?
3. What would help to reduce the asthma rate in your community? Allergies?  
Homes? (probe—air quality, mould, smoking)  
Schools?

#### **GAPS**

4. Who is most affected by asthma in your community? Allergies?
5. What are the existing barriers to accessing resources?  
To Diagnosis?  
To Treatment?  
To Intervention?
6. What resources exist in your community to address asthma? Allergies?
7. What type of resources would help families to identify asthma/allergies in their children?
8. Are you aware if families receive an Asthma Action Plans when their children are diagnosed?
9. Are written materials for asthma tailored to address cultural sensitivities of your community? Allergies?
10. Are health professionals in your community aware of clinical guidelines for asthma?
11. Are you aware of the # of hospitalizations from your community due to asthma?  
Allergies?
12. Is there any practice of tracking or collecting information of clients with asthma in your community? Allergies?  
If yes, what do you collect? (Number of clients, age, sex, years with asthma, etc)

## **ASSETS**

13. What expertise is available to address asthma problems in your community?  
Allergies?

14. What skills do families have to address asthma? Allergies?

15. Was there another serious health problem that was addressed effectively in your community?

16. What innovative ideas do you have that would help to address asthma in your community? Allergies?

## Appendix 2: Focus Group Questions

### **COMMUNITY PRIORITIES**

1. Tell me about the health priorities in your community. What would you say are the top three?
2. What factors do you think contribute to that high rate of asthma in your community? Allergies? Why do you think that is?
3. What would help to reduce the asthma rate in your community? Allergies?
4. Do you have a child /children with asthma? Allergies?  
What did you understand about asthma when your child was first diagnosed?  
Allergies?

### **GAPS**

5. Who is most affected by asthma in your community? Allergies?
6. What are the existing barriers to accessing resources?  
To Diagnosis?  
To Treatment?  
To Intervention?
7. What resources exist in your community to address asthma? Allergies?
8. Has asthma caused any limitations for your child? Allergies?  
How has this affected your family?
9. What type of resources would help you to identify asthma/allergies in your child?  
What is needed to help your child/ or other children in the community to manage their asthma? Allergies?

### **ASSETS**

10. What expertise is available to address asthma problems in your community? Allergies?
11. What skills do families have to address asthma? Allergies?
12. Was there another serious health problem that was addressed effectively in your community? (Facilitator can provide context/probe for former examples of advocating for services/gaining knowledge, etc.) How?

13. What innovative ideas do you have that would help to address asthma in your community? Allergies?

### **SPECIFIC QUESTIONS**

14. For those of you that have a child with asthma, do you remember getting the diagnosis? How did knowing you have a child with asthma make you feel? Allergies?

15. What's it like having a child with asthma?  
What's it like having a child with allergies?

16. What interactions or experiences have you had with school(s); tell me about that?

17. Does your child's teacher play any role in his/her asthma? Allergies?

18. Have you ever had a negative interaction with the school around your child's asthma? Allergies?

19. Do you think your child's asthma affects her/his daily life at school? Allergies?

20. Are you concerned about your child's asthma while he/she is at school? Allergies?

### **EXPERIENCES**

21. Do you think you treat your child differently because of his/her asthma? Allergies?

22. Has your child felt excluded because of asthma? Allergies?

23. Has your child had an adverse reaction since his/her diagnosis?

24. Does your child always carry an inhaler? EpiPen?

25. Has your child ever forgotten to take his/her inhaler? EpiPen?

26. Has your child ever had to use his/her inhaler while at school? EpiPen?