Asthma.ca™
Asthma Society of Canada

FINAL REPORT

An Exploration of First Nations and Inuit Perspectives on Community Respiratory Health Awareness Initiatives

Number:

6281-15-2009/9010963

Submitted:

August 31st, 2010

To:

The Public Health Agency of Canada
Lung Health Program

By:

Asthma Society of Canada

4950 Yonge Street, Suite 2306
Toronto, ON M2N 6K1
Telephone: 416-787-4050
Fax: 416-787-5806
Email: info@asthma.ca

Table of Contents

Acknowledgements

This report was made possible through the generous contributions of a number of groups and individuals. We thank them for providing their input, sharing their experiences, expertise and feedback.

First, we would like to thank the members of the Advisory group: Joni Boyd, Dr. Kim Barker, Tanya Davoren, Dr. Heather Castleden, Donna Atkinson, Dr. Wayne Warry, Dr. Dilini Vethanayagam, Dr. Brenda Louise Giles, Catherine Turner, Tina Buckle, Gail Turner, Ada Roberts and Sonia Young. Your input was invaluable and your guidance was integral to the completion of this project.

We would like to thank the Asthma Society of Canada's project team including Dr. Oxana Latycheva, Vice President, Programming and Rupinder Chera, Project Manager for undertaking project implementation, data collection, analysis, and report writing.

From the Asthma Society of Canada specific thanks go to Christine Hampson, Sabrina Panetta, and Zhen Liu. We would also like to thank our summer students Maite Beaudoin and Ivan Telitsyn for their combined work on data transcription and analysis, and Mary Wong for helping with the graphical design of the community outreach and engagement model.

We would also like to thank Treena Chomik from the British Columbia Lung Association, and Michelle Doucette from the Government of Nunavut for helping with the development of data collection tools. Further, we would like to thank Ainsley Chapman and Tara Zupancic for conducting statistical analysis on the focus group and community survey results.

We would like to extend our sincere thanks to the individuals, groups and communities who participated in this research, specifically the participants who completed the community surveys and attended the focus groups in the following communities: Listuguj, QC, Gesgapegiag, QC, Wendake, QC, Wolf Lake, QC, Conne Rivers, NL, Eskasoni, NS, Postville, NL and Prince George, BC. Without your insights, personal stories and experiences, this project could not have been undertaken.

A special thanks to community Health Directors, community outreach workers/representatives for assisting in reaching the goals and objectives of the project by completing the activities of the project.

French translation of the report summary was provided by Olivier Depenweiller from Alpe Translations.

Finally, we also would like to thank our partners: the Assembly of First Nations (AFN), in particular Dr. Kim Barker; the Inuit Tapiriit Kanatami (ITK), in particular Joni Boyd, Métis Nation British Columbia (MNBC), in particular Tanya Davoren, AllerGen NCE Inc, in particular Dr. Diana Royce and the National Collaborating Centre for Aboriginal Health (NCCAH), in particular Donna Atkinson for their collaboration and support in the project implementation. We also would like to extend our thanks to the Public Health Agency of Canada (PHAC) for providing funds for this important project. The Asthma Society of Canada also acknowledges the leadership role of the National Lung Health Framework in shaping the national lung health agenda.

Executive Summary

Asthma and associated allergies represent a significant issue for First Nations, Inuit and Métis communities across Canada. It has been estimated that the prevalence of asthma is 40% higher in First Nations and Inuit communities than in the general Canadian population (the Public Health Agency of Canada, "Life and Breath" Report, 2007). There is no current data available for Métis communities. The findings from the "A Shared Vision" report (2009) indicated the need for the development of culturally appropriate educational materials to increase awareness and knowledge about chronic respiratory disease and the risk factors for its development. The lack of culturally appropriate materials and resources was identified as one of the key barrier to accessing community resources on respiratory health. Further, implementation of public awareness and educational initiatives was named as one of the key strategies to address major gaps in the existing community resources for managing asthma and associated allergies. The current project was designed to evaluate existing educational materials and resources that are available for First Nations, Inuit and Métis communities as well as understand what kind of materials and programs on respiratory health and the risk factors for chronic respiratory disease needs to be developed to meet the unique needs of Aboriginal communities. Another goal of the project was to help gain a better understanding about how the existing materials can be further adapted and/or modified to be culturally relevant for First Nations, Inuit and Métis communities.

Two sources of data were used to compile the findings of this report. First, qualitative in-depth focus groups were conducting to elicit the perspectives of community members and their preferences on the type, content, format, and language of educational materials and resources as well as to identify appropriate methods of community outreach activities and initiatives. The Asthma Society of Canada (ASC) conducted a total of **eight** focus groups (five First Nations, two Inuit and one Métis) in **seven** communities with a total of **57** individuals in attendance. Prior to the focus group sessions, a pre-assessment questionnaire was distributed to all focus group participants to evaluate their knowledge on respiratory health and assess their awareness of the existing community resources and educational materials. Second, a community survey was conducted to strengthen the research methodology and complement the findings of the focus groups by collecting quantitative data. The survey was created to assess the knowledge and awareness of community members in regards to respiratory health and the risk factors for chronic respiratory disease. In total, the ASC collected **162** community surveys from **six** communities (68 from First Nations, 51 from the Inuit, and 43 from the Métis communities).

Important findings from this project revealed that overall there was low level of awareness and knowledge on the social determinants of health and how they can affect respiratory health. Overall, there was a strong sense among project participants that respiratory health was an important issue facing their communities. However, the level of awareness and detail of respiratory knowledge (e.g. respiratory conditions, risk factors, and disease management) among individuals varied greatly as many participants indicated surprise, confusion, and in some cases, communicated misinformation about some of the specific topics. Based on the project findings,

one of the main barriers in accessing information on respiratory health is a lack of information and resources available at the community level. Even though some materials and resources are available, many community members also did not know about their existence and how to access appropriate resources and support required for dealing with issues related to respiratory health. The project findings confirmed that there was a strong need for more information on the prevention (e.g. the risk factors) and management of chronic respiratory disease in their communities, and identified potential educational and awareness strategies that could be implemented to bring the right information and resources to Aboriginal community members and make them more relevant to their culture and traditional practices. As a main project outcome, a community outreach and engagement model that could be effective, culturally appropriate and sensitive to the needs of First Nations, Inuit and Métis communities has been developed based on the project findings and results.

The findings from this project support six key recommendations related to the potential implementation of the designed community outreach and engagement model as well as to the development and/or adaptation of educational materials on respiratory health and the risk factors for chronic respiratory disease and other educational strategies to be applied during the model implementation.

The **first** recommendation is the pilot implementation of the designed community outreach and engagement model in selected Aboriginal communities. The main components of the model need to be verified by the communities that will be involved in the pilot implementation and tailored to their unique needs and priorities. As well, graphical changes are required to make the model more appealing and relevant to each of the Aboriginal communities by, for example, developing the background image that would reflect the unique cultural traditions/images of each Aboriginal group (First Nations, Inuit, and Métis). Proper community infrastructure should be established to coordinate the model implementation with a National Coordination Centre being created to guide and support the implementation process nationally. The Centre would be also used to provide Aboriginal communities from across Canada with appropriate educational resources and disseminate the existing educational materials on respiratory health.

The **second** recommendation is the development of the core content for awareness and educational materials and resources that are to be used under the main model components (e.g. Community Education, Community Participation, Community Awareness, etc.). Based on the project findings, a number of general guidelines should be applied such as: information should be culturally relevant and appropriate; be tailored to different audiences in the community; be focused predominantly on the family to address the gaps in basic information available for parents; and, be available in the preferred format and topics identified during the project. One of the main suggested strategies is the development of a comprehensive toolbox/toolkit of tools, resources and materials that offer a variety of communication and learning methods to target different audiences. Special consideration should also be given to developing/adapting materials for community members who are not currently personally affected by chronic respiratory disease to increase broader community awareness about the issues related to respiratory health (e.g. asthma awareness). Amongst specific materials that are recommended for development are the following: print materials with practical, action-oriented solutions on topics where educational materials do not currently exist; group discussions series on respiratory health topics that can be offered by trained healthcare professionals (e.g. community health representatives, nurse, etc.) and/or community leaders; and public services announcements for local TV and radio channels.

The **third** recommendation is the development of a comprehensive dissemination network for printed and other materials on respiratory health. Printed and other materials should be available in both health-focused areas (such as health centres, pharmacies, nursing stations, health fairs, etc.) as well as in the wider community (such as cultural centres, community centres, bingo halls, community stores, etc.). Several distribution strategies should be identified by working with a particular community and based on the preferences of community members as well as common community practices. Further, it is suggested that information, tools and educational materials are to be developed/adapted should also be available online for communities that have access to the Internet.

One of the key outreach model components is Community leadership, which calls for buy-in from community leaders in order to be effective in bringing respiratory health awareness to Aboriginal communities. Based on the project findings, it is also evident that community leaders and Elders could play a crucial role in delivering health-related messages. Therefore, a **fourth** recommendation is to develop tools to engage, train and support community leaders in delivering respiratory health education messages. The development of tools to train and support community leaders in becoming respiratory health “champions/advocates” is suggested to ensure their proper engagement and involvement in community awareness activities.

During the model implementation, a proper liaison should be established with healthcare professionals working in the community and nearby healthcare facilities. A **fifth** recommendation is to develop strategies/tools to ensure adequate participation of community-based healthcare providers/representatives and have tools that could facilitate a connection between community-based awareness activities/resources and healthcare professionals working in the community. Another strategy that also should be considered is the identification and promotion of individuals in the community that can provide one-on-one education (e.g. community health representatives, nurse, etc.) and answer questions on different risk factors and disease management.

Lastly, it is crucial to continue engaging Aboriginal community members in the development of awareness materials and resources; therefore, a **final** recommendation is to develop tools and resources to ensure broader community involvement in awareness initiatives and facilitate the engagement process for various community organizations. Specifically, given the prevalence of mould problems in both on- and off-reserve buildings/houses in First Nations, Inuit and Métis communities, resources/materials are needed to communicate the magnitude of the problem and provide information about indoor air quality risk factors and solutions to building owners/managers.

This project creates an opportunity for further community based initiatives to be implemented along with the pilot testing of the designed community outreach and engagement model as well as the development of culturally appropriate materials and resources on respiratory health and the risk factors for development of chronic respiratory disease. The pilot implementation of the model should include feedback and suggestions from particular First Nations, Inuit and Métis communities involved in the pilot allowing for community capacity building and community empowerment.

I. Background

1. Brief Organizational Overview

Asthma and associated allergies represent a significant issue for First Nations, Inuit and Métis communities. It has been estimated that the prevalence of asthma is 40% higher in First Nations and Inuit communities than in the general Canadian population (the Public Health Agency of Canada, "Life and Breath" Report, 2007). There is no current data available for Métis communities. Social determinants of health play an important role in the prevalence of respiratory diseases, including asthma and associated allergies amongst First Nations and Inuit populations. 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.

The Asthma Society of Canada (ASC) is a national charitable volunteer-supported organization solely devoted to enhancing the quality of life and health for people living with asthma and associated allergies through education and research. The ASC has a 37-year reputation of providing health education services to consumers and health care professionals. The ASC offers evidence-based and age-appropriate asthma and allergy education, and disease management programs. Our *vision* at the ASC is to empower every child and adult with asthma in Canada to live an active and symptom-free life. Our *mission* is to be a balanced voice for asthma in Canada, advancing optimal self-management, prevention, research and health care. We help patients to take control of their disease by providing credible and leading edge information and the guidance and education they need to live their lives symptom free. The *goals* established by our Board of Directors and operationalized in our three-year strategic plan are to: be the balanced voice in Canada advocating for patients with asthma; promote the best interest of asthma patients through effective collaboration with policy-makers, researchers and health care providers; educate and counsel patients to take control of their symptoms through effective self-management; engage in meaningful research to improve asthma prevention and management strategies; and be a respected role model and a well-managed association in the non-profit disease management sector in Canada.

The Asthma Society of Canada (ASC) has a special interest in helping adults and children with asthma and associated allergies in remote communities to achieve a symptom-free life by providing them with up-to-date information about asthma and its management. The ASC also works towards empowering the communities to strive for better asthma control through the understanding of asthma as a chronic disease and the connection between social determinants of health (i.e. outdoor air quality, housing and smoking) and how they can have an effect on respiratory health. In 2008, the ASC took the lead on a research project and completed a baseline assessment of asthma and allergy programs and resources available in First Nations and Inuit communities, as well as identified needs and gaps in asthma/allergy programs. The project was implemented in collaboration with the Assembly of First Nations (AFN) and Inuit Tapiriit

Kanatami (ITK), with support from AllerGen NCE Inc., the National Centre of Excellence for allergy and asthma research, and was supported by the First Nations and Inuit Health Branch (FNIHB), Health Canada. The report “A Shared vision: Ensuring quality of life for adults and children with asthma and allergies in First Nations and Inuit Communities in Canada” was released in January 2009 and presented to all participating stakeholders with a copy publicly available on the ASC and AFN websites. Our current project entitled “An Exploration of First Nations and Inuit Perspectives on Community Respiratory Health Awareness Initiatives” builds on the findings and one of the recommendations from the “A Shared Vision” report (Asthma Society of Canada, 2009).

2. Project Development

The findings from the “A Shared Vision” report showed that there is a need for the development of culturally appropriate materials to increase public awareness and education about chronic respiratory disease and the risk factors for its development. The lack of culturally appropriate materials and resources was identified as one of the key barrier to accessing community resources. Further, implementation of public awareness and education initiatives was named one of the key strategies to address major gaps in family and community resources for managing and coping with asthma and associated allergies as well as to reduce the rates of asthma in First Nations and Inuit communities. It is well recognized that First Nations and Inuit communities may be more at risk to develop asthma and associated allergies due to their exposure to well-known determinants of respiratory illness such as smoking, poor housing, wood burning, poor indoor/outdoor air quality, etc. Development of community-based awareness campaigns and public information materials should consider the importance of relevant cultural practices (e.g. the reliance on wood burning for home heating, etc.) and should tailor materials and resources to the needs of particular populations. The ASC is using its experiences and expertise gained during the “A Shared Vision” project (Asthma Society of Canada, 2009) to continue conducting community-based initiatives in First Nations, Inuit and Métis communities to improve respiratory health awareness and education amongst community members. Though the asthma prevalence data for Métis communities are not as well known, the current project encompassed activities to explore this issue in Métis communities and identified their perspectives on respiratory health education and awareness.

The ASC took the lead in developing the project “An Exploration of First Nations and Inuit Perspectives on Community Respiratory Health Awareness Initiatives”, which main goal was to perform a baseline needs assessment of community members’ perspectives on the kind and type of resources and materials that needs to be developed for Aboriginal communities. The insights provided by community members was planned to be used to develop a community outreach/engagement model that could be effective in First Nations, Inuit and Métis communities. The model would be developed by identifying the current respiratory health awareness resources/materials as well as the gaps in existing health promotion and awareness programs. The ASC worked closely with the AFN, ITK and AllerGen to develop and implement the current project by continuing building strong partnerships with them. The ASC also created new partnerships with other organizations, such as Métis Nation British Columbia (MNBC) and the National Collaboration Centre for Aboriginal Health (NCCAH).

II. Project Description

1. Project Goals and Objectives

The proposed objective of the project "An Exploration of First Nations and Inuit Perspectives on Community Respiratory Health Awareness Initiatives" was to provide directional insights and recommendations towards the development of an effective model of community outreach for First Nations, Inuit and Métis communities. The project was also designed to provide recommendations on the types of educational materials and awareness resources that would be useful for Aboriginal communities. Based on the findings from the "A Shared Vision" report (Asthma Society of Canada, 2009), there is a need to develop a community outreach and engagement model to be used to deliver health-related information and education for First Nations, Inuit and Métis communities. One of the main purposes of this project was also to explore Aboriginal people's perspectives on the types of community activities and initiatives that would be useful and beneficial for community members. As a main project outcome, creation of a community outreach model which is effective, culturally appropriate and sensitive to the needs of First Nations, Inuit and Métis communities would be performed based on the project findings and results.

The project was designed to evaluate existing educational materials and resources that are available for First Nations, Inuit and Métis communities as well as understand what kind of materials and programs on respiratory health and risk factors for chronic respiratory disease needs to be developed to meet the unique needs of Aboriginal communities. Another goal of the project was to help gain a better understanding about existing chronic disease prevention and management programs and how awareness/educational materials can be further adapted and/or modified to be culturally relevant for First Nations, Inuit and Métis communities.

The ultimate goal of the initiative was to create better awareness and information resources, services and materials available for members of First Nations, Inuit and Métis communities. The development of culturally appropriate materials and resources can help increase public awareness about risk factors of chronic respiratory disease including the social determinants of health; improve people's knowledge about the role of social determinants in respiratory health, and lead to improved early detection of chronic respiratory diseases.

The primary goals of the project as outlined in the proposal have not been changed and are presented below as follows:

- Evaluate existing successful health promotion and chronic disease prevention programming and materials specific to First Nations, Inuit and Métis communities, both nationally and internationally by reviewing relevant policy documents

- Assess and review current existing awareness materials and resources available for First Nations, Inuit, and Métis communities; identifying gaps in available information/resources; and evaluating the necessity of developing new materials and services
- Identify what kind of information/awareness initiatives will be appropriate and effective for First Nations, Inuit, and Métis communities to increase their awareness about risk factors for asthma and associated allergies as it relates to the social determinants of health
- Determine what models of community outreach (e.g. a community workshop/public forum, a health/information fair, etc.) will be appropriate to implement in First Nations, Inuit, and Métis communities
- Identify what elements should be incorporated in future public awareness campaigns and materials to ensure the adequacy and cultural appropriateness of promotional/awareness materials related to asthma and associated allergies, and their risk factors

The project was also designed to inform and set a stage for further community-based initiatives (e.g. implementation/pilot of a community outreach and engagement model). As a next step, the newly designed outreach model could be piloted nationally taking into consideration the transferability of the needs of the target population. If the pilot initiative is successful upon evaluation, this model could be replicated in other First Nations, Inuit and Métis communities across Canada. In addition, relationships with community health directors and community leaders established during the project will serve as a platform for further engagement of community residents in education/awareness initiatives and ensure their ownership of the resources and materials that are to be developed.

2. A Brief Project Overview

The ASC commenced the project with an evaluation of the existing successful health promotion and chronic disease prevention programming and materials specific to First Nations, Inuit and Métis communities. This information was gathered by a means of an environmental scan and helped identify existing resources and materials related to risk factors for chronic respiratory disease. It also informed the development of a checklist that was further used to lead focus group discussions. Based on the findings of the environmental scan, a community survey was also designed and included questions about the current level of awareness of respiratory health and knowledge of risk factors for chronic respiratory diseases (e.g. non-traditional tobacco use, housing, and indoor/outdoor air quality).

One of the main project activities was to conduct focus groups in target populations. The focus groups were designed to gather community members' perspectives on the type, format and language of public information resources and materials that would be beneficial and useful for Aboriginal communities. They were also conducted to gather insights on the most suitable methods of community outreach and engagement. The *first stage* of the project consisted of activities aimed to prepare for focus groups and started with identifying participating communities. The ASC worked closely with the AFN and ITK to select communities to be involved in the project. Initially, it was planned to recruit five communities (two First Nations, two Inuit and one Métis). The AFN and ITK guided the selection process to ensure that selected communities reflected the geographical (including remote and isolated communities), social and cultural diversity of First Nations, and Inuit communities across Canada. A newly established partnership with the Métis Nation British Columbia (MNBC) helped identify an appropriate Métis community to participate in the project. When outreaching to potential communities, more than five communities expressed an interest to be involved in the project and the decision was made to accommodate all of them. Once the communities were identified, a proper agreement was signed with each participating community and outlined main community responsibilities in the project (Appendix 1). The communities were given a choice of tailoring project activities based on the unique characteristics and practices of each and every community while following the general guidelines and instructions established for the project. The communities were also provided with all promotional materials to outreach to community members and invite them to participate in the project. Each of the communities hired community outreach workers/representatives to assist in completing the outlined project activities.

An interview checklist (Appendix 2) and community survey (Appendix 3) were developed and distributed to the communities. Community outreach workers disseminated the interview checklist to potential participants ahead of time to give them an opportunity to complete and prepare prior to the focus group discussions. Additionally, a short pre-assessment questionnaire (Appendix 4) was designed to evaluate focus group participants' knowledge on respiratory health and risk factors for chronic respiratory disease and sent out to each of the focus group participants prior to the group sessions.

To expand and strengthen the findings from the focus groups, and complement them with the quantitative data, a community survey was specifically developed for the purpose of this project. The survey was designed based on the checklist questions, and distributed to community residents by community outreach workers/representatives who were responsible for its administration and participant recruitment. The survey was intended to assess community members' knowledge and awareness of risk factors for chronic respiratory disease as well as gather broader perspectives on their specific needs for educational materials and resources. The initial goal was to complete 250 surveys (100 First Nations, 100 Inuit and 50 Métis).

The focus groups were then conducted during *the second stage* of the project. The project manager hired for the purpose of this project acted as a focus group facilitator and travelled to each of the communities involved in the focus group participation. Furthermore, a community survey was also distributed during this stage to each of the communities who expressed interest in participating in survey completion.

The *third stage* of the project was to analyze and summarize the data collected during the project (e.g. the focus group recordings, pre-assessment questionnaires, community surveys). Project findings and results were then presented to the Advisory Group members and used to create an outreach/engagement model. Recommendations were also developed to inform future implementation/development of awareness materials and resources including suggestions on the key elements that needs to be taken into consideration in order to make materials culturally relevant. They also made references to specific tools, best practices and strategies that could fill in existing gaps identified during the project.

The Advisory Group was established to oversee and guide the project implementation (refer to Appendix 5 for the list of the Advisory Group members). The representatives from key partner organizations (the AFN, ITK, and MNBC) as well as project supporters (AllerGen, the NCCAH) were invited to participate in the work of the Advisory Group. Invitations were also sent to representatives from the communities involved in the project. Additionally, key opinion leaders in the area of First Nations, Inuit and Métis communities were offered the opportunity to be involved in the Advisory Group in a consultative role.

III. Project Activities

In order to meet project goals and objectives, the following activities were implemented that can be divided into four main components: A) Developing the environmental scan, B) Conducting focus groups and pre-assessment questionnaires, C) Conducting community surveys, and D) Developing the community outreach and engagement model.

1. Environmental Scan

The purpose of the environmental scan was to evaluate existing successful health promotion and chronic disease prevention programs and educational materials that are specific to First Nations, Inuit and Métis communities. A search for materials was conducted both on a national and international level by reviewing relevant policy documents and existing literature. The environmental scan also assisted in assessing and reviewing current existing awareness materials and resources available for First Nations, Inuit, and Métis communities; identifying gaps in available information/resources; and evaluating the necessity of developing new materials and services. This has allowed us to identify what kinds of information/awareness initiatives would be appropriate and effective for First Nations, Inuit, and Métis communities in order to increase their awareness about risk factors for asthma and associated allergies. Further, this scan provided contextual material related to the social determinants of health such as outdoor air quality, housing and tobacco use and gathered ideas about a framework model that could benefit the First Nations, Inuit and Métis communities across Canada. Information summarized in the environmental scan also served to support the results from focus groups and surveys conducted during the project and presented later in this report.

1.1. Methodology

The initial scan involved a broad search for asthma educational materials and resources available provincially and nationally to determine what asthma and related allergy resources exist that are specific to First Nations, Inuit and Métis communities. The second step was to extend the search to other jurisdictions by investigating international organizations. The third step was to identify all chronic disease prevention programs including respiratory health promotion resources currently available that are targeted at First Nations, Inuit or Métis communities across Canada. The forth step was to compile an "environmental scan" spreadsheet of all information related to models of community outreach in asthma as well as other chronic diseases which had materials and resources available to First Nations, Inuit and Métis communities.

An Internet search was conducted using Google search engine as well as accessing library databases (e.g. the Pub Med and Elsevier Health Sciences Periodicals) and health-related websites. Furthermore, an academic search for literature reviews and papers was conducted on Google Scholar and Medline databases. Key search words were 'Aboriginal' or 'indigenous' and 'asthma', 'COPD', 'allergies' or 'chronic disease'. Beyond the key word search, health - related Canadian sites were included, such as the Public Health Agency of Canada, Health Canada and non-governmental organizations such as the Heart and Stoke Foundation and the Canadian Diabetes Association as well as an array of Aboriginal specific association (e.g. the National Aboriginal Diabetes Association). The online search was accompanied by a number of phone and email inquiries, including email contacts with the provincial and territorial health ministries and some individual contacts were made with knowledgeable informants.

The environmental scan is resented in Appendix 6. The environmental scan revealed five main elements/indicators of culturally appropriate materials: (1) general access to resources and the use of plain language; (2) inclusion of Aboriginal pictures, art, and images; (3) translation/interpretation; (4) alignment of traditional and medical knowledge; and (5) integration of traditional and scientific knowledge at the community level that are to be verified by community members during the focus group discussions. These indicators can be applied when adapting existing educational materials and/or developing any new resources on respiratory health for Aboriginal communities. The environmental scan also represented a first step in the process of determining major gaps in existing resources, and that will be further complemented by data collected by the focus groups and community surveys which are the focus of this project.

2. Focus Groups and Pre-assessment Questionnaires

The ASC in partnership with the AFN, ITK and MNBC conducted qualitative in-depth focus groups to elicit the perspectives of community members on the type, content, format, and language of public information resources and materials, as well as a method of community outreach/awareness that was most suitable for First Nations, Inuit and Métis communities. The main objectives of the focus group were the following:

- Determine community members' knowledge and understanding about risk factors for chronic respiratory disease, in particular asthma and associated allergies;
- Assess community members' awareness of the existing educational programs on respiratory health and services available in their communities;

- Explore gaps in existing awareness programs and materials, and
- Identify appropriate community outreach activities and initiatives.

Prior to the focus group sessions, the pre-assessment questionnaire/test was distributed to all focus group participants to evaluate their knowledge on respiratory health and assess their awareness of the existing community resources and educational materials. The focus groups were conducted to further touch on the topics from the pre-assessment questionnaire giving the participants an opportunity to provide their personal insights in a group setting.

According to the proposal, the ASC had intended to conduct five focus groups (two First Nations, two Inuit and one Métis). However, due to the high response rate from the communities showing an interest to participate in the project, particularly in the focus group sessions, the ASC conducted a total of **eight** focus groups (five First Nations, two Inuit and one Métis) in **seven** communities (refer to Table 1 below for the list of participating communities).

2.1. Recruitment of Focus Group Participants

Communities for participation were chosen through consultation and with the guidance of the key project partners (e.g., AFN, ITK, and MNBC). A special consideration was given to recruit communities to reflect the geographical (including remote and isolated communities), social, and cultural diversity of First Nations, Inuit and Métis communities across Canada. This project was built on our previous successful collaboration with the AFN and ITK established during the preparation of the "A Shared Vision" report (Asthma Society of Canada, 2009). One of the objectives of the current project was also to explore whether asthma and allergies represent an issue for Métis communities. Therefore, one focus group was conducted in a Métis community as a way of exploring gaps in respiratory health education and awareness in these communities. To outreach to Métis communities, a new partnership was established with the MNBC in order to seek Métis communities' participation in the project.

When communities were identified with support of the key project partners (e.g. AFN, ITK and MNBC) and confirmed their participation in the project, the project manager contacted each of the health directors in the participating communities and outlined activities to be undertaken during the project. Each individual community was given the opportunity to choose how they wanted to be involved in the project either participating in the focus groups or completing community surveys or hold both activities in their community. The ASC had signed agreements (Appendix 1) with each community outlining their responsibilities in the project based on their level of involvement. Each community was also given a reimbursement amount depending on the level of participation in the project. They were advised to hire a community outreach worker/representatives who acted as a liaison for the project and assisted in participant recruitment. Community outreach workers promoted the project within the community by using promotional flyers (Appendix 7) and connecting with community members who had a history of chronic respiratory condition by phone or "word of mouth". A list of potential community participants was created in consultation with community outreach workers/representatives. Focus group participation was offered but not limited to the following community members: parents with children suffering from asthma and associated allergies; extended family members; school personnel, and the Elders. Additionally, adults affected by asthma, associated allergies or/and COPD, people who are at risk of developing asthma and associated allergies, general public, cultural/community leaders, and Community Chiefs were also invited to participate in focus group discussions. This project only included adults above the age of 18 years.

As mentioned previously, the number of participating communities exceeded our initial goal for the focus groups. Our intention was to recruit 10 participants per each focus group having 50 focus group participants in total. Because of the increase in the number of participating communities, a total of **57** individuals took part in the focus group sessions (refer to Table 1 for details).

Table 1: The number of focus group participants in First Nations, Inuit and Métis communities

Focus Group Participation in First Nations Communities	
Community	**Number of Participants**
Listuguj, QC	11
Gesgapegiag, QC	7
Wendake, QC (French-speaking)	10
Conne Rivers, NL	5
Eskasoni, NS	4
Total Participation	**37**
Focus Group Participation in Inuit Communities	
Community Names	**Number of Participants**
Postville, NL	10
Total Participation	**10**
Focus Group Participation in Métis Communities	
Community Names	**Number of Participants**
Prince George, BC	10
Total Participation	**10**
Grant Total	**57**

To ensure proper participant recruitment and focus group participation, the health directors were asked if there was a language barrier that could be potentially faced by focus group participants and whether or not an interpreter was needed to assist the focus group facilitator and participants.

An interpreter was only needed in the French community (Wendake, QC), and there was no need to provide translation in any of the other communities.

2.2. Focus Group Preparation

In preparation for the focus groups, several documents were prepared and distributed to the communities involved in the focus group activities. The documents created are described in details below and included: facilitator checklist; participant checklist; pre-assessment questionnaire; letter of information (LOI)/consent form; promotional flyers to assist in participant recruitment; a package of educational materials to be assessed during the focus groups, and a cover letter to the communities outlining the tasks involved in the project and target population for recruitment. All documents were translated for the participants in the French-speaking First Nations community, except the facilitator checklist which was intended to be used only by the focus group facilitator.

2.2.1. Facilitator checklist

According to the topics to be discussed, the facilitator checklist (Appendix 8) was divided into five categories: 1) Outdoor pollution – Air Quality Index; 2) Housing/Indoor Air Quality; 3) Smoking – use of commercial cigarettes/smoking and chewing tobacco; 4) Respiratory Knowledge – Chronic Respiratory Conditions; and 5) Community resources. These sections were further broken down into a chart form with three columns: topics to discuss, main questions and probing questions. The facilitator checklist represented a more in depth list of questions that were prepared based on the questions in the pre-assessment questionnaire and the community survey. The list was intended to be used only by the focus group facilitator.

2.2.2. Participant checklist

The participant checklist (Appendix 2) was created out of the facilitator checklist only mentioning the topics to be discussed so that the participants would be prepared for the discussion. The checklist also provided contact information for the community outreach worker/representative and/or project manager if the participants had any questions or concerns about the project. The checklist was translated for the participants in the French-speaking First Nations community.

2.2.3. Promotional flyer

A promotional flyer (Appendix 7) was created to assist the community outreach workers/representatives in recruiting participants for the focus group as well as the community survey. The flyer outlined the main activities that the community had taken in the project. It also included the basic information about the project including its name, target population group, as well as provide contact information for community outreach workers/representatives for further communication on the project.

2.2.4. A letter of information /consent form for focus group participation

A letter of information (LOI)/consent form (Appendix 9) was created providing information about the investigators; the title of the project; its purpose; the procedures involved in the project, potential harms, risk or discomforts; potential benefits; confidentiality, and participation and withdrawal. Confidentiality was assured by the use of pseudonyms, and participant ID numbers. It was also indicated that the data (transcripts) obtained during the project would be coded and stored in a secure location in the office of the project team.

2.2.5. Pre-assessment questionnaire/test

A pre-assessment questionnaire/test (Appendix 4) was developed based on a couple of sources such as: findings from the “A Shared Vision” report (Asthma Society of Canada, 2009), and the environmental scan of the literature related to successful health promotion and chronic disease prevention programming and materials specific to First Nations, Inuit, and Métis communities. It was also designed in consultation with key project stakeholders (e.g. the AFN, ITK, MNBC, and AllerGen) and with input from the Advisory Group members.

The pre-assessment questionnaire was prepared to determine the current knowledge of community members about existing resources and materials related to risk factors for chronic respiratory disease, as well as facilitators and barriers to accessing these resources. The topics of the pre-assessment questionnaire were consistent with the focus group checklist and included: 1) Outdoor Air Quality; 2) Housing/Indoor Air Quality; 3) Non-Traditional Tobacco Use; 4) Knowledge on Respiratory Lung Disease; and 5) Demographics/Additional Information. The topics were kept the same in each of the research tools to assure consistency throughout the project.

The pre-assessment test questions were also adapted from the existing validated data collection tools (e.g. Asthma Knowledge Assessment Test; and the Bristol COPD Questionnaires well as based on the statistics from the World Health Organization (WHO) and on the previous questionnaires developed for the PLATE (Partnership in Lung testing and Education) Programme[1] and the Air Quality Health Index Awareness Program[2]. The smoking/tobacco use section of the test was further reviewed by the project manager working on the project “Smoking: Can We Change?/Ajisitijirunnaqp” that was under implementation by the Government of Nunavut Organization in partnership with the Nunavut Department of Health and Social Services and funded through the National Lung Health Framework (NLHF) (NLHF

---

[1] The PLATE (Partnership in Lung Age Testing and Education) program is a community-based initiative which evaluated the effectiveness of a population-based approach for management of asthma, association allergies and COPD (2008).

[2] The Air Quality Health Index (AQHI) project is assessing the level of awareness of the AQHI amongst people with asthma and associated allergies, as well as the preferences in receiving AQHI information (currently under implementation by the ASC).

Secretariat, 2010). The project leads for this project provided feedback on the smoking and tobacco use section to make sure that the asked questions were culturally relevant and sensitive. Moreover, the British Columbia Lung Association who was working on the project entitled: "Establishing Need for Awareness Initiatives about Risk Factors for Respiratory Diseases among Health Professionals Working with First Nations, Inuit and Métis Communities" (NLHF Secretariat, 2010) provided us a link to the questions that were used in their project to survey health care professionals working with Aboriginal communities.

Finally, the pre-assessment questionnaire was reviewed by the Advisory Group members to assure that the questions were appropriate and culturally sensitive to First Nations, Inuit and Métis communities. Feedback was also provided by the National Inuit Committee on Health (NICoH) to ensure cultural relevance and appropriateness of the asked questions to Inuit community members. The pre-assessment questionnaire was sent out to participants prior to the focus group session to assess their knowledge and awareness level before attending the focus groups.

2.2.6. Educational materials presented during the focus groups

A package of existing educational materials developed for Aboriginal communities was compiled based on the results of the environmental scan and additional searches for respiratory health materials geared towards First Nations, Inuit and Métis communities. Existing awareness materials on social determinants of health as risk factors for chronic respiratory conditions were also included in the package. Materials were identified based on the five main topics for discussion during the focus group sessions. The purpose of showing existing materials was to get an idea of what materials Aboriginal community members preferred and get their opinions on and how the existing materials would need to be tailored or modified to be culturally relevant to their communities. The packages were also used to determine whether the participating communities were aware of and able to access the existing educational materials. A brief description of materials included in the package is presented in Appendix 10.

3. Focus Group Sessions

The focus group sessions took place in First Nations, Inuit, and Métis communities across Canada in the month of June/July 2010 (refer to Appendix 11 for the schedule of focus groups conducted). The focus group sessions were conducted by the project manager visiting each of the individual communities, except for Conne Rivers, NL, where the Nurse Practitioner who is a member of the Advisory Group facilitated the focus group session. The focus groups dates and times were coordinated with each of the communities depending on availability of participants and health directors to be present during the focus groups.

During the focus group sessions, a Traditional Opening Ceremony was delivered by one of the focus group participants, the Elder. The traditional opening ceremony began with a prayer. However, not all of the communities participated in conducting an Opening Traditional Ceremony as not all of the communities maintained traditions. Following the prayer, participants were welcomed to the focus group session, and the pre-assessment questionnaires and consent forms were collected from the participants prior to starting the session. Participants were instructed to place both documents into a sealed envelope, which was collected by the facilitator in the beginning of the focus group session. The focus group facilitator discussed confidentiality aspects as outlined in the consent forms and explained how the session would be recorded. The participants were given the opportunity to ask questions if they were concerned about the project or the consent form.

Refreshments during the focus group sessions were provided by the communities, and in some communities, there were also homemade lunches prepared for the participants. Initially the focus group sessions were allotted one hour each. However, as the sessions proceeded, the length of the sessions became longer anywhere from two to three hours, because of the in-depth conversation that was occurring with the community members. A thank you card (Appendix 12) and a reimbursement cheque for $50 was mailed out to the focus group participants by the ASC. Participants were reimbursed, regardless of the level of participation (only completing the pre-assessment questionnaire or only participating in the focus group discussion).

4. Community Surveys

The purpose and objective of the community surveys was to strengthen the research methodology and complement collected qualitative data. A community survey was expanded based on the pre-assessment questionnaire and distributed by the community outreach workers/representatives appointed to coordinate the project implementation in the selected communities. The survey was created to assess the knowledge and awareness of community members in regards to respiratory health and risk factors for chronic respiratory disease. It was also aimed to gather broader perspectives on the type and kind of awareness resources and materials that could benefit the communities from participants who lived in remote areas and were not able to attend the focus group sessions.

4.1. Development of the Community Survey

The community survey questions (Appendix 3) were developed based on the pre-assessment test to maintain the universal approach and ensure consistency. The community survey, similar to the pre-assessment questionnaire, was reviewed by the key project partners, the Advisory Group members and the NICoH. Furthermore, the project team from the Nunavut Department of Health and Social Services provided their feedback on the smoking section of the community survey to ensure relevancy of the questions and whether they were appropriate. As well, a health director in one of the participating communities (Eskasoni, NS) requested to review all project documents prior to them being distributed to the community members.

A letter of information and a consent form (Appendix 3) was also attached to the community survey and participants were advised to keep the letter of information for their records while the consent forms should be signed and remained with the community surveys. Once completed, the community surveys were collected in sealed envelopes by the community outreach workers/representatives.

4.2. Research Ethics Board (REB) Approval

Once all the project documents were developed and approved by all the project partners, an application was submitted to the REB of McMaster University for approval. Dr. Wayne Warry, an anthropologist at McMaster University and a member of the Advisory Group, acted as a Principal Investigator. The ASC was successful in its application and was granted the REB approval from McMaster University on June 11, 2010. Refer to Appendix 13 for the REB certificate issued by McMaster University.

4.3. Distribution of the Community Surveys

The community surveys were distributed to the community residents by community outreach workers/representatives who served as community liaisons for this project. Individual packages were sent to the participating communities with the tools needed to fulfill the project activities. The packages were put together based on what project activities the communities had chosen to participate. A sample package for the community participating in both activities (focus groups and community surveys) would have included the following documents:

- 10 envelopes, one for each focus group participant with:
    - One pre-assessment questionnaire/test
    - Two consent forms – one for the participants to keep and one to be signed and handed back to the ASC
    - One participant focus group checklist
- Community surveys and envelopes
- Promotional flyers for recruitment of participants for both focus groups and community surveys
- Oath of confidentiality (Appendix 14) – to assure confidentiality of participants. Community outreach workers/representatives who were involved in collecting surveys or pre-assessment questionnaires were asked to sign this document.
- Personalized cover letter addressed to the health director and community outreach workers/representatives explaining what was in the package and outlining criteria for participant recruitment (Appendix 15)
- Prepaid postage envelopes

Many of the communities had already started recruiting participants for the focus groups and were asked to distribute the focus group packages to be filled out one week prior to the focus group sessions.

4.4. Collection of the Community Surveys

Our project goal for collecting community survey was a total of 250 surveys (100 from First Nations and Inuit each, and 50 from Métis community residents). The ASC completed community surveys in a total of **six** communities (four First Nations, one Inuit and one Métis). Overall, the ASC collected **162** surveys (68 from First Nations, 51 from Inuit, and 43 from Métis communities). The community distribution of the surveys completed is presented in Table 2 below.

We received fewer than expected questionnaires from participants in each of the communities due to a variety of reasons. Many members in the Inuit community, Newfoundland and Labrador (with a population of 250 members) were not all on reserve during this time of the year. During the summertime, many community members were taking time off to visit their family and friends off reserve. This factor reduced the amount of available participants to complete the survey within the project completion deadline. In addition, the ASC received REB approval on June 11, 2010 and no activities could be conducted prior to the REB approval being granted. Due to the overall short project timelines, the project activities took place from June 11, 2010 to the August 6, 2010; we allowed an extra week in August for surveys to be returned to make sure all communities had the opportunity to submit any outstanding surveys. However, despite the challenges, the ASC still had a total response rate of **65%** for the completion of surveys.

Table 2: The number of community surveys completed by First Nations, Inuit and Métis community members

Community Survey Participation in First Nations Communities	
Community Names	**Number of Surveys Completed**
Wolf Lake, QC	19
Wendake, QC (French-speaking)	6
Conne Rivers, NL	20
Eskasoni, NS	23
Total Participation	**68**
Community Survey Participation in Inuit Communities	
Community Names	**Number of Surveys Completed**
Postville, NL	51
Total Participation	**51**
Community Survey Participation in Métis Communities	
Community Names	**Number of Surveys Completed**
Prince George, BC	42
Total Participation	**43**
Grand Total	**162**

5. Overall Project Participation

Table 3 below presents overall participation of the communities in the project. There were a few participants who had completed the pre-assessment questionnaire but did not participate in the focus group session or they did participate in the focus group session but did not complete the pre-assessment questionnaire. The information that was gathered from these participants was still used in the overall analysis as the participants had signed consent forms, thereby agreeing to participate in focus groups. There were no negative consequences and the participants were still provided with compensation for their focus group participation. In total, the ASC received **56** pre-assessment questionnaires.

Table 3: Overall participation in the focus groups, pre-assessment tests and community surveys

Community	Focus Group Participation	Completed Pre-assessment test	Completed Surveys
First Nations Communities			
Conne River, NL	5	5	20
Gesgapegiag, QC	7	7	0
Listuguj, QC	11	10	0
Eskasoni, NS	4	3	23
Wendake, QC (French-speaking)	10	9	6
Wolf Lake, QC	0	1	19
Inuit Community			
Postville, Labrador	10	11	51
Métis Community			
Prince George, BC	10	10	43
Grand Total:	**57**	**56**	**162**

The community outreach workers/representatives were responsible for collection of the community surveys and for sending them back to the ASC. In total, **162** completed community surveys were received by the ASC (Table 3).

6. Project Governance and Implementation

6.1. Project Team

The project was implemented over a period of 6 months, starting on February 22, 2010. The Project Team included Dr. Oxana Latycheva, Vice-President, Programming at the ASC and Rupinder Chera, Project Manager. In addition, the project team included community outreach workers/representatives who were hired by the community health directors/leaders to work within their respective First Nations, Inuit and Métis Communities. The Project Team further solicited advice and support through a core Working Group of partners (included representatives from the AFN, ITK and the MNBC) and a wider Advisory Group of experts.

6.2. The Advisory Group

The Advisory Group was established to fulfill the following objectives:

- Oversee and guide the project implementation;
- Provide input into the development of research tools and make necessary recommendations for changes;
- Assist in identifying focus group locations and securing community participation; and
- Be involved in designing the outreach model and making key recommendations for future development of awareness initiatives, resources and materials that are culturally appropriate for First Nations, Inuit and Métis Communities.

The representatives from key partner organizations (the AFN, ITK, and MNBC) as well as project supporters (AllerGen, the NCCAH) were invited to participate in the work of the Advisory Group (refer to Appendix 5 for the list of the Advisory Group members). Invitations were also sent to representatives from the communities involved in the project. Additionally, key opinion leaders in the area of Aboriginal health and culture were offered the opportunity to be involved in the work of the Advisory Group in a consultative role. Throughout the duration of the project, the Advisory group members met via three conference calls and key partners and community representatives attended the focus group meeting in Toronto, while other members joined via conference call. A brief summary of the meetings is presented below.

6.2.1. Advisory Group meeting, April 29th 2010 at 1:00pm

At the First Advisory Group meeting, the goals, objectives, and project milestones were discussed by the Group members through a conference call. An agenda and conference call details were then sent out to each of the Advisory Group members. The meeting agenda included:

- A discussion and agreement of the executive summary that outlined the project goals, objectives and time lines;
- A review of the potential communities to be involved in the project;
- A review of draft research tools;
- A discussion about the need to translate project documents;
- A discussion about pending Research Ethics Board (REB) approval; and
- An outline of project milestones – next steps in the project.

6.2.2. Advisory Group meeting, June 8th 2010 at 11:00am

At the second Advisory Group meeting, the goals, objectives and project milestones were discussed by the project team members through conference call and then distributed to the Advisory Group members. The meeting agenda included:

- A review of communities selected to be involved in the project and signing of agreements;
- Finalized research tools and REB approval;
- Timelines to conduct research analysis and preparation of a final report;
- Documents to be reviewed by the Advisory Group members; and
- Project milestones – next steps in the project.

6.2.3. Final Advisory Group/focus group meeting, July 27th 2010, 9:00-4:00pm

The final Advisory Group/focus group meeting involved the preparation of an in-depth meeting agenda for presenters/facilitators as well as a simplified agenda for the members of the panel. The meeting was held at the MaRS building in downtown Toronto from 9:00am-4:00pm. The purpose of the Advisory Group focus group meeting was to present preliminary focus group results analyzed from the data collected, review and discuss a draft community outreach and engagement model, establish timelines for completion of the final report, and finalize the communication plan to disseminate project results and the final report. A meeting folder was prepared and distributed to participants attending the meeting in person in Toronto. Members who joined through conference call received a copy of each of the documents through email. The Meeting Folder included the following material:

- A draft environmental scan;

- Power point presentation of the preliminary focus group results;
- Sample educational materials presented to the communities during the focus groups;
- Samples of different chronic disease management/ community outreach and social determinants of health models; and
- Expense form.

The meeting agenda included:

- Overview of the project – review the main objectives and main goals of the project;
- Review the communities involved in the project;
- Review and discuss the environmental scan – done with the members present in Toronto and solicited feedback from members who joined by conference call;
- Conference call line was opened at 11:00am;
- Review the preliminary focus group results;
- Discuss the outreach model components;
- Discuss the next steps in the project – result dissemination and moving forward with a phase II application to the National Lung Health Framework (NLHF).

The environmental scan was discussed with the key partners from the AFN, ITK, MNBC, and AllerGen who were present in Toronto. The environmental scan was reviewed section by section, giving the partners time to address their concerns and put forward suggestions where they deemed necessary. Members who joined the meeting via the conference call were also given the opportunity to provide their feedback on the environmental scan through email. The rest of the Advisory Group members were invited to join the meeting by conference call at 11:00am, at this time the preliminary results for the focus groups were presented and discussed. All members were further advised to send any additional feedback or suggestions on the environmental scan and the focus group results through email.

7. Development of the Community Outreach Model

The main purpose of this project was to design a community outreach and engagement model, which would be effective, culturally appropriate and sensitive to the needs of First Nations, Inuit and Métis communities. The components of the model were discussed and reviewed during the final Advisory Group/focus group meeting, identifying what was necessary to include in the model. The model was created to provide information and awareness to communities about the risk factors for chronic respiratory disease (e.g. asthma and associated allergies) as it relates to the social determinants of health. The components outline ways of outreaching to communities not only on a community level but also on an individual and family level. The model was designed to conduct public awareness campaigns and disseminate educational materials through community workshops/public forum or through health/information fairs to ensure the adequacy and cultural appropriateness of promotional/awareness programs related to chronic respiratory conditions, and their risk factors.

All partner organizations were involved in designing the outreach model and making recommendations for future development of public information/educational materials. The initial model draft was designed by the project team based on the findings from the environmental scan, preliminary focus group results, and existing examples of community outreach and engagement models. The model components which were discussed during the Advisory Group meeting in Toronto included but were not limited to the components described below in detail.

The central core of the model shows how the individual (child, youth and adult), family and community is connected in First Nations, Inuit and Métis communities, further connecting to social determinants of health that could lead to the improvement of health outcomes. Five distinct components were developed linking to social determinants of health:

1) Community education
2) Community awareness
3) Community participation
4) Community leadership
5) Community health care delivery

Other components of the model such as Community Empowerment and Capacity Building and Community Coordination are connected to the five components mentioned above, which empower the communities enabling them to take part in creating materials and resources, as well as establishing community policies, in a way that will improve knowledge and awareness on respiratory health.

Currently no resource centre exists for all First Nations, Inuit and Métis communities to readily access and retrieve existing resources and materials on social determinants of health and how they affect respiratory health. Therefore, it was proposed to establish a Clearing house (e.g. the National Aboriginal Asthma/Respiratory Health Information Centre), which would be the central location for First Nations, Inuit and Métis communities to access, retrieve and request all the resources and materials. This Centre will also allow individual communities to provide feedback and ongoing suggestions for improvement.

The ASC took all the feedback provided by the Advisory Group members and worked on finalizing the model components. The final individual components of the community outreach model are further discussed in the Project Results section of this report. As a next step, the draft model was graphically designed by the ASC through the adaptation of two other models: “Integrated Life course and Social Determinants Model of Aboriginal Health” (Reading and Wien, 2009) and from the “Social Ecological Model of Health” (Dolan et al, 2008). The graphical design is based on the feedback and suggestions provided initially by the Advisory Group members.

The draft model was also presented to participants who attended the results dissemination/ grant writing workshop for phase II application (see Appendix 16 for the list of participants). The workshop was jointly organized by the ASC and AllerGen and will be discussed in detail in the Results Dissemination section of this report. Additional changes were made to the model based on the feedback and suggestions from the participants at the AllerGen workshop. The ASC then designed two versions of the model and both versions were presented to the Advisory Group members for their final vote on one of the models and approval (refer to Appendix 17 for the final model). The ultimate goal is to implement this model by presenting the model to the communities for their feedback and piloting it in the selected communities prior to piloting it nationally while taking into consideration the transferability of the needs of the target population.

8. Analysis of the Project Results

The community surveys were mailed to the ASC office using the prepaid postage envelopes provided by each of the communities involved in this activity. Quantitative analysis was done on the pre-assessment questionnaires and the community surveys once they were collected and received by the project team. The community surveys included consent forms outlining how the data would be used and how confidentiality would be ensured for each of the participants.

The data from the focus group sessions was collected by tape-recording the discussions during the focus groups. The participants were asked to sign consent forms that included how the information would be collected. They were also asked to mention their name a few times while answering the questions so that the collected data could be transcribed accurately after the focus group sessions. After the focus groups, the project team members transcribed the recordings for further qualitative analysis. The focus group data was coded and actual names were not used in the final analysis for confidentiality purposes. The main themes were generated both deductively based on the objectives outlined in the proposal/ the interview checklist, and inductively as they emerged during the focus groups sessions. The Advisory Group members were also involved with the evaluation of the results and provided their feedback on the data collected.

IV. Participation of Population Group

Communities for participation were chosen through consultation and with the guidance of the key project partners (e.g., AFN, ITK, and MNBC). A special consideration was given to recruit communities to reflect the geographical (including remote and isolated communities), social, and cultural diversity of First Nations, Inuit and Métis communities across Canada. Initially, it was planned to recruit five communities (two First Nations, two Inuit and one Métis). A newly established partnership with the Métis Nation British Columbia (MNBC) helped identify an appropriate Métis community to participate in the project. When outreaching to potential communities, more than five communities expressed an interest to be involved in the project and the decision was made to accommodate all of them.

1. Description of the Communities involved

The communities involved do not represent all of Canada as all First Nations communities involved in the project are from the East Coast and Quebec. However, the results of the project can be used as an initial starting point and then be adapted to meet the needs of each of the First Nations, Inuit and Métis communities across Canada.

1.1. First Nations Communities

Wolf Lake, Quebec

Wolf Lake is a small community, with a population size of 205 on and off reserve members. Wolf Lake is situated near the Ontario border. The community is hoping that someday Wolf Lake will be recognized as a reserve. Wolf Lake is involved with several programs related to health issues which are funded by Health Canada. Furthermore, the education programs are funded by First Nations Education Council (FNEC) and additional funding was received from Commission de la santé et des services sociaux des Premières Nations du Québec et du Labrador (CSSSPNQL) for Wolf Lakes child care program. Wolf Lake community is supported by the Band from Indian and Northern Affairs Canada (INAC), which limits the funds received by Wolf Lake.

Listuguj, Quebec

Listuguj is a Mi'gmaq community situated on the border of Quebec and New Brunswick with a population size of 3,413 on and off reserve members. It falls within the tribal district of Gespe'gewa'gi, and it is a member of the Mi'gmawei Mawiomi Assembly. Listuguj community functions under the Indian Act of Canada. Its administration includes a Chief and twelve councilors, who are elected every two years by the Listuguj community members. Together, they convey important information and developments in certain program areas to their community members.

Gesgapegiag, Quebec

Gesgapegiag is a First Nations reserve on the south shore of the Gaspésie, and has a predominately Mi'kmaq ancestry, with a population size of 1,308 on and off reserve members. The majority of the members live on the federal Indian reserve that was allotted by the legislature of Lower Canada in 1853 for the restricted use of the Mi'kmaq in the region. The remaining members reside off the reserve in the eastern part of the United States of America and across Canada. However, these individuals remain in contact with the larger community through contemporary communications and in some cases, travel. Regardless of their residence, all community members partake in democratic elections, which are held every two years. They elect one Chief and twelve Councilors. The community is associated with other Mi'kmaq communities in the Gaspé region of Quebec and in northern New Brunswick. Collectively, their selected Chiefs proceed with ancestral claims to self-government and to the territory called Gespe'gewa'gi ('Kespékewáki), the last land.

Wendake, Quebec City (French-speaking First Nations Community)

Wendake is the current name for the Huron-Wendat reserve, an enclave within Quebec City, Quebec. One of the Seven Nations of Canada, this was formerly known as Village-des-Hurons ("Huron Village"). The Huron-Wendat of Wendake (formerly called the Hurons of Lorette) originally had territory in the Georgian Bay region. The current population of the Indian reserve is 1,341 persons within the community, and 1,696 persons outside the community. The land area is only 1.46 km^2 (about 360 acres).

Eskasoni, Nova Scotia

Eskasoni First Nation is the largest Mi’kmaq community in the world. Deeply rooted within Eskasoni is the Mi'kmaq culture. Eskasoni is the largest Mi’kmaq speaking community with close ties to traditional culture and beliefs. The community of Eskasoni is located about 50 kilometers from Sydney, the third largest city in Nova Scotia. Over the last several years, Eskasoni has made great strides in developing a solid infrastructure on which to grow and prosper. The community has its own community-operated school system from kindergarten to grade 12. Economic development is growing and new development is welcomed in the community. The community of Eskasoni has a proud history of supporting its young population with events that promote a healthy and active lifestyle among its 4,000 community members. With a dedication to improving the lives of its future generation, the Eskasoni community strives to be culturally rich and respectful of its ecosystem based on concepts of shared responsibility.

Conne River, Newfoundland and Labrador

Miawpukek is the traditional Mi'kmaw name for the community, while “Conne River” (meaning “Middle River”) is the more commercially used name. Miawpukek was established as a permanent community around 1822. The Miawpukek Reserve was established later in 1870, and was designated as Samiajij Miawpukek Indian Reserve under the Indian Act in 1987. Currently, the reserve is one of the two fastest growing communities in Newfoundland and Labrador, and serves as a model community for other First Nations.

1.2. Inuit Community

Postville, Newfoundland and Labrador

Postville began as a trading post and was originally called 'the Post.' The community of 250 people is located 25 - 30 km into the scenic interior of Kaipokok Bay, 110 air miles north-northeast of Goose Bay. The first known settler in Kaipokok was a Quebec merchant named D.D. Stewart who carried on a trading business which he sold to Hudson's Bay Company in 1837. The population began increasing in 1951 when a school and church were built. Contrary to other communities, Postville's main religion is Pentecostal. The local community council serves the people of the community. Health care is available at the nursing station staffed with a nurse and an assistant. Postville does not have a road providing access to other communities. However, the community recently completed a groomed snowmobile trail, which provides access to and from the community during the winter season.

1.3. Métis Community

Prince George, British Columbia

Prince George, with a Métis population size of 700 is known as "BC's Paper Mill Capital”. It is situated at the confluence of the Fraser and Nechako Rivers, and the crossroads of Highway 16 and 97; the city plays an important role in the province's economy and culture. Prince George Métis community is a very active community and holds numerous community gatherings through the Prince George Métis Community Association (PGMCA), an organization for the Métis citizens residing in Prince George, with a mission to represent the interest and rights of the Métis constituents and their citizenship, bringing unity inclusiveness to Métis people. The Métis community also holds several community celebrations and work closely with the several groups within the PGMCA such as the Nechako Métis Elders, Prince George Métis Elders, and Kikino Métis Children & Family Services in the areas of health and family well-being.

2. Working closely with the Communities on Project Implementation

2.1. Preparing for Focus Groups and Community Surveys

Once the communities were identified, a formal agreement was signed with each participating community which outlined main community responsibilities in the project (Appendix 1). The communities were given the ability to tailor project activities based on the unique characteristics and practices of their community while following the general guidelines and instructions established for the project. Each of the communities hired community outreach workers/community representatives to assist in completing the outlined project activities.

Project documents were designed with input from the communities involved in the project. For example, a health director in one of the participating communities (Eskasoni, NS) requested to review all project documents prior to them being distributed to the community members. All materials were also reviewed by the National Inuit Committee on Health (NICoH).

The communities were provided with all promotional materials to be used to outreach to community members and invite them to participate in the project. Community outreach workers promoted the project within the community by using promotional flyers (Appendix 7) and connecting with community members by phone or "word of mouth". A promotional flyer was distributed in each of the communities by the community outreach workers/representatives in helping recruit participants for the focus group as well as the community surveys. The flyer included the background information about the project as well as provided contact information for community outreach workers/representatives in case community members would like to participate in the project. Many communities distributed the promotional flyers everywhere to assist in the recruitment of participants. For example, Prince George community placed flyers on and off reserve as well as applied other outreach strategies such as sending emails directly to community members living in Prince George who had respiratory health conditions. The emails provided details on the focus group sessions, information on who was conducting the project, and included reimbursement details for participation. Prince George community recruited participants who were of First Nations ancestry, be they Métis, status or non-status, or Inuit who suffered from asthma or other chronic respiratory conditions.

Overall, the recruitment process went well in the majority of communities without facing many barriers to attract community members to participate in the project. However, in some communities such as Eskasoni (NS), the community representative had to overcome a few challenges when recruiting participants. The lack of participation was due to the lack of community outreach activities and creation of awareness about the project. Many participants who had agreed to attend the focus group sessions, decided not to attend on the day of the session. This was the challenge faced by the community representative who felt that there needed to be a more effective way to outreach to community members than one directly going to the houses of community residents or by "word of mouth" through the Elder female (the Grandmother).

The communities compiled a list of potential focus group participants and community survey participants. The main outreach activities were conducted out of the Health Care Centres; therefore, community outreach workers/representatives had knowledge on which individuals in their respective communities had or were connected to chronic respiratory conditions. The focus group and community survey participation was offered but not limited to the following community members: caregivers for children affected by asthma and associated allergies and their extended families; the Elders; school personnel; adults with chronic respiratory disease; general public; cultural/community leaders, and Community Chiefs. This project only included adults above the age of 18 years.

2.2. Recruitment Challenges

Overall, the ASC was effective in its recruitment strategies and met our recruitment targets for focus groups. However, some communities faced challenges in recruiting participants to participate in both focus groups and in the community survey. In Eskasoni, NS, the community representative indicated that there was little interest shown in many of the health programs in the community. In general, many community members do not like visiting the health clinic and if there are any health group sessions in the community, it is really hard to recruit participants. There are many who will agree to participate, but when the day comes for the sessions, each participant has to be called for confirmation and at this point, many participants will refuse to attend the sessions.

The best way to get community members to come to such sessions is if they have a female Elder living in the house, especially a Grandmother. The community members will listen to the Elder females in the house and if they tell them to attend sessions, everyone will comply. An Elder female is highly respected in the community and you may get a few youth who do not have a proper family structure and therefore, they are less compliant due to the lack of an Elder female role model in the house. The community also has many foster kids or kids without proper family structure. Further, another challenge they faced was that people would not attend any session unless you provided incentives for them to come, especially if they feel that this is not an issue of concern to them. This observation made while working with the communities shows how an outreach model needs to be applied at a community level in order to make it adaptable for individual communities depending on their needs, practices and traditions.

The timing of the project was the second biggest challenge in securing adequate participation, especially in completing community surveys. For example, the population size of the Inuit community in Postville, Newfoundland and Labrador is 250 people, and not all of the community members reside on reserve during this time of the year. During the summertime, many community members were taking time off to visit their family and friends off reserve. This factor decreased the number of available participants to complete the community survey within the project timelines.

2.3. Project Implementation

During the project, an effective liaison was established between the project team and the participating communities. Communication lines were kept open between community outreach workers/representatives and the project team at the ASC throughout the project. Individual packages were sent to the participating communities with the tools needed to fulfill the project activities. The packages were put together based on what project activities the communities had chosen to participate. While the participants were being recruited, the pre-assessment test (from the package) was distributed to the community residents by community outreach workers/representatives.

To ensure meaningful input of each community in the project, representatives from the communities were also invited to participate in the work of the Advisory Group and represent their communities. They were also asked to provide suggestions and ideas on a larger scope that would assist in designing a community outreach and engagement model and move towards developing educational materials and resources on respiratory health that could be used in First Nations, Inuit and Métis communities across Canada.

The dates for the focus groups were determined and finalized with the community leaders and community outreach workers. The focus groups dates and times were coordinated with each of the communities depending on availability of participants and health directors to be present during the focus groups (see Appendix 11 for details). In Postville, the project team and the community outreach worker had agreed initially to hold the focus groups on July 12th and 13th; however, due to a senior's lunch which was held at the same date and time, the focus group could not be carried out. This shows that having lunch with the Elders/seniors of the community is something that is valued highly by the community leaders. The focus group was rescheduled for the next day and facilitated by the community outreach worker.

The focus group venues were chosen by each of the respective communities, based on the central location for their community members. The venues that were chosen were mostly the community health centres, a familiar place to all the community members. The only venue that was not in a health care centre was in Prince George, BC where the focus group session was hosted in a youth centre called "Bladerunners", which is a youth program to assist youth in getting certificates required to work in the trade industry.

During the focus group sessions, a Traditional Opening Ceremony was delivered in some communities depending on their use of traditional practice. All necessary documents were collected prior to the focus group discussions. Confidentiality issues and any other concerns were also addressed before the start of the focus groups sessions. Refreshments during the focus group sessions were provided by the communities, and in some communities, there were also homemade lunches and dinners prepared for the participants. Initially the focus group sessions were allotted one hour each but in some cases they went for two to three hours as many participants had many things to share and discuss.

During the focus group discussions, community members were presented with various educational materials to gather their opinion about them and any other feedback. The main objective of this activity was to give participants a better idea of what kind of materials on respiratory health currently existed and gain a better understanding whether or not these materials could be useful in their communities. The environmental scan conducted at the beginning of the project was used to select the materials for review. As well, findings from the "A Shared Voice" report (Asthma Society of Canada, 2010) were used to compile the package of materials for assessment. Many of the selected materials were not designed specifically for First Nations, Inuit and Métis communities and were included in the package to understand how these materials could be modified to better suit the needs of the target population. The materials and resources were categorized and presented under each of the topics that were discussed in the focus group sessions (e.g. outdoor/indoor air quality, smoking, etc.). Refer to Appendix 10 illustrating the materials and resources shown during the focus group sessions. The community participants were asked throughout the focus group their opinion about the materials presented, whether they liked the format, style and/or images. They were also asked them how the material could be modified or adapted to be more culturally appropriate. The community participants in the focus group provided their opinions openly on several of the materials and their views are summarized in the Project Results section of this report. In brief, many found that checklists on mould were not "eye catching", while booklets with colorful tabs would be highly used in their communities. In Gesegiapeg, QC, many of the community participants felt that the chart "Anaphylaxis, asthma and allergies" developed by the Ontario Physical Health Education Association (OPHEA) in partnership with the Ontario Lung Association (OLA) and the ASC was the best way to present information. It was suggested that adding something like magnets on the back would be useful so community members could place the chart on their fridges and the educational tool would be of great benefit and something that the community members would want to have in their homes. Table 40 on page 91 shows the list of materials that were rated highly by First Nations, Inuit and Métis community members.

A thank you card (Appendix 12) and a reimbursement cheque for $50 was mailed out to the focus group participants by the ASC. Individuals were reimbursed for their participation, regardless of whether they only participated in the focus group or if they only completed the pre-assessment questionnaire. The community surveys were collected by the community representatives and then sent to the ASC for analysis. No reimbursement was provided by the ASC for the survey participation. The reimbursement of participants was left up to the communities who had been funded for their participation. This was specified in the agreement letter with each participating community. It was up to the community's discretion on how they wanted to reimburse the survey participants according to what they felt would be a good incentive to give in order to have the community surveys completed.

After the focus groups, many communities requested having packages sent to them with information about asthma and associated allergies. Several packages were prepared by the ASC depending on the need and request made from the communities (see Appendix 18 for the package distribution). The French-speaking First Nations community of Wendake, QC, was interested in any materials the ASC could provide in French which they could start to distribute or use in their health clinic. For example, they requested a video that taught about asthma, even though it was not specifically designed for First Nations communities. The healthcare workers in Wendake were willing to use the existing materials because they felt that starting with any materials would be beneficial to the community. If later on, a video was developed targeting French-speaking First Nations communities, they felt that it would overall benefit the community as well. In Postville, Newfoundland and Labrador, the nurse practitioner pointed out that they could get resources on respiratory conditions from lung health organizations. However, they do not usually get enough resources to distribute to community members and use in many existing programs. Being able to access the sufficient amounts of resources in hard copy was one of the challenges that this community faced. The community nurse practitioner expressed a willingness to promote awareness on how social determinants affect one's respiratory health and just needed the right information and resources that she could pass around.

3. Description of Project Participants

Participants involved in the project can be characterized based on their age, gender, place of residence, Aboriginal status, education level, role in the community as well as their connection to chronic respiratory disease, and smoking status. The mentioned above demographic characteristics are presented below for focus group and survey participants separately.

3.1. Focus Group Participants

3.1.1. Demographics and culture

The majority (76.8%) of the focus group participants were women (n=43). Out of the total number of participants (n= 56), most (80.4%) were mature adults over the age of 35 with 30% of the total group being above the age of 60 (refer to Appendix 19 for graphical presentation of age distribution).

The majority of participants were First Nations community members (66.1%) followed by Inuit (14.3%), Métis (12.5%), and then non-Aboriginal community members living in Aboriginal communities (7.1%) (refer to Appendix 20 for graphical presentation of results). When asked about whether they spoke their Native language, less than one third (29.1%) reported that they spoke an Aboriginal language and of those, most (81.9%) spoke Mic Mac (identified in the pres-assessment test as Mic Mac, Migmag or Mikimak). One respondent spoke Cree (9.1%), while another spoke "*Mischief-Cree Base*" (9.1%). Only 4 respondents (8.2%) read an Aboriginal language or syllabics.

Among the focus group participants, 47.3% resided in Quebec, 29.1% resided in Newfoundland and Labrador, 18.2% resided in British Columbia, and 5.5% resided in Nova Scotia (refer to Appendix 21 for graphical presentation of distribution by province). While half of the participants (50.0%) reported that they lived 'on reserve', another 14.3% lived 'off reserve' (19.6% reported living 'in the village' and 16.1% reported living 'in the city').

3.1.2. Participant education level and role in the community

When participants were asked about their education level, 50% of the participants completed some form of post-secondary education and another 32.7% received a high school diploma. Two respondents (3.8%) reported that they had received 'no schooling'. One person wrote that they completed "*online studies*".

When asked about their role in the community, the majority of participants (73.2%) identified themselves as a 'community member' followed by 'family member to someone with chronic respiratory disease' (chosen by 32.1% of participants). Table 4 below provides the complete breakdown of reported roles in the community by project participants.

Table 4: Participant self-reported role in the community, focus group participants

Community member	**73.2%**
Family member to someone with chronic respiratory disease	32.1%
Elder	17.9%
Community leader	8.9%
Friend to someone with chronic respiratory disease	10.7%
Healthcare provider (please specify):	12.5%
Nurse	1.8%
Diabetes educator	1.8%
Community health representative	3.6%
Health director	1.8%
Community health worker	1.8%
Medical receptionist	1.8%
Other (please specify):	12.5%
'taxi driver'	1.8%
'someone with chronic respiratory disease'	1.8%
'boards'	1.8%
'administration worker'	1.8%
'social worker'	1.8%
'elected government member'	3.6%
Teacher	7.1%
Community Chief	3.6%

3.1.3. Participants connection to chronic respiratory disease

Over half of participants (57.7%) reported that they suffered from a chronic respiratory condition. Among those, 42.9% suffered from asthma, 14.3% from chronic bronchitis, 5.4% from Chronic Obstructive Pulmonary Disease (COPD) and 5.4% from recurrent respiratory infections (refer to Appendix 22 for graphical presentation of results). Some open ended descriptions of their respiratory conditions also included: "*coughing spells*", "*allergic reaction for some stings and food*", and "*seasonal allergies*". The same pattern was observed for each Aboriginal community with the lowest percentage of participants affected by chronic respiratory disease (37.5%) in the Inuit community and the highest percentage in the Métis community (71.4%). Amongst chronic respiratory conditions, asthma was the most commonly identified in all communities followed by chronic bronchitis.

Almost half of participants (48.0%) were a parent/caregiver or guardian of an individual who suffered from a chronic respiratory condition. Among this group, the specific conditions are provided in Table 5 below.

Table 5: Participant-reported connection to chronic respiratory disease as a caregiver, focus group participants

Asthma	**32.1%**
Allergies	23.2%
Chronic Bronchitis	7.1%
Recurrent respiratory infections	3.6%
Reactive Airway Disease	1.8%

Over half of participants (59.6%) reported that they suffered from allergies. The types of reported allergies are broken down into the following categories and presented in Table 6 below.

Table 6: The type of self-reported allergies among focus group participants

Seasonal allergies (hay fever) due to:	**32.1%**
Tree Pollen	23.2%
Grass Pollen	19.6%
Ragweed Pollen	17.9%

Perennial allergies due to:	**32.1%**
Pet Dander	19.6%
Dust mites	17.9%
Mould and Mildew	10.7%
Cockroaches	1.8%

Food allergies	**14.3%**

Of those with allergies, 30.4% reported that their condition was confirmed by allergy testing, for 25% of participants it was confirmed by a physician, and 23.2% of participants reported that they had symptoms.

3.1.4. Smoking status

The current smoking status was confirmed by 23.1% of participants. When asked to choose from a list to identify ‘which products do you smoke each day’, 21.4% chose ‘manufactured cigarettes' and only 3.6% chose 'hand rolled cigarettes'. The graphs in Appendix 23 depict the reported number of years that current smokers have been smoking and the reported number of cigarettes smoked per day.

Another 46.9% of participants reported being ex-smokers and of this group, 53.6% used to smoke manufactured cigarettes, 14.3% smoked hand rolled cigarettes, and only 5.4% smoked pipefuls of tobacco. Only 12 people reported the year they quit smoking and the dates ranged from 1975 to 2010.

3.2. Survey Participants

3.2.1. Demographics and culture

The majority of the survey participants (67.8%) were women (n=101). The largest age group was '45 to 49' (16.5% of participants) followed by 'age 60 and over' (13.3% of participants) and '35 to 39' (12.7% of participants). The smallest group was 'age 20 to 24', making up only 4.4% of the participants (refer to Appendix 19 for graphical representation of age distribution). Overall the project was not intended to capture participants 18 years of age and younger; however, the level of participation for young adults appears to be very low. Many of the participants were of older age, suggesting that involving youth and young adults by creating more education and awareness should be considered when outreaching to communities through the community outreach and engagement model.

The majority of the survey participants were members from First Nations communities (50.3%) followed by Inuit (23.3%), non-Aboriginal (14.5%) and Métis (11.9%) (refer to Appendix 20 for graphical representation of the results). Three respondents did not report their Aboriginal heritage. Furthermore, only 19.2% (n=30) spoke an Aboriginal language and of those, most participants spoke Mic Mac (62.9%), followed by Inuit, Algonquin, Cree and Carrier (7.4% each); Ojibwe (3.7%) and "Hungarian" (3.7%). A small number of participants (5.3%) reported reading an Aboriginal language or syllabics.

Among survey participants, 43.5% resided in Newfoundland and Labrador, 26.7% resided in British Columbia, 14.3% resided in Quebec, 14.3% resided in Nova Scotia and 1.2% in Ontario (refer to Appendix 21 for graphical presentation of distribution by province). Further, 31.4% of participants reported that they lived 'on reserve', 17.6% lived 'off reserve' (with 29.6% lived 'in the village' and 21.4% 'in the city').

3.2.2. Participant education level and role in the community

When participants were asked about their education level, out of 144 who answered the question, 43.8% completed some form of post-secondary education, another 30.6% received a high school diploma, and another 21.5% completed elementary school (4.2% were 'not comfortable to answer' the question).

When the survey participants were asked about their role in the community, most (65.4%) identified themselves as a ‘community members’ followed by a ‘family member to someone with chronic respiratory disease’ (chosen by 15.4% of participants). Table 7 below provides the complete breakdown of reported roles in the community by survey participants.

Table 7: Participant self-reported role in the community, survey participants

Community member	**65.4%**
Family member to someone with chronic respiratory disease	15.4%
Friend to someone with chronic respiratory disease	14.8%
Other (please specify)(18 different answers, i.e. volunteer, lawyer and daycare operator :	11.1%
Elder	9.3%
Community leader	5.6%
Healthcare provider (please specify):	6.2%
Caregivers	1.2%
Home visitor	0.6%
Nurse	0.6%
Teacher	4.9%
Community Chief	2.5%

3.2.3. Participants connection to chronic respiratory disease

When looking at the connection the survey participants had to chronic respiratory conditions, the majority (65.6%) reported that they did not suffer from a chronic respiratory disease (refer to Appendix 22 for graph representation of the results). Those who had a respiratory condition were further asked to list any respiratory conditions that they suffered from, if any, and 19.3% chose ‘asthma’. The percentage by which other chronic respiratory conditions were chosen is presented in Table 8 below. Eight respondents also provided written descriptions of their respiratory condition including: “*sinus*”, “*pneumonia*”, “*possible lung cancer*”, “*I cough a lot, smoking*”, “*cystic fibrosis*”, and “*bronchitis as a baby*”.

Table 8: Participant-reported connection to chronic respiratory disease, survey participants

Asthma	**19.3%**
Chronic bronchitis	6.8%
Recurrent respiratory infections (common cold)	4.9%
Chronic Obstructive Pulmonary Disease (COPD)/Emphysema	2.5%
Reactive Airway Disease	0.6%

Having most focus group participants (57.7%) with chronic respiratory disease and most survey participants (65.7%) without a respiratory condition allowed us to collect perspectives of both groups: people affected and not affected by chronic respiratory disease.

When we looked for the number of people affected by the disease by the individual Aboriginal group, the same distribution was observed (Table 9). Among the disease mentioned most commonly in each of the communities, asthma was identified most often in all of the communities followed by chronic bronchitis.

Table 9: Participant-reported connection to chronic respiratory disease, by Aboriginal community

Do you suffer from a choric respiratory condition?	First Nations	Inuit	Métis	Non-Aboriginal
Yes	31.2%	37.8%	44.4%	31.8%
No	68.8%	62.2%	55.6%	62.8%

Overall, 20.9% of survey participants were a parent/caregiver or guardian of an individual who suffered from a chronic respiratory condition. Of this group, the specific conditions identified are presented in Table 10 below. Two respondents also provided open ended answers under 'Other' and wrote: "*sinus*" and "*sinusitis*". When looked at the individual Aboriginal communities, the similar percentage of caregivers was observed in the First Nations and Inuit community (21.5% and 29.7% respectively) with a lower level of caregiver participation in the Métis community (11.1%) as well as non-Aboriginal participants (13.6%).

Table 10: Participant-reported connection to chronic respiratory disease as a caregiver, survey participants

Asthma	**14.8%**
Allergies	6.8%
Chronic Bronchitis	3.1%
Recurrent respiratory infections	2.5%
COPD/Emphysema	1.9%
Reactive Airway Disease	1.9%

Almost half of survey participants (49.4%) reported that they suffered from allergies. The types of allergies are broken down and presented in Table 11 below.

Table 11: The type of self-reported allergies among survey participants

Perennial allergies due to:	31.5%
Mould and Mildew	19.8%
Pet Dander	19.1%
Dust mites	17.9%
Cockroaches	1.2%
Seasonal allergies (hay fever) due to:	24.1%
Tree Pollen	16.0%
Grass Pollen	15.4%
Ragweed Pollen	10.5%
Food allergies	13.0%

Of those with allergies, 24.7% of participants had their allergies confirmed by a physician, 21% reported that they had symptoms, and 14.8% reported that their condition was confirmed by allergy testing. Additional open ended responses to the question 'who told you that you had allergies?' included: "*nurse*", "*allergy test in hospital*", "*hospitalized a few times*", and "*burning eyes*".

In summary, there was consistency in demographic characteristics between the focus group and survey participants. Most participants in both activities were mature adults, identifying themselves as 'community members', and completed some post-secondary education or high school. There was also consistent participation amongst First Nations, Inuit and Métis community members in the focus group and community surveys. The majority of participants in both activities (the focus group sessions and the community surveys) were from First Nations communities (66.1% and 50.3% respectively) followed by Inuit (14.3% and 23.3%, respectively) and Métis (12.5% and 11.9%, respectively). Less than one third of the participants in both activities (focus groups and community surveys) reported that they spoke an Aboriginal language (29.1% and 19.2% respectively).

Despite the commonalities outlined above, there were some differences between the population groups who participated in the project. Focus group participants mostly came from Quebec and Newfoundland and Labrador while the majority of survey participants were from Newfoundland and Labrador and British Columbia. Further, focus group participants were mostly from on reserve (50.0%) with this percentage being lower (31.4%) for the survey participants. The majority of focus group participants suffered from chronic respiratory disease (57.7%) in comparison to survey participants who were mostly not affected by any chronic respiratory condition. As well, a higher number of caregivers of an individual who suffered from a chronic respiratory condition participated in the focus groups sessions (48.0%) compared to the community surveys (20.9%).

There were also some similarities related to self-reported connections to chronic respiratory disease between focus group and survey participants. In both groups, people who were affected by chronic respiratory disease mostly reported suffering from asthma. Further, caregivers who participated in both focus groups and community surveys mainly cared for people with asthma. There were also a higher number of people involved in both activities who suffered from allergies (59.6% in focus groups and 49.4% in community surveys).

The observed commonalities between the population groups participating in the focus groups and community surveys allowed us to summarize the results of projects by combining these two activities. The observed differences helped bring additional perspectives from both individuals affected and not affected by chronic respiratory disease as well as people living on and off reserve.

V. Partnerships and Intersectoral Collaboration

The main partnerships that were maintained and/or established for this project can be divided into four main categories based on the partner's involvement, their role and their contribution to the project as follows: 1) Key Partners; 2) Community Partners, 3) Support Partners, and 4) Project Advisors (the Advisory Group). Detailed information about each of the partners and their respective involvement in the project implementation and activities is summarized below.

1. Key Project Partners

The project was initially developed in partnership with the AFN and ITK and built on the previous successful collaboration between the ASC and these organizations. In 2008/09, the ASC, the AFN and ITK conducted a baseline needs assessment of asthma and allergy resources and programs available for First Nations and Inuit communities and produce the "A Shared Vision" report (Asthma Society of Canada, 2009). This project did not include issues related to asthma/associated allergies and other chronic respiratory conditions that were faced by Métis communities; therefore, one of the goals of the current project was to create a partnership with a Métis organization to conduct project activities in one of the Métis communities. The ASC approached the Métis Nation British Columbia and secured them as the key partner to implement the project in one of the Métis communities in British Columbia.

The overall goal of the established partnerships (the AFN, ITK, and the MNBC) was to ensure proper implementation of the project in First Nations, Inuit and Métis communities by using approaches and strategies that are respectful and appropriate for community members. The invaluable expertise of these organizations in working closely with Aboriginal communities and their knowledge of the unique issues in these communities made significant contribution to achieving the project objectives. They were also instrumental in securing specific communities to be involved in the project and establishing connections with the key community contacts. Further, the key partners participated in the development/review of all data collection tools and other documents related to the project to ensure that all documents were culturally sensitive. In addition, a representative from each organization was a member of the Advisory Group.

Overall, the project helped strengthen the relationship with the AFN and ITK as well as create new partnerships with Métis Nation British Columbia (MNBC). A brief organizational overview of the key partners and their specific role in delivering the project activities is presented below.

1.1. Assembly of First Nations (AFN)

Background: The Assembly of First Nations (AFN) is the national organization representing First Nations citizens in Canada. The AFN represents all citizens regardless of their age, gender or place of residence. Dr. Kim Barker, an AFN representative, helped select potential communities to participate in the project and establish agreements with five of the First Nations communities from Quebec and Nova Scotia.

Participation of the sixth First Nations community from Newfoundland and Labrador in the project was secured by the community nurse practitioner, Ada Roberts who was involved previously with the ASC on the implementation of the "A Shared Voice" project (Asthma Society of Canada, 2010). The community had expressed great interest to be involved in future projects conducted by the ASC and was invited to participate in the current project. Ada Roberts also represented her community on the Advisory Group.

Role: The AFN contributed to the project implementation by reviewing materials developed by the project team and making necessary recommendations for changes. It also assisted in identifying focus group locations, helped with securing participants, and identified strategies to assure adequate participation in focus groups. The AFN was instrumental in developing the community outreach model and bringing the unique perspectives of First Nations community members from across Canada. The AFN will be also involved in disseminating project results to First Nations communities (see the Results Dissemination section of this report for detail).

1.2. Inuit Tapiriit Kanatami (ITK)

Background: Inuit Tapiriit Kanatami (ITK), formerly Inuit Tapirisat of Canada, is the national voice of Canada's Inuit. Founded in 1971, the organization represents and promotes the interests of Inuit. In its history, ITK has been effective and successful at advancing Inuit interests by forging constructive and co-operative relationships with different levels of government in Canada, notably in the area of comprehensive land claim settlements, and representing Inuit during the constitutional talks of the 1980s. ITK is comprised of four regional Inuit organizations; these groups have specific mandates to represent Inuit on a variety of regional, national and international issues that fall outside the terms of the land claim settlements.

Role: ITK was involved in identifying communities for the project by helping the project manager to connect to each of the Inuit regions and explore their willingness to work on the project. As well, ITK helped the project manager to understand Inuit considerations for research and prepare all necessary documents to be compliant with the established research-related practices.

Joni Boyd, Senior Policy Advisor, Department of Health and Environment, ITK helped to identify potential communities to participate in the project and to secure participation of the Inuit community in Postville, Newfoundland and Labrador. Joni Boyd also served as a liaison between the project team and the National Inuit Committee on Health (NICoH) which participated in reviewing and approving of all documents related to the project.

1.3. Métis Nation British Columbia (MNBC)

New partnerships and collaborations were built throughout the project and a valuable new partnership was established with Métis Nation British Columbia (MNBC). This newly created collaboration helped identify an appropriate Métis community to participate in the project.

Background: MNBC is a provincially governed body for the Métis National Council (MNC). The MNBC was created in 1996 and was formally incorporated as the Métis Provincial Council of British Columbia (MPCBC). MNBC represents thirty-seven (37) Métis chartered communities in British Columbia. Their mandate is to develop and enhance opportunities for Métis communities by implementing culturally relevant social and economic programs and services.

Role: As the issues related to chronic respiratory disease for Métis communities are not as well identified, this partnership allowed the ASC to explore this issue in Métis communities and learn about their perspectives on respiratory health education and awareness program and materials. The MNBC helped the project team to identify a Métis community in British Columbia and to work with the community towards achieving the project goals.

The MNBC demonstrated great interest in participating in the current project as well as collaborating on future projects conducted by the ASC. The MNBC represents the Métis Nation Council (MNC) on the project, the larger governing body for Métis communities across Canada. Tanya Davoren, Health and Sport Director at MNBC helped establish a connection with the MNC and served as its representative on the project. Tanya Davoren was very instrumental in developing all project documents, specifically bringing information about the programs available for Métis community members to be included in the environmental scan.

In summary, the ASC continues to strengthen its partnerships with the core existing partners (the AFN and ITK) as well as its new partners (MNBC). This has further established an intersectoral collaboration where ITK, AFN and MNBC work together in representing their respective communities of First Nations, Inuit and Métis individuals across Canada. This collaboration will continue to grow and knowledge gained in this project will be used to implement the community outreach model and develop culturally appropriate materials and resources for Aboriginal communities.

2. Community Partners

This project also provided the opportunity to collaborate and form partnerships with the communities and community leaders/representatives in their respective First Nations, Inuit and/or Métis communities. The ASC worked closely with the AFN, ITK and the MNBC to secure community participation in the project. Initially, it was planned to recruit five communities (two First Nations, two Inuit and one Métis). However, because of the interest to participate in the project, eight communities were secured (six First Nations, one Inuit and one Métis). The communities involved in the project and their leaders/representatives are listed in Table 12 below. The communities have shown a great interest in continuing to participate in future projects conducted by the ASC as well as made a commitment to be involved in piloting the community outreach and engagement model designed as part of this project.

Role: The communities assisted in reaching the goals and objectives of the project by completing the activities of the project and will continue to provide assistance during results dissemination activities and the potential implementation of the model as well any future projects conducted by the ASC.

Table 12: The list of community leaders involved in the project, by community

Community	Community Leaders/Representatives	Affiliation
Listuguj, QC	Donna Metallic	Director of Health, Community Health Services
Gesgapegiag, QC	Eleanor Pollic	Health Director
Wolf Lake, QC	Sonia Young	Health Director
Wendake, QC (French-speaking)	Michielline Roy	Health Director
Conne Rivers, NL	Theresa O'keefe	Director, Health & Social Services
Eskasoni, NS	Sharon Rudderham	Health Administrator, Eskasoni Community Health Centre
Postville, NL	Keith Decker Shirley Goudie	Mayor of Postville Town Clerk
Prince George, BC	Tom Spence	Prince George Métis Community Association (PGMCA) President

With regard to Inuit communities specifically, we had to take into consideration methods and processes that are typical for research conducted in Inuit communities. For example, completing any projects on Inuit Land requires approval from the governing body of that community. ITK assisted in finding an Inuit community, Postville in Newfoundland and Labrador to participate in the project. Postville community is governed by the Nunatsiavut Government, which is an Inuit regional government within the province of Newfoundland and Labrador designed to operate at both the regional (departmental) level and on a community level. The community level is comprised of five Inuit communities, Postville being one of them. Any form of research conducted in Nunatsiavut needs to be disclosed to the Nunatsiavut government with their full knowledge and participation as well as that of the community participants. The current practice for any potential research/baseline needs assessment proposal is that the project team must first approach the Inuit Research Advisor (IRA) and submit an application for consideration and approval before the project can proceed with any project activities in the specific Inuit community. This is done to ensure that the privacy and identity of participants within the community are respected and protected.

The ASC project team submitted an application to the Nunatsiavut government. Assistance in completing the application and supporting documents was provided by Tina Buckle, a Nunatsiavut government representative and member of the Advisory Group. John Lampe, the IRA for the Nunatsiavut government reviewed the application and other related documents. The ASC were successful in its application and received a letter of support by the Nunatsiavut government on May 26, 2010 (refer to Appendix 24 for the letter of support issued by the Nunatsiavut government).

3. <u>Support Partners</u>

3.1. AllerGen NCE Inc.

Background: AllerGen, National Centre of Excellence (NCE) for asthma and allergy research represents a network of researchers across Canada. Its main goal is to improve the quality of life for allergy and asthma suffers by conducting research that leads to an understanding of the causes of inflammatory diseases such as asthma and allergies and reductions in the impact of allergic and related immune diseases nationally and globally. Part of its mission is to support networking, capacity building, and knowledge translation that contribute to reducing the morbidity, mortality and socio-economic burden of allergic and related immune diseases.

Role: the ASC was previously involved with AllerGen NCE Inc. on several projects including the “A Shared Vision” report (Asthma Society of Canada, 2009). For this project, AllerGen provided its research and academic expertise on the data collection design by evaluating and reviewing the data collection tools and advising on appropriate data collection methodology and approaches. It also guided the ASC in the overall project implementation as well as provided its expertise on community engagement approaches and the development of the community outreach model. Further, it was involved in reviewing/completing the environmental scan by giving suggestions on what kind of literature/resources should be included in the scan. Dr.

Heather Castleden, Assistant Professor, School for Resource and Environmental Studies, Dalhousie University represents AllerGen on the project and sits on the Advisory Group. Principal investigators (Drs. Heather Castleden, Miriam Stewart and Jeffrey Masuda) of projects funded by AllerGen in the area of respiratory health and Aboriginal communities were also kept informed on the current project.

As other partners and project supporters, AllerGen will be involved in dissemination of project results through its respective network of researchers, trainees, and partners.

3.2. National Collaborating Centre for Aboriginal Health (NCCAH)

Background: The NCCAH supports a renewed public health system in Canada that is inclusive and respectful of First Nations, Inuit and Métis community members. The NCCAH uses a holistic, community-centered and strengths-based approach to health, fostering the links between evidence, knowledge, practice and policy. The NCCAH also helps advance self-determination and Indigenous knowledge in support of optimal health and well-being.

Role: The NCCAH came on board as a new support partner and brings its knowledge and expertise on social determinants of health. It also provided their knowledge and expertise on culture, language and traditions of First Nations, Inuit and Métis communities. Further, the NCCAH provided support by being involved in the work of the Advisory Group and reviewing data collection tools and other documents (e.g. the environmental scan). The Centre was also involved in developing the community outreach model as one of the models developed by the NCCAH (the Integrated Life Course and Social Determinants Model of Aboriginal Health, Dolan A.H., Ommer R., 2008) was used as a base to design the draft community outreach and engagement model for this project (Reading C.L., Wien F., 2009).

As other partners, the NCCAH will be involved in the dissemination of the final report (refer to the communication plan in the Results Dissemination section of this report).

4. Project Advisors (the Advisory Group)

The Advisory Group was established to oversee and guide the project implementation. The representatives from the key partner organizations (the AFN, ITK, and MNBC) as well as project supporters (AllerGen, the NCCAH) were invited to participate in the work of the Advisory Group. Invitations were also sent to representatives from the communities involved in the project. Additionally, key opinion leaders in the area of First Nations, Inuit and Métis communities were offered the opportunity to be involved in the Advisory Group in a consultative role.

The Advisory Group panel consists of **14** members (refer to Appendix 5 for the Advisory Group list) with various backgrounds and diverse knowledge, expertise, and experience in working with First Nations, Inuit and Métis communities. The Advisory Group consists of representatives from our key partners: Dr. Kim Barker (the AFN), Joni Boyd (ITK), and Tanya Davoren (MNBC) as well as our support partners: Dr. Heather Castleden (AllerGen) and Donna Atkinson (the NCCAH).

Expertise in respiratory health and Aboriginal communities is provided by Dr. Dilini Vethanayagam, MD, FRCPC; Associate Professor, University of Alberta and Dr. Louise Brenda Giles, Pediatric Respirology Program Director, University of Manitoba. Dr. Wayne Warry, Professor, Department of Anthropology, McMaster University, is a medical anthropologist who provided a wealth of expertise and knowledge of Aboriginal culture, language and traditions. He also acted as a Principal Investigator for the project to receive the REB approval.

In addition, the Advisory Group included the following community representatives: Ada Roberts, Nurse Practitioner (Conne Rivers, NL); Sonia Young, Health Director (Wolf Lake, QC); and Catherine Turner, a Métis representative. Catherine Turner also brings her own perspectives as someone personally affected by chronic respiratory disease.

On a government level, Tina Buckle Community Health Nursing Coordinator, Nunatsiavut Government, Department of Health and Social Development represents the Nunatsiavut Government on the Advisory Group and project.

Each member of the Advisory Group fully participated in the work of the Group and provided their expert knowledge on data collection tools, the environmental scan, other documents as well as the development of the community outreach and engagement model. All Advisory Group members were involved in designing the outreach model and making recommendations for future development of educational materials and resources. The Advisory Group also provided overall guidance and advice on project implementation and its activities.

5. Other Project Partnerships and Collaboration

During the project, the ASC collaborated with the project leads of two other projects funded through the National Lung Health Framework (NLHF) phase I funding to assure that the projects complemented one another as follows:

1) The project "Smoking: Can We Change?/Ajisitijirunnaqp" was implemented by the Government of Nunavut Organization in partnership with the Nunavut Department of Health and Social Services and funded through the National Lung Health Framework (NLHF) (NLHF Secretariat, 2010). As smoking-related information and materials available for Aboriginal communities were assessed as part of the ASC project, the project lead for this project was asked to provide feedback on the smoking and tobacco use section of the data collection tools (e.g. the pre-assessment questionnaire and the community survey) to make sure that the asked questions were culturally appropriate and sensitive.

2) The British Columbia Lung Association who were working on the project “Establishing Need for Awareness Initiatives about Risk Factors for Respiratory Diseases among Health Professionals Working with First Nations, Inuit and Métis Communities” provided the ASC project team with a link to the questions that were used in their project to survey health care professionals working with Aboriginal communities. This helped develop questions for community members to be included in the data collection tools for the ASC project while maintaining consistency with the questions targeted at healthcare professionals.

In addition, the ASC informed the Canadian Action Network for the Advancement, Dissemination and Adoption of Practice-informed Tobacco Treatment (CAN-ADAPTT) about the project and is planning to collaborate with them more widely on the development of educational programs/materials to address issues related to tobacco use and second-hand smoke exposure in First Nations, Inuit and Métis communities.

VI. Project Results

One of the key project activities was to conduct focus groups with Aboriginal community members to explore their perspectives on what kind of resources and educational materials should be available in their communities to raise awareness of risk factors for chronic respiratory disease. This activity consisted of two main components: (I) Administering the pre-assessment test (Appendix 4) to determine a basic level of knowledge about risk factors for chronic respiratory disease as well as identify people’s awareness about existing community resources on respiratory health, and (II) Conducting the focus groups with community members. Main findings from both activities are presented below in detail.

1. Pre-assessment Test Results

The pre-assessment test was administered before the focus group discussion to all participants. Participants were asked a set of questions with three possible answers: ‘Yes’, ‘No’, and ‘I do not know’. A total of **56** pre-assessment questionnaires were completed. The data was entered into SPSS v.14 program for quantitative analysis. Answers to closed-ended questions are reported below as percentages inferred from the frequency counts. Open-ended responses were counted and grouped with excerpts quoted or paraphrased where appropriate.

The main aim of the pre-assessment test was to determine participant knowledge of risk factors such as (1) outdoor air quality, (2) housing/indoor air quality, and, (3) non-traditional tobacco use, which can lead to chronic respiratory disease such as asthma, COPD/emphysema, and chronic bronchitis. At the end, participants were also asked questions to test their understanding of chronic respiratory disease. A summary of their responses was compiled under each category as follows:

1.1. Outdoor Air Quality

Of all the respondents who answered this section of the test (n=54), 100% believed that human health could be affected by outdoor air pollution. Most participants (75.9 %) felt that the air quality in their community is affecting the health of people living in their community (18.5% chose ‘No’ and 5.6% chose I don’t know’). These responses were consistent when analyzed by each cultural community.

Almost all of the participants (98.1%) thought that air pollution can increase the risk of developing respiratory diseases (e.g. COPD/emphysema and/or asthma). The majority of participants also felt that reducing outdoor air pollution levels can help reduce respiratory infections (3.8% said ‘No’ and 5.7% chose ‘I don’t know’). Further, participants were asked about potential sources of outdoor air pollution in their communities. The majority of them believed that both road dust and non-traditional tobacco smoke in public places were a source of outdoor air population in their communities (Table 13). Most of them also confirmed that ‘wind carried from nearby communities’ could be a source of air pollution.

Table 13: Participant-identified potential sources of air pollution in their communities

	Yes	No	I don’t know
Do you feel that road dust is a source of outdoor air pollution?	87.0%	3.7%	9.3%
Do you feel that wind carried from nearby communities can be a source of outdoor air pollution?	77.8%	11.1%	11.1%
Do you feel that non-traditional tobacco use (cigarette smoking) is a source of outdoor air pollution (i.e. public places)?	85.2%	11.1%	3.7%

Participants were also asked to specify if any information on outdoor air quality was available in their community and whether or not they were aware of any community resources on respiratory health and outdoor air pollution (Table 14). Almost half of the participants (42.6%) did not know if any information was available and 37% of participants believed that this information did not exist. Further, half of the participants (51.8%) did not know or were not sure about existing community resources on outdoor air quality and respiratory health (29.6% answered ‘No’ and 22.2% ‘I do not know’).

Table 14: Participant awareness of community resources on respiratory health and outdoor air quality

	Yes	No	I don’t know
Is there any information on outdoor air quality available in your community?	20.4%	37.0%	42.6%
Are you aware of any resources in your community that offer advice/information/educational materials about lung disease and outdoor air quality?	48.1%	29.6%	22.2%

Amongst Aboriginal communities, the Métis community was more aware about information on outdoor air quality available in their community as most (71.4%) agreed that the information was available. The majority of Métis participants (71.4%) were also aware of community resources that offer advice and educational materials about lung disease and outdoor air quality. Responses provided by First Nations and Inuit communities were consistent with the overall data (Table 15).

Table 15: Participant awareness of community resources on respiratory health and outdoor air quality, by cultural community

Is there any information on outdoor air quality available in your community?	**First Nations**	**Inuit**	**Métis**	**Non-Aboriginal**
Yes	8.6%	25.0%	**71.4%**	25.0%
No	**45.7%**	**35.7%**	0%	25.0%
I don't know	**45.7%**	**35.7%**	28.6%	25.0%
Are you aware of any resources in your community that offer advice/information/educational materials about lung disease and outdoor air quality?				
Yes	45.7%	50.0%	**71.4%**	25.0%
No	34.3%	37.5%	0%	25.0%
I don't know	20.0%	12.5%	28.6%	50.0%

1.2. Housing/Indoor Air Quality

The majority of respondents (80.4%) thought that 'not having good indoor air quality could increase the risk of chronic respiratory diseases such as COPD/emphysema and/or Asthma' (5.4% chose 'No' and 14.3% chose 'I don't know'). These results were consistent with answers obtained from participants in each Aboriginal community except a slightly lower number of participants (62.5%) agreeing with the statement in the Inuit community. While 78.6% of respondents felt that 'cooking and heating with solid fuels (wood or coal) on open fires or stoves without chimneys' could lead to poor indoor air quality, 16.1% of participants believed that it did affect it and 5.4% did not know how to answer this question. Fewer respondents (56.4%) thought that using solid fuels (e.g. wood or coal) could lead to COPD development. Another 32.7% reported that they did not know if cooking with solid fuels could lead to COPD and 10.9% thought it would not lead to the disease. The majority of participants (76.8%) also thought that indoor temperature, humidity and air circulation had an effect on the development of respiratory diseases (7.1% chose 'No' and 16.1% chose 'I don't know').

All 56 respondents (100%) believed that mould could influence air quality in their house and that its growth happened in moist/damp areas. Almost all respondents (94.6%) thought that mould could cause lung disease and allergies (1.8% chose 'No' and 3.6% chose 'I don't know'). The answers provided were consisted across Aboriginal groups with the majority of participants believing that mould could cause lung disease and allergies (agreed by 94.6% of First Nations participants; 100% of Inuit participants and non-Aboriginals living in Aboriginal communities, and 85.7% of Métis participants).

Most respondents (89.1%) believed that dust mites could influence air quality in their house (7.3% chose 'No' and 3.6% chose 'I don't know'). As well, 96.4% agreed that dust mites could gather in carpet or beddings. Fewer respondents (62.5%) thought that dust mites in carpet and beddings could lead to the development of asthma (16.1% chose 'No' and 21.4% chose 'I don't know'). The same tendency was observed in each Aboriginal community; however, Métis participants appeared to be slightly less knowledgeable about the issue (Table 16).

Table 16: Participant awareness of dust mites as a risk factor for asthma development, by cultural community

Do you think that dust mites in beddings, carpets in your house can lead to the development of asthma?	**First Nations**	**Inuit**	**Métis**
Yes	64.9%	50.0%	**42.9%**
No	13.5%	25.0%	28.6%
I don't know	21.6%	25.0%	28.6%

When asked if they knew of any materials or resources in their community that could help them understand how to prevent mould in their household, 53.6% answered 'Yes', and 46.4% said that they did not know. The higher number of Métis participants (71.4%) reported that they knew about resources on mould in their community. Almost half of First Nations and Inuit participants did not know if these resources were in existence (48.6% and 49.5%, respectively).

When asked if they were aware of any resources in their community that offered advice/information/educational materials about lung disease and indoor air quality, 43.6% chose 'Yes', while 56.3% answered 'No' and 'I don't know'. The same trend was observed in each of the Aboriginal groups separately as the slight majority of First Nations (56.7%), Inuit (57/2%), and Métis (57.2%) participants answered 'No' and 'I don't know'.

1.3. Non-traditional Tobacco Use

The majority of respondents (87.5%) thought that non-traditional tobacco use (cigarette smoking) was harmful to their health (7.1% chose 'No' and 5.4% chose 'I don't know'). Most of focus group participants (96.4%) also thought that second hand smoke from cigarettes was harmful to them and their children (1.8% chose 'No' and 1.8% chose 'I don't know'). Similarly, 87.5% thought that non-traditional tobacco use including second hand smoke could lead to the development of asthma/breathing problems (3.6% chose 'No' and 8.9% chose 'I don't know'). However, fewer participants (70.9%) thought that non-traditional tobacco use including second hand smoke could lead to the development of COPD/emphysema (10.9% chose 'No' and 18.2% chose 'I don't know'). These results were consistent with the answers provided by each of the Aboriginal groups. A substantial number of Inuit (37.5%) and Métis (28.6%) participants did not know that non-traditional tobacco use could lead to the COPD development. Almost 20% of First Nations participants believed that cigarette smoking and COPD were not related with 13.9% of participants not knowing the connection.

When asked about the risk of COPD development, almost half of participants (43.4%) thought that they could stop the risk of getting COPD with another 41.5% answered that they did not know. Another 15.1% believed that someone could not stop the risk of getting COPD. The majority of participants (82.1%) agreed that if someone stopped smoking, it would reduce the risk of lung damage (14.3% chose 'No' and 3.6% chose 'I don't know'). Fewer participants (76.8%) felt that lung function would improve if someone stopped smoking (10.7% answered 'No' and 12.5% 'I don't know'). While most respondents (64.3%) did not think that women were less vulnerable than men to the effects of non-traditional tobacco use, 23.2% reported that they did not know and 12.5% thought that women were less vulnerable.

When asked if they were aware of any resources in their community that offer information/educational material about lung disease and non-traditional tobacco use, the majority (67.9%) said 'Yes', 17.9% chose 'No' and 14.3% chose they did not know. The number of participants who were aware about resources on smoking was a little bit higher amongst Inuit (87.5%) and Métis participants (71.4%). Almost a quarter of First Nations participants (24.3%) chose 'No' when answering this question.

1.4. Knowledge of Chronic Respiratory Disease

When asked to select from a list 'Which one of the following respiratory conditions have you heard about?', asthma was chosen most frequently followed by bronchitis and the flu (see Table 17 below for a complete list).

Table 17: Participant-identified awareness of respiratory disease

Asthma	92.9%
Bronchitis	87.5%
Flu	83.9%
Pneumonia	82.1%
Common Cold	80.4%
COPD/Emphysema	60.7%
Reactive Airway Disease	19.6%

Most respondents (85.7%) disagreed that if asthma was left untreated, it would eventually go away, while the equal number of participants 7.1% (n=4) chose they did not know and 'Yes'. When asked if a cough and/or shortness of breath could mean you have asthma, 42.6% answered 'Yes', 38.9% chose 'No' and 18.5% chose that they did not know. The Métis community appeared to be more knowledgeable about early signs of asthma as the majority of participants (66.7%) agreed that cough or shortness of breath could represent asthma symptoms. An equal number of Inuit participants (42.9%) answered either 'Yes' or 'No' to this question. Almost half of First Nations participants (45.9%) were not aware that cough and/or shortness of breath could be asthma symptoms. Overall, most (81.8%) disagreed that everyone who had asthma would have the same triggers (12.7% chose "Yes" and 5.5% chose 'I don't know'). While 63.6% thought that dust mites could trigger an asthma episode, 32.7% said that they did not know (3.6% chose 'No').

With regards to COPD, over 63% thought the word chronic in COPD meant it is severe but another 24.1% reported that they did not know and 13% chose 'No'. Similarly, while 63.6% agreed that asthma, if left untreated, could develop into COPD, another 29.1% reported that they did not know (7.3% answered 'No'). When asked if crushing chest pain is a common symptom of COPD, 46.3% said that they did not know, 31.5% answered 'Yes' and 22.2% chose 'No'. The participants were unsure about the relationship between COPD and non-traditional use of tobacco (cigarette smoking). When asked if COPD is caused by cigarette smoking, 40.7% responded 'Yes', however the majority of participants (59.2%) either said 'No' (25.9%) or 'I don't know' (33.3%). The same tendency was observed in each Aboriginal group except Inuit participants as the majority (57.1%) of them thought that smoking could cause COPD. The majority of Métis participants (57.1%) did not know about the connection while more than a half of First Nations participants (58.4%) either said 'No' (30.6%) or 'I don't know' (28.8%).

At the end of the pre-assessment test, participants were asked how they would like to receive health-related information. The majority of participants expressed a preference towards traditional printed materials available in English (60.7%) followed by audio-visual materials (42.9% chose video/DVD and 41.1% radio in English). Further, just over a third (39.3%) would like to receive in-person education and be educated by a community health representative (CHR) or nurse. Inuit participants would also like to see information available through local media such as radio/ TV in English (chosen by 87.5% and 75.0% of participants, respectively). The majority of Métis participants (71.4%) also identified ‘TV in English’ as one of the preferred communication channels.

Only 7.1% would like to have pamphlets or audio files (radio) available in their Aboriginal language with 5.4% of participants wanted to get health-related information through TV in their Aboriginal language (refer to Table 18 below for details).

Table 18: Participant-identified approached for receiving health-related information

Pamphlets written in English	**60.7%**
Video/DVD in English	42.9%
Radio in English	41.1%
In English from a CHR or nurse	39.3%
TV in English	33.9%
Video DVD in my aboriginal language	10.7%
Pamphlets in aboriginal language	7.1%
Radio in my aboriginal language	7.1%
TV in my aboriginal language	5.4%
In my aboriginal language from a CHR or nurse	3.6%
Other:	
“the Web”	3.6%
“French pamphlets”	3.6%
“Francais”	3.6%
“My family doctor”	1.8%

2. Focus Group Results

A combination of content analysis and thematic analysis was conducted with the focus group transcripts to track participant responses to the focus group check list (Appendix 8) as well as to identify additional themes and issues that emerged during the discussions. For data analysis, a combination of manual coding and qualitative data analysis software (NVivo 8) was used to conduct a thematic analysis of the data. The analysis was conducted by identifying the themes and issues that were raised in focus group discussions, under the following categories:

- Awareness of respiratory conditions (such as asthma, COPD, etc.)
- Awareness of risk factors for development of chronic respiratory disease, including:
    - views on whether indoor and outdoor air quality, smoking and other factors are affecting the respiratory health of community members
    - individual knowledge and community awareness of how factors such as outdoor and indoor air quality, smoking, and other factors can lead to the development of chronic respiratory conditions

- Awareness of and access to current resources/sources of information on risk factors, prevention and management interventions
- Current barriers/facilitators in the community to accessing and receiving information
- Materials, resources, delivery mechanisms, and other considerations for an awareness raising outreach model

A summary of the issues from the perspective of participants highlighting both self-identified and observed gaps and misinformation was developed and presented below. The section is broken down into a narrative discussing some of the observed trends and highlights across the focus groups, followed by a table indicating what specific issues were raised by participants from each of the three cultural communities (with the First Nations communities broken down into separate English-speaking and French-speaking First Nations communities).

Overall, there was a strong sense among focus group participants that respiratory health was an important issue facing their communities. However, the level of awareness and detail of respiratory knowledge (e.g. respiratory conditions, risk factors, and disease management) among individuals varied greatly as many participants indicated surprise, confusion, and in some cases, communicated misinformation about some of the specific topics that were discussed. Participants confirmed that there is a strong need for more information on the prevention (e.g. risk factors) and management of chronic respiratory disease in their communities, and provided suggestions as to how best target this information to their community members.

2.1. Outdoor Air Quality

2.1.1. Awareness of outdoor air quality issues

Participants were asked to discuss what they knew about outdoor air quality/air pollution and its link to respiratory health, what impact it might have on members of the community, and whether there was awareness throughout the community about outdoor air quality. Participants felt very aware of issues related to the air quality in and around their community, and had a strong sense that it had an impact on their respiratory health. However, many participants suggested that this issue was not widely recognized by all community members and there was a low level of awareness throughout the community.

When asked about potential sources of outdoor air pollution, a number of sources were identified that can be organized into three categories, which could help inform how awareness activities are developed and who they should target. These categories include: (A) Industrial and commercial-based risk factors; (B) Community-based risk factors; and (C) Environmental/natural-based risk factors. A brief description of these factors as well as perceived main sources of outdoor air pollution identified by the project participants (Table 19) are described below under each category.

A. Industrial- and commercial-based risk factors

These are risk factors that are driven by industrial or commercial activities that are in or near the community. Because these factors are generally under the control of private industry, they may be very difficult for a community to influence. For example, politics, economics, the size of the activity and the volume of pollutants that result from the commercial or industrial activity may make any attempts at reducing its impact on a community difficult. Awareness activities, however, could play an important role in both supporting a community's efforts to influence these factors as well as empowering individuals with chronic respiratory disease to better manage their chronic conditions.

Many of the participants expressed concern over pollutants that were being emitted by industrial facilities such as pulp and paper mills, power plants, storage plants, refineries and mines located in the region or near their community, and felt that many of the respiratory health problems in their community could be traced back to these sources of pollutants. These facilities are still active in and near some communities (especially in Prince George, BC), and were among the first examples identified by participants as a potential risk factor for respiratory problems. In other cases, the facilities were located a fair distance from the community, but the potential for having airborne pollutants blown to the community by wind and weather was also identified as a problem.

The legacy of now-closed industrial facilities and of the acceptable working conditions at the time remains alive among some participants. While the mill that was located near one community had been closed for some time, participants shared that many of the community members that had worked in the mill have been experiencing serious respiratory problems and that many of those workers have since passed away from lung cancer. These participants were particularly concerned about the potential long-term effects the mill had on the air quality of the community. Other participants attributed their respiratory health problems to the direct exposures that they had while working in and around these facilities. Some participants mentioned that they were concerned about fertilizer that is sprayed on commercial farms in the area. In the case of fertilizer, the smell during the spraying reaches nearby residential communities, and is both unpleasant and alarming to community members.

Many participants were interested in knowing what effects industrial and commercial facilities in their region are having on the air quality of their community.

B. Community-based risk factors

These are factors that are found within a community. Awareness activities have the potential to positively influence the policies, practices and behaviours that lead to these risk factors as well as play a strong role in disease management. Participants identified a number of activities that took place within their community that affected the outdoor air quality, and which had an impact on its members (particularly those living with asthma).

- **Grass fires**

During certain times of year (primarily spring), some of the community members burn fields of grass, however, not all the participants fully understood why it is done. Some felt that it was primarily done by youth in the community for fun, while others proposed that it was an efficient way of removing long grass in large fields. Others felt that it was in part a community tradition, and marked the transition of the seasons. Regardless of the reasoning, those with asthma felt that the smoke from these fires made it difficult for them to manage their asthma.

- **Cooking and heating fires (wood stoves, BBQs, bonfires/open pit fires)**

Wood stoves were identified as a source of heat for some participants (either used directly or by other community members). Open fires outdoors and BBQs were identified as something that is a regular part of community activities and events, but which made it a challenge for community members with asthma to participate. In one community, participants expressed concern over the chemicals in treated wood that is sometimes burned in their community.

- **Burning garbage**

Some participants indicated that some residents in their community burned their garbage near housing or in yards. This was particularly concerning for several participants because the smell was unpleasant, and they were concerned about the toxins that were being released because of the plastic that was burning. In Postville, one participant raised the issue that the local hospital and garbage dump both burn their garbage.

- **Unpaved roads**

During certain times of year, homes become very dusty from unpaved roads and fields in the community, and it makes it difficult to keep the windows open. One participant indicated that their community used fire trucks to hose down roads during periods of dryness, but felt that it was not frequent enough to match the level of dust that was being produced. Other participants expressed concern over other products that are currently sprayed to keep road dust down, and felt that what was being used by the community to control road dust was bad or worse for their respiratory conditions than the actual dust itself. Participants in Prince George, BC indicated that their community was burdened by the legacy of the old approach of spraying oil on the roads. According to participants, this practice has caused environmental damage and contamination to the soil, and has had an impact on the value and sell-ability of some local property.

- **Pesticide/herbicide spraying**

A number of participants mentioned that they were concerned about the spraying that the community was doing to fight mosquitos, and the impact it had on the respiratory health of the community, however, other participants indicated that an allergy to mosquito bites made mosquitos a trigger for their asthma. Some mentioned that they thought the spraying was necessary to prevent other health problems such as the West Nile virus. One participant in Wendake expressed concern over the chemicals and pollution used as part of lawn maintenance.

- **Transportation in the community**

Some participants explained that the culture around idling vehicles was starting to change. Businesses seem to be more aware of the problems associated with idling vehicles, and were starting to post "idle-free zone" signs. While not widespread, it suggests that education and awareness has had an impact on some individual and community behaviours. There was some confusion around what the risks and triggers are associated with different types of motor fuel, and whether one had less of an impact on air quality than others. For example, one participant suggested that he wanted to switch his gas-powered lawn mower to a propane-powered lawnmower because it is "cleaner", but felt that the smell associated with it would generate complaints from the neighbours.

C. Environmental/natural-based risk factors

These factors are naturally occurring in the environment. While these risk factors may not be preventable, awareness activities have the potential to support the community to reduce the impact of these risk factors, and play a strong role in symptom and disease management. Participants identified a number of concerns about aspects of the natural environment that had an impact on their breathing and respiratory health such as:

- **Forest fires**

The smoke from forest fires (both near and far from the community) was identified as a problem for community members with respiratory problems, and was a factor that made it difficult for many community members to open the windows in their homes.

- **Physical geography of the region**

The participants in Prince George, BC indicated that the physical geography of the region causes air pollutants to sit and become trapped in the region. Because Prince George is a "bowl", surrounded by mountains, there is a lack of natural air circulation in the whole region. There is also a high-number of industrial facilities surrounding the community and releasing pollutants into that region's air. Participants explained that the combination of these two factors mean that the community faces a very serious and chronic outdoor air quality issue.

Table 19: Participant-identified sources of outdoor air pollution, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
Environmental: • Forest fires		*Environmental:* • Forest fires • Geographical location	*Environmental:* • Forest fires
Industrial/Commercial : • Mills • Power/storage plants	*Industrial/Commercial:* • Factories		*Industrial/Commercial:* • Hydro plant • Jets flying overhead
Community Based: • **Road dust** • **Pesticide/herbicide spraying** (mosquitos) • Grass fires • **Wood stoves** • Bonfires/fire pits/campfires • Burning garbage • **Transportation** (car exhaust)	*Community Based:* • **Road dust** • **Pesticide/herbicide spraying** (lawn maintenance) • **Transportation** (car exhaust from neighbouring communities)	*Community Based:* • Chemical-based spraying for road dust • **Wood stoves**	*Community Based:* • **Road dust** • **Pesticide/herbicide spraying** (insects) • **Wood stoves**/oil stoves • Bonfires/fire pits/campfires/BBQ • Burning garbage • **Transportation** (car exhaust, tractors, trucks, skidoos, etc.)

*Content highlighted in bold denotes responses that are common across three or more cultural communities

2.1.2. Awareness of outdoor air quality information resources in the community

Participants were asked to identify the information about outdoor air quality that was available in their community. While participants were able to identify a number of sources of information on outdoor air quality (Table 20), there is a lack of information on outdoor air quality at the community level as outlined in section 2.1.3: Barriers to accessing information about outdoor air quality in the community.

Many participants had heard of the Air Quality Health Index, and in some focus groups participants were able to identify where it could be found (i.e. on television), but did not necessarily know how to read it. Some participants mentioned it alongside other tools such as the pollen index and the humidex, and based on the comments provided, some of the participants may have confused the tools. There was a sense among participants that did understand what the AQHI was, that the data coming from the AQHI was too regional and not specific enough for their area/community.

Table 20: Participant-identified information resources on outdoor air quality, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• Pamphlets (from Health Director) • From a clinic at the hospital	• AQHI (TV)	• Northern Health • AQHI in the local media (TV, the newspaper)	• Department of Health and Social Development (DHSD) • Newsletters • Internet

2.1.3. Barriers to accessing information on outdoor air quality

Participants were asked to identify the barriers that they faced when accessing information on outdoor air quality in their communities (Table 21). There was agreement across the focus groups that there was very little information that was available on outdoor air quality in their community, and many participants felt that there was a low awareness level of available resources and where to find them.

Participants acknowledged that while tools such as the AQHI would help them reduce their exposure to poor air quality, it would not necessarily reduce or eliminate the source of pollutants, and in some communities, industrial facilities are responsible in large part for the poor air quality.

Table 21: Participant-identified barriers to accessing information on outdoor air quality, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• **No resources in the community** • No info on air quality at the community level • **Lack of awareness where to find resources**	• **No resources in the community**	• **Lack of awareness on where to find resources** • Lack of awareness amongst children • Lack of resources for elders	• **No resources/information in the community** • Is not recognized as a problem in the community • **Lack of awareness where to find resources**

*Content highlighted in bold denotes responses that are common across three or more cultural communities

2.1.4. Information needs on outdoor air quality

Participants were asked to identify, from their perspective, what information their community needed on outdoor air quality (Table 22). There was general agreement across all communities that more information was needed on air quality, including raising awareness of its link to respiratory health as one participant noted: "*There should be awareness, there should be information, and promotional materials that we can pass into the community*". They also would like to learn about steps to reduce air pollution, have information on local air quality conditions available for community residents, and be provided with practical tips on how to manage respiratory disease during period of poor air quality (e.g. stay indoors, do not open windows, avoid outdoor activities, etc.). Additionally, project participants would like to see more education delivered to children at school as well as have information on idling and grass fires. First Nations and Inuit community members have indicated that there is a need to develop policies on the use of organic products for spraying and establish permits to start fires.

Table 22: Participant-identified information needs on outdoor air quality

First Nations	First Nations (Francophone)	Métis	Inuit
• **Have more info/educational resources in general** • Policies/permits to start the fire • **Practical recommendations on what to do** • Info on idling • Info on grass fires • Info on air quality in the community	• **Have more info/educational resources in general**	• Education for local businesses • Specific programs for elders • Education for children and youth (at school) • Education for family members • **Practical recommendations on what to do** • Info on idling	• **More info/educational resources in general** • Policies on the use of organic products (e.g. bug repellent) • Education for children and youth (at school) • Public awareness • Establish a way to monitor air quality • How to reduce air pollution

*Content highlighted in bold denotes responses that are common across three or more cultural communities

2.1.5. Tools and approaches for communicating information on outdoor air quality

Participants identified the kinds of materials, tools and resources on outdoor air quality that would be useful in their community (Table 23). The responses varied across the focus groups and cultural communities, and included:

- Printed materials (booklets, flyers, magnets, posters, newsletter)
- Workshops, community sessions and group discussions
- Audio-visual tools (radio and television based public service announcements, videos/DVDs)

Table 23: Participant-identified tools and approaches for providing information on outdoor air quality, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
Printed: • Booklets delivered to house to house (or mailbox) • Flyers with magnets	*Printed:* • Pamphlets (for distribution by nurses)		*Printed:* • Posters/displays • Information in newsletter • Pamphlets
Group Discussions: • **Quarterly workshops/discussion groups**			*Group Discussions:* • **Community sessions**
Audio-visual: • **Reports on TV/Radio** (community channel)	*Audio-visual:* • **Video/DVD** available in waiting rooms		*Audio-visual:* • **Local radio station**
	Other: • Health Fairs • Information Kiosk	*Other:* • Use existing resources (e.g. the Friendship Centre) • In person interactions (word of mouth)	*Other:* • Info sharing associated with other activities • Door to Door info • Websites

Other suggestions included: to use existing programs/resources to provide information on outdoor air quality (e.g. the Friendship Centre), present it during community events (e.g. Christmas dinner) and/or have it delivered "door-to-door". It was a caution expressed about online resources as no everybody in the community has easy access to Internet and "*not everybody is just able to go on computers and find this information*".

Some community members showed preferences for certain material formats. For example, the Inuit community was very positive about having posters/displays on outdoor air quality as one participant indicated: "*One thing that seems to work well here is posters and displays*".

2.2. Indoor Air Quality

2.2.1. Awareness of indoor air quality issues

Participants were asked to discuss what they knew about indoor air quality and its link to respiratory health, what impact it might have on members of the community, and whether there was awareness throughout the community about indoor air quality issues. Participants identified a number of indoor air problems that stemmed from their built environment, ranging from relatively minor and controllable to serious structural problems affecting large portions of the community (Table 24).

- **House dust and dust mites**

Many participants living with respiratory conditions (or who had someone in the home with a respiratory condition) discussed the amount of work that was required to control dust in the home (on surfaces, on fans, etc.). Most of the dust was attributed by participants to what was coming in through the windows from unpaved roads outside. Some participants explained that they felt that certain items in their home collected dust at much higher rates, such as the television. In one case, a parent of a child with asthma removed the television as an approach to minimize the amount of dust the child was exposed to and felt that it helped reduced dust in her home. Other participants mentioned that they used special pillow cases designed to reduce dust mites, and vacuumed their mattresses regularly. One participant felt that other community members were not aware that the bed needs to be cleaned regularly. Another participant expressed concern over the many community members that hang their bedding outside to air out, which she felt was exposing it directly to pollen.

- **Mould**

The problem that was discussed in most detail by participants was mould in homes. All focus groups identified mould as the main problem in their community, and most participants agreed that it had serious negative impacts on respiratory health of community members (especially children). However, not all the participants understood the exact impact mould had on air quality and respiratory health. There was consistent agreement that mold problems were partially caused by fundamental home structural problems such as: (a) not being built properly (i.e. not built to accommodate the soil structure and had chronic leaking in the basement); (b) overcrowding; (c) not fitted with the proper ventilation and heating systems; and/or (d) not properly maintained (i.e. leaks coming through the roof or through fans when it rains and not being repaired). The result, according to participants, is that many homes experience mould on and around windows, on interior walls and behind furniture, on the underside of furniture and mattresses (including cribs), inside the walls, inside attics, and/or throughout the basement. The impact, as described by participants, is seen most prominently in the children that are often being diagnosed with asthma and other respiratory problem.

Table 24: Participant-identified air quality information resources available in their community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• **Mould** • **Dust/Dust mites** • Chemicals (household cleaners and perfume) • Poor housing conditions/overcrowding • Radon	• **Mould** • **Dust/dust mites**	• **Mould**	• **Mould** • **Dust/dust mites** • Chemicals (heavy perfumes, paints, scented candles and cleaning supplies) • Smoking • Pets • Wood heating

*Content highlighted in bold denotes responses that are common across three or more cultural communities

- **Radon**

Two First Nations communities in Quebec mentioned radon as a potential problem in their communities. While radon was identified as a problem by participants, its effect on respiratory health was not fully understood. Among those that had heard of radon, there was agreement that it was a risk factor, but many were not clear on whether or not it caused immediate or long-term respiratory problems. Many were also unclear as to what their community was doing about it, if anything. These participants were concerned not only about existing structures, but about new construction taking place in their community, and did not feel confident that the builders were taking radon into consideration.

2.2.2. Awareness of indoor air quality information resources

Participants were asked to identify what information resources on indoor air quality were available in their community (Table 25). Participants indicated that there was little information on indoor air quality, with the exception of a number of resources on mould and how to clean it. Participants in one of the Inuit focus groups felt that there had been plenty of information circulated about mould in their community; however, a link between mould and respiratory health was not emphasized. Participants in the Métis community had very little information coming from health or housing department, and have some information available from local retailers such as Home Depot. The problem with the Home Depot based information was that it focused on mould removal, and not raising awareness of the link between mould and respiratory health.

Table 25: Participant-identified information resources/policies on indoor air quality, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• Printed materials on mould cleaning • Workshops on air quality and housing • Word of mouth • Info from the Health Centre and housing department	• Little information is available • Internet	• Info on how to prevent mould from happening • Info from retailers (Home Depot)	• Internet • Info from the Department of Health and Social Development *Policies:* • Some buildings are scent-free (e.g. schools, college)

2.2.3. <u>Barriers to accessing information on indoor air quality</u>

Participants were asked to identify what barriers their community faced when accessing information on indoor air quality (Table 26). All comminutes identified a lack of information on how mould affects respiratory health as a main barrier to deal with the mould problem. They also indicated that there was not enough information on how to access available resources on mould. While providing information, lower cost tools and activities aimed at preventing and reducing mould build up in homes would be well received and may result in some improvements.

While access to practical tips and information on home cleaning and maintenance is needed, many participants identified other problems that can lead to mould in homes and poor indoor air quality, in particular: (a) poor and inappropriate construction and building maintenance; (b) overcrowding; (c) lack of proper heating and ventilation, and (d) lack of community resources to implemental practical measures in regards to mould remediation. One participant indicated that homes continue to be built poorly because of the lack of funds that are available in the community. Proper mould clean up and structural remediation as well as the purchase of dehumidifiers, ventilation/air purification systems and air conditioners are costly so not everyone in the community can afford them. The community itself sometimes does not have sufficient funds to deal with the mould problem. One participant mentioned that a local physician, upon identifying the connection between mould in the home and a child’s respiratory problems, requested that the Community Health Centre for that reserve pay for the mould clean-up and removal, but the Health Centre did not have the budget to cover that cost.

Table 26: Participant-identified barriers to accessing information on indoor air quality, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• **Not enough info/awareness on how mould affects respiratory health** • Out-dated information	• **Not enough info/awareness on how mould affects respiratory health**	• **Not enough info/awareness on how mould affects respiratory health**	• **Not enough info/awareness on how mould affects respiratory health** • Lack of awareness where to find resources on mould
Other issues raised: • **Poor construction/poor building maintenance** • Not enough individual control over heating • Personal financial limitations • Insufficient funding for new housing • Lack of community resources to implement practical measures • Lack of support from the Band Council and Chiefs	*Other issues raised:* • Information about air quality in buildings has been collected but not shared	*Other issues raised:* • **Poor construction/poor building maintenance** • Fear of being evicted from rental units	*Other issues raised:* • **Poor construction/poor building maintenance**

*Content highlighted in bold denotes responses that are common across three or more cultural communities

Another important issue raised was the challenge of knowing when mould removal should not be done by a resident or home owner, but rather by professionals (i.e. when it has entered the walls, or when the removal process would cause further illness to the individual doing the cleaning), and more importantly, who is responsible for covering the cost. Most of the participants were not the owners of their homes and had little or no control over proper mould removal and remediation. In some cases, the Bands responsible for the structural integrity of its community's buildings did not have the financial resources for clean-up, repairs and remediation. In other cases, participants rented their homes and did not have the resources to move, and did not know what rights they had to force their landlord to test for mould and address the issue properly. There was also much concern around landlords that would make minor fixes and cover-ups without addressing the source, and then renting an apartment with mould to families.

Some participants indicated that it is not just homes, but mould in their workplaces was responsible for respiratory health problems. Some attributed this to structural problems/poor building maintenance that allowed moisture to penetrate the structure, while others attributed the problem to poor maintenance and cleaning of the heating, ventilating and air conditioning (HVAC) systems, or relying on HVAC systems that did not provide proper filtration of the outdoor air. Participants from the Wendake community indicated that information about the indoor air quality of some of their community's buildings had been collected; however, the results of that inspection were not shared with community members.

2.2.4. Information needs on indoor air quality

Participants were asked to identify, from their perspective, what information their community requires on indoor air quality in general and mould in particular (Table 27). Simple tips and information on how to clean and maintain a home properly including practical learning about dust and dust mite prevention were identified as something that would be useful to community members. This could include information on how, when and where to clean to keep dust in the home at a minimum (i.e. vacuuming furniture, dusting furniture and blinds, etc.) as well as the low-cost dust mite prevention tools such as pillow and mattress covers that ideally should be available in the community.

Table 27: Participant identified information needs on indoor air quality, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• **Info on how mould affects respiratory health** • **Practical learning/tips on how to clean and maintain a home** • Info about mould as a risk factor for asthma development (and specifically targeting young mothers) • Info on mould prevention	• **Info on how mould affects respiratory health** • Info on how to clean mould • Info on mould prevention	• **Info on how mould affects respiratory health** • Education for tenants • **Practical learning/tips on how to clean and maintain a home** • Education for construction workers (e.g. Carpenters) • Policy on mould testing of renting properties • Info on how to clean mould	• **Info on how mould affects respiratory health** • **Practical learning/tips on how to clean and maintain a home** • Education targeting the housing industry • Info on dust mites and dust (incl. access to dust mite protection products available in the community) • How to prevent poor air quality in homes • Healthy living information • Availability of organic cleaning products

*Content highlighted in bold denotes responses that are common across three or more cultural communities

The number one piece of information that participants felt would be useful to their community is on mould and how it affects respiratory health. Some of the suggestions that participants provided on what information would help residents reduce mould growth in mould-prone homes, include but not limited to the following:

- **Information about how to use existing ventilation systems and dehumidifiers**

Many participants indicated that while they were provided with various tools to help with air circulation and humidity, they were not provided with the proper information and training on how to use them. As a result, many did not understand how to use them, where in the house the tools should be placed, what their purpose was, and when they should be turning them on and off. In some cases, tools were being used inefficiently or incorrectly, were not being used at all, or had broken due to improper use. In one on-reserve community, there was confusion over who was responsible for changing the filters (i.e. whether it was the responsibility of the resident or in the case of communities living on reserve, someone from the band).

- **Information on how to prevent mould and clean up existing mould**

Some participants suggested that some homes had more mould than others because those residents did not clean regularly. Other participants disagreed, and felt strongly that even homes that were kept very clean still experienced mould. There were also disagreeing viewpoints on whether chlorine bleach was necessary to remove and prevent mould. One community had established that water and soap was all that was necessary and was better for the respiratory health of the person cleaning, while others relied on a bleach solution.

- **Information on ventilation/proper air circulation**

Some participants felt that many residents did not understand the need to open windows and blinds regularly, and to have fresh air circulating in the home as a preventative measure. Other participants mentioned a number of outdoor air quality factors that made it challenging to keep the windows open (i.e. seasonal pollen, grass and field burning, dust from unpaved roads, etc.).

While there are some general tips and guidelines that can be followed in most homes, participants emphasized that each home is different, with different needs. One participant felt that the information that was shared with her from an indoor environmental assessment conducted on her home helped her understand where the risks were, and gave her targeted, specific actions that she could take to improve the air quality in her home. Participants in the First Nations focus groups that were aware of radon in their community also expressed interest in learning more about what steps were being taken by their community to test homes and to remediate the structures where radon is present.

2.2.5. Tools and approaches to communicating information on indoor air quality

Participants identified the kinds of materials, tools and resources on outdoor air quality that would be useful in their community (Table 28). The responses varied across the focus groups and cultural communities, and the most common choices included the following:

- Personal interactions (Workshops/wellness fairs , one on one information sharing, educational sessions at school, education provided by community leaders, etc.)
- Audio-visual tools (radio and television based Public Service Announcements (PSA))
- Printed materials (booklets/brochures, posters, newsletter)
- Online information (website)

The First Nations French speaking community residents suggested having incentives /prizes for community members to ensure their participation.

Table 28: Participant-identified tools and approaches to providing information on indoor air quality, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
Printed: • Visual materials • Newsletter	*Printed:* • **Booklets** • Pamphlets	*Printed:* • **Booklet**	*Printed:* • **Brochure** • Pamphlets • Posters across the community • Newsletters
Audio-visual: • **PSA – (Radio/TV)**	*Audio-visual:* • Videos/DVDs	*Audio-visual:* • **PSA (TV, radio)** • Video, DVDs	*Audio-visual:* • **PSA (TV/radio commercials)**
Personal interactions: • Workshops • Wellness/Health fairs • One-on-one interaction • From community leaders		*Group Discussions:* • Educational sessions • Education at schools	
	Other: • Incentives	*Other:* • Awareness week (displays)	*Other:* • Website (one portal)

*Content highlighted in bold denotes responses that are common across three or more cultural communities

2.3. Smoking and Tobacco Use

2.3.1. Awareness of smoking and tobacco use as a risk factor

Participants were asked about their knowledge of the links between smoking and respiratory conditions, the awareness within the community of the effects of smoking on respiratory health, and the use of traditional tobacco versus commercial tobacco. Questions were also asked about youth and tobacco use in their communities as well as resources available to support people who would like to quit smoking. A summary of participants’ perspectives on smoking and related issues in their communities is presented below.

- **Smoking of commercial tobacco**

There was agreement among everyone that smoking was a serious problem in their community, and that it had a negative impact on respiratory health of community members. While participants agreed that smoking is a risk for everyone who smokes, many participants were particularly concerned about mothers who smoke during pregnancy and the risks it posed to the baby (though not everyone understood exactly what risks those were).

Some participants were not clear on whether smoking natural tobacco, or cigarettes advertised as "natural" (like American Spirit brand) posed the same health risk as commercial cigarettes. Many felt that these "natural" cigarettes did not contain the same added chemicals as commercial cigarettes, and may not even contain nicotine, and thus were a safe alternative.

- **Youth and tobacco use**

Many participants expressed concern that youth are smoking commercial tobacco, as well as marijuana, at much younger ages. They were also concerned with youth chewing tobacco. Participants in one focus group explained that youth find ways of being able to afford to smoke by selling individual cigarettes and packages at an inflated cost, providing them with the income that they need to cover their own cigarettes. In one community, participants expressed concern that a recent closure of the local community centre made activities targeting youth more inaccessible and felt that it put more youth at risk for smoking because they had more free time on their hands. First Nations communities pointed out that some young girls smoked to lose weight. The Inuit community members noticed that there was an increase rate of smoking amongst kids with asthma. All the participants thought that peer pressure ("*being cool*") was amongst the main reasons why kids smoked and agreed that youth did not pay attention to current advertising about risk of smoking. There was also an observation made by members of First Nations communities that kids of non-smokers tend to smoke more often.

- **Second hand smoke**

Most participants understood that second hand smoke was a problem for people who were around smokers. Some participants felt that second hand smoke from other family members in the home was leading to an increase in COPD and other respiratory problems in their community. A number of participants indicated that many smokers in the community understand the risks of second hand smoke and make an effort to not smoke in homes, but noted that community members have been slower to adopt a no-smoking policy in cars. Some participants expressed concern over mothers that smoke while breastfeeding. These participants were interested in knowing if there were harm-reduction techniques that these mothers could use (such as waiting a minimum amount of time between smoking and breastfeeding) if they were unable to quit completely.

Despite a good general understanding about the impact of second-hand smoke, its detailed effects were not fully understood by everyone. For example, one focus group expressed surprise that smoking in a home can increase an infant's risk of sudden infant death syndrome.

- ### Third hand smoke

There was a lack of information on the risks of third hand smoke (e.g. residue that clings to clothing, carpet, furniture, etc.) for most participants, as only a few participants had heard of the concept of third hand smoke and its potential impact on health. For some participants, this was a controversial topic, and sparked discussion around how far individual smokers need to go to protect others around them.

- ### Traditional tobacco

Many participants explained that traditional/ceremonial tobacco use was not something that was part of their community's traditions and activities, or that they themselves did not personally participate in activities that involved traditional tobacco because it was not part of their personal or family tradition. They also indicated that traditional tobacco has been not recurrently widely used (Table 29).

Table 29: Participant views on the use of traditional tobacco, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• **Not widely used** • **Sweet grass/sage is used for smudging** • Traditional tobacco does not have chemicals (i.e. untreated leaves) • Traditional tobacco is also Sacred Medicine • A belief that it does not affect respiratory heath • Some people are affected by smoke from traditional ceremonies • Used as a gift	• **Not widely used (used by leaders)** • Tobacco is mixed with or replaced by sage • Rarely smoked, usually burned	• **Not currently using traditional tobacco** • **Sweet grass is used for smudging (in some cases)** • No difference between traditional and commercial tobacco ("*Smoke is smoke*") • Using commercial tobacco for smudges	• **Not widely used** • **Sweet grass is often used** • Do not know the difference between traditional and commercial tobacco • Used for ceremonial purposes at powwows • Traditional tobacco does not have chemicals • A sense that it is OK if it's part of their culture

*Content highlighted in bold denotes responses that are common across three or more cultural communities

Among those who did participate in traditional activities where tobacco is used suggested that commercial tobacco is often used in place of the traditional plant. They expressed concern that community members were being exposed to the same risks as second hand smoke from commercial cigarettes, and wondered if the risk would be lessened if traditional tobacco products were used instead of commercial tobacco. In one community, participants suggested that when traditional tobacco is used ceremonially, it is just burned and not smoked, and often it is mixed with or replaced with sage. There was also confusion among some participants over the risks of being exposed to smoke from smudging and burning of sweet grass or sage. While many participants indicated that being exposed to this smoke did aggravate their symptoms and put them at risk of an asthma attack, not everyone was sure as to whether this was a risk factor or trigger for respiratory conditions, since sage and sweet grass were perceived to be natural plants and not laden with the added chemicals of commercial cigarettes. One participant mentioned that when traditional tobacco is burned inside during a closed meeting of community leaders in a community building, others in the building are exposed to the smoke circulating through the air vents.

2.3.2. Awareness of information on smoking and tobacco use

Participants were asked about what information is available in their community on smoking and tobacco use. Participants felt that there was good awareness of the risks of smoking and many sources of information linking smoking to health risk such as: advertising on cigarette packages and television; awareness raising days such as No Smoking Days and Weed less Wednesdays; wellness fairs at school, printed materials circulated by health care providers, etc. (Table 30)

Participants also mentioned a number of policies in their community that have been helpful at both raising awareness and taking steps to reduce smoking and/or exposure to second hand smoke. For example, eliminating smoking in public buildings, and in cars with kids.

Many participants felt that there was already "*more than enough resources and information*" on why someone should not smoke (i.e. posters, messages from their health professionals, information on cigarette packages, etc.). For these participants, what is needed are comprehensive prevention programs that target the reasons that many people take up smoking (e.g. self-esteem issues and/or dealing with trauma), policies (such as the "no smoking in public places") which had a positive impact on individual and community smoking behavior as well as cessation programs, tools, and resources that provide concrete actions that they can take to reduce and stop smoking.

Table 30: Participant-identified information resources and existing policies on smoking and tobacco use, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
Resources: • **Risks widely advertised** (cigarette packs, TV commercials) • **No smoking days and Weed less Wednesdays** • Info at a Wellness fairs and schools • Good access to education and smoking cessation aids through Health care providers *Policies:* • No smoking in public buildings/bingo halls • No smoking in cars with kids	*Resources:* • **Risks widely advertised** (commercials) • Signs/posters • Pamphlets • Activities for youth	*Resources:* • **Risks widely advertised** • Screening lung function testing was available during a health fair	*Resources:* • **Risks widely advertised** (cigarette packs, TV commercials) • Good awareness of the risks • A lot of resources from the Department of Health and Social Development (e.g. posters, newsletter, presentation at schools) • **No smoking days and Weed less Wednesdays**

*Content highlighted in bold denotes responses that are common across three or more cultural communities

2.3.3. Barriers to accessing information on smoking and tobacco use

Participants were asked to identify barriers to accessing information on smoking and tobacco use (Table 31). The key issue for participants in terms of barriers to information is the lack of resources and support for smoking cessation. Community members need more information, tips, solutions and support on how to quit smoking as one participant stated: "*People could be made more aware of the different resources for quitting*". Some participants expressed frustration that successful smoking cessation programs in their communities had been cancelled as not sustainable funding was available, and that smokers were not being offered enough support to quit. As well, there is a lack of knowledge about smoking as a leading cause of COPD, especially in the Inuit community.

Further, participants were clear about the risks of first hand smoke, many were clear about the risks of second hand smoke, and almost no one had information about third hand smoke and how it affects respiratory health.

Table 31: Participant-identified barriers to accessing information on smoking and tobacco use, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• Cutting funds to smoking cessation programs • **Not enough info on and support for quitting** • Not enough info on smoking during pregnancy and breastfeeding • **Not enough info on second or third hand smoke and how it affects respiratory health**	• No input provided	• **Lack of awareness about the risks of exposure to second-hand smoke for children** • Smoking as a form of socializing	• Lack of education/awareness of smoking risks amongst children and youth children • **Not enough info on and support for quitting** • Lack of knowledge about smoking and link to COPD • Info is available but not being listened to

*Content highlighted in bold denotes responses that are common across three or more cultural communities

Participants also discussed a number of barriers that make raising awareness about smoking challenging. One First Nations community indicated that profits from cigarettes were an important source of funding for the community. Another First Nations community indicated that the low cost of cigarettes in their community made it easy for community members (and in particular youth) to smoke.

2.3.4. Information needs on smoking and tobacco use

Participants were asked to identify what information their community requires on smoking and tobacco use (Table 32). The concern that was raised in all communities was the need to target education and prevention efforts at children and youth as one participant commented: "*Start with the newer generation, carry on from there and hopefully the next generation or two will be better*". For some participants, this translates into workshops and programs at school starting at the elementary level. For participants in one First Nations community, this translates into more local and easy to access activities and social programming for children and youth to keep them occupied and less likely to try smoking. Participants from the French First Nation community suggested developing PSAs that would show to children and youth that: "*It is cool not to smoke and be running and being in front of the running team instead of being behind huffing and* *puffing*". A general focus on education for children and youth was mentioned by all of the communities as many participants felt that the more information that was available on smoking prevention, the better - especially if it targeted younger members of the community.

Table 32: Participant-identified information needs on smoking and tobacco use, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• **Ongoing education** • **Education targeting children and youth** (at school, all grades) • **Support for cessation/motivation to quit** (info that is better connected to "real life") • Info on and support for prenatal/postnatal exposure • More activities in general for children and youth to keep them occupied • Info that is more relevant to FN culture	• **Education targeting children and youth** • **Support for cessation/ motivation to quit** • Incentives (contests)	• **More information and education** • **Education targeting children and youth** (at school) • Reinforcing the existing info • Info on financial benefits of quitting	• **Education targeting youth** • **Support for cessation/ motivation to quit** (tips, info on resources and quitting aids, access to quitting aids) • Info on second-hand smoke • Quitting aids available free of charge and proper access to them • Personal stories from smokers and people who have quit

*Content highlighted in bold denotes responses that are common across three or more cultural communities

All the participants emphasized the role of ongoing education with proper reinforcement of the existing information and messaging. The focus of the content for smoking related information needs to be on practical solutions/tips and support for smoking cessation, rather than on simply raising awareness of the risks of smoking.

2.3.5. Tools and approaches to communicating information on smoking and tobacco use

Participants were asked to identify what materials, tools and approaches to providing information on smoking and tobacco would be useful in their community (Table 33). The responses varied across the focus groups and cultural communities, and included but not limited to:

- Audio-visual tools (videos, Public Service Announcements)
- Workshops and round table discussions including support groups for people who would like to quit (e.g. Elders speaking about traditional tobacco, personal stories)
- Printed materials (posters targeting youth)
- Online resources (website info targeting youth)
- Promotional events using incentives (e.g. contests)

Table 33: Participant-identified tools and approaches to providing information on smoking and tobacco use, by community

First Nations	First Nations (Francophone)	Métis	Inuit
Printed: • **Posters targeting youth** • Culturally relevant images/photos *Group Discussions:* • **Workshops** • Elders speaking about traditional tobacco *Audio-visual:* • Public Service Announcements, commercials	• No input provided	*Printed:* • Pictures of lungs affected by smoking *Group Discussions:* • **Education sessions** • Personal stories *Other:* • Online material targeting children and youth	*Printed:* • **Posters targeting youth (schools)** • Billboards *Group Discussions:* • Presentations targeting youth (at schools) • **Round table discussion** • Support groups for people who would like to quit *Audio-visual:* • Videos *Other:* • Promotional events (e.g. contests)

*Content highlighted in bold denotes responses that are common across two or more cultural communities

2.4. Chronic Respiratory Disease

2.4.1. Awareness of respiratory conditions

Participants were asked about the respiratory conditions that they felt were affecting their community the most (Table 34). Throughout the focus groups, participants were able to identify by name a number of respiratory conditions, including asthma, allergies, Chronic Obstructive Pulmonary Disease (COPD), bronchitis, tuberculosis, cold and flu, and emphysema. Most of the focus group discussion focused on chronic respiratory diseases (e.g. Asthma and allergies), while passing reference was made to infectious respiratory disease (e.g. tuberculosis, cold and flu). In all participating communities, asthma and allergies were named as a number one concern and the most prevalent chronic respiratory disease in the communities.

The discussions mostly focused on how individuals in the focus groups and elsewhere in the community experienced these conditions, and more specifically, in relation to specific symptoms and triggers. For participants, developing a better understanding of the practical aspects of these conditions (what causes the condition, what triggers asthma attacks and/or worsens symptoms, and how they can be prevented and managed) was very important.

Table 34: Participant-identified respiratory conditions affecting their community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• **Asthma** • **Allergies** • COPD	• **Asthma** • **Allergies** • COPD/emphysema	• **Asthma**	• **Asthma** • **Allergies**

*Content highlighted in bold denotes responses that are common across three or more cultural communities

- **Asthma**

Many participants spoke at length with personal examples of how asthma affected them directly as well as their children and other community members. This was the most frequently discussed respiratory condition. Participants discussed throughout the focus groups the role of triggers in asthma and its proper management and expressed a wide range of understanding of what triggers were found in the community, what role these triggers played in preventing and managing asthma attacks, and how to reduce an individual's exposure to triggers.

There was agreement among most participants that asthma can be treated and controlled with medication, however, some indicated that it was not always practice by everyone (including children) to have their medication on them. There was a lot of confusion around the different types of medication that was being prescribed, how and when it was supposed to be used, what expiry dates mean, etc. Some participants were also not as convinced of the value of pharmacological-based medicine, and suggested that "*sometimes the "cure" is worse than the disease*". Some participants emphasized that preventing and managing stress and generally taking care of oneself were important components in asthma management.

- **Allergies**

Much time was also spent by participants discussing allergies and the impact of allergens on their respiratory health. Allergies to pollen, plants (indoor and outdoor), and insects were identified by many participants as a trigger for asthma. In many cases, these allergies are tied to the seasons, and participants indicated that depending on the individual allergen, certain seasons or times of the year make them much more vulnerable to asthma exacerbations/attacks and worsening of their symptoms. One participant indicated that she found that the mould and mildew associated with outdoor plants and gardening acted as a trigger and required her to stop gardening. Participants suggested that they would find seasonal information and reminders about monitoring and self-management very useful.

Some participants indicated that sensitivity and allergy to certain foods and medications can worsen their symptoms and trigger an asthma attack. A number of participants indicated that the scents that came from cleaning products, air fresheners (including Febreeze for clothes and upholstery), perfume, and scented body products worsened their symptoms, and that reducing their exposure to these chemicals was helpful. One participant explained that their community has been promoting using just water, or mild soap and hot water instead of a bleach solution to clean dust and mould in their homes as a way of reducing exposure to bleach.

While many participants understood that animals with fur (such as dogs) were a risk factor and could worsen symptoms, there was confusion over whether there were any actions that could be taken to keep pets in the home and minimize the risk to family members with respiratory conditions. One participant explained that she had hoped she could get a dog as a pet for her child who had asthma and eliminate the risk to her child by washing the dog regularly and keeping it clean. Her doctor explained to her that the pet dander was the risk factor, and it could not be washed out.

- **COPD**

Participants within each focus group had a very mixed level of knowledge of COPD. Some participants identified it as something they had seen firsthand in their community, while others, when prompted, suggested that they had heard of it but knew very little or could not identify any COPD related symptoms. Others had never heard of it at all. There was some understanding among some participants that COPD was a result of smoking, and in the case of one English-speaking First Nations focus group, exposure to second hand smoke. Among the Métis participants in Prince George (BC), no one was able to identify any symptoms or were able to discuss any knowledge of COPD.

2.4.2. The role of colonization on respiratory health

While participants were not directly asked about the role colonization has played on the respiratory health of their community, it was an issue that was identified by participants in the Inuit and English-speaking First Nations focus groups as having had a negative impact.

These participants felt that their own lifestyle as a child or past lifestyles of older generations did not expose them to as many risk factors (Table 35). They felt that there were fewer chemicals in the food that they ate, less pollution and fewer cars, and that the lifestyle of communities was such that they ate better, had more exercise, and generally were healthier. Some of the Inuit participants felt that there were far fewer cases of asthma in the past.

Table 35: Participant perspectives on respiratory health of their community pre-colonization, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• **Different lifestyle** • More exercise • More nutritious food • Homemade medications • **Healthier population** • **Less or no pollution** • No bleach in the water	• No input provided	• **Different lifestyle** • No chemicals in environment	• **Different lifestyle** • **Less or no pollution** • **Healthier Population** (fewer cases of asthma) • No chemicals in food, environment • Less smoking (mostly pipes)

*Content highlighted in bold denotes responses that are common across three or more cultural communities

2.4.3. Awareness of information resources on chronic respiratory conditions

Participants were asked to identify what information resources on respiratory conditions were available in the community. Examples that participants provided of the sources of information on respiratory conditions that is available to community members varied across focus groups and cultural communities (Table 36).

Table 36: Participant-identified information resources on respiratory health, by community

First Nations	First Nations (Francophone)	Métis	Inuit
• Health Care Providers (doctors, nurses, respiratory therapists) • Info provided by community leaders • CPR courses (info about an asthma attack)	• Workshops • Health Fairs • Posters	• Health Care Providers (physicians, walk-in clinics, pharmacies)	• Some resources on asthma (e.g. the Clinic, brochures, from a public health nurse, online, DHSD, etc.)

The majority of participants in the Métis, Inuit, and English-speaking First Nations communities identified health care providers as a main source of information on respiratory health and indicated that visits and interactions with health care professionals were very helpful in learning about chronic respiratory conditions. For some, these interactions were an opportunity to have their asthma medication explained in detail, including information about why a particular medication needs to be taken and how it is supposed to be used correctly.

In other cases, it was an opportunity to learn about the environmental conditions that trigger or aggravate respiratory problems. In one situation, a parent brought their child to the hospital with respiratory problems. The physician began asking the parent questions about the home and correctly identified that there was a serious mould problem, which was likely contributing to aggravating the child's respiratory problems. Most participants emphasized the essential role of education in chronic disease management as one participant noted: "*I went through all that learning, but without it, I find that he suffered a lot* (about her son with asthma)". One participant felt that it was very important to work with his physician, and to make sure that the physician is aware of how the different medications and interventions were working (or not working), how they made him feel, etc., and then adjusting the management plan together. This level of communication with physicians was not widespread, as a number of participants were surprised to hear that this much detail information had been discussed with the physician, and did not reflect their experience with healthcare professionals.

While some participants saw a hospital-based health professional as a source of information, others expressed surprise that they could access detailed information about their condition, their medication and/or the risk factors and triggers in their environment at the hospital.

Participants also identified that some printed materials on respiratory health were available through local health centres and clinics, public health nurses, as well as could be accessed online. One participant mentioned that a local CPR course offered info about how to manage an asthma attack.

2.4.4. Barriers to accessing information on respiratory health

Participants identified a number of barriers to accessing information on chronic respiratory conditions in their community (Table 37) and expressed willingness to work towards creating better awareness and understanding.

Table 37: Participant-identified barriers to accessing information on respiratory conditions, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• Lack of regular primary care • Poor understanding of asthma among physicians • **No resources on asthma at the community level** • Lack of information/ understanding about asthma medications • No statistics on asthma prevalence in the community • **Lack of community awareness of asthma** • **No education on respiratory health**	• Not enough time with physicians • **Lack of pamphlets and info on respiratory health** • Lack of interest in existing resources	• **Lack of community awareness of asthma** • Lack of interest in existing resources • Lack of awareness/ knowledge about COPD • Absence of an universal access point (for info)	• Lack of awareness/ knowledge about COPD • Lack of interest in existing resources (low community participation in sessions) • **Lack of community resources/ information on respiratory health, including asthma**

*Content highlighted in bold denotes responses that are common across three or more cultural communities

While each Aboriginal community reported a different set of barriers that were unique to their cultural group and structure of their community, a number of common themes emerged as follows:

- **Lack of community awareness of asthma**

Base on the focus group discussions, there is a lack of community awareness of asthma which is not perceived being a top health issue in comparison to other chronic disease (e.g. diabetes, mental health disorders, etc.). Focus group discussions also revealed that in many cases there is a lack of clarity around what roles different community members and community leaders play when it comes to providing/accessing information about risk factors and asthma self-management. While many participants indicated that they could access information about some topics from their health director, when it came to understanding and managing the impact of indoor and outdoor air quality on respiratory health conditions such as asthma, many participants were not sure who was responsible for providing this type of information, or there was disagreement among participants as to who they could contact. Participants also had different expectations of their caregivers and health care providers in terms of information and support.

Some participants also felt that community participation is too low in information sharing opportunities (such as community workshops or group sessions), or that many community members (including themselves) do not look for information, do not notice if it is available, and/or are not particularly aware that information is available or have low interest in accessing that information. This could be partly attributable to the fact that community members do not fully understand why they need to learn about respiratory health and be aware of the risk factors that can lead to development of chronic respiratory disease.

- **Lack of community-based resources/information on respiratory health**

All focus group participants indicted that there was a lack of community-based resources/information on respiratory health and in general and asthma in particular as one participant said: "*Nowhere can you get information on asthma and allergies here* (in the community)". Often, they needed to visit their healthcare providers or a local hospital to receive education on asthma and/or other chronic respiratory conditions. Some members also specified that there is a lack of information about and support for asthma management and use of medication in the community, particularly for parents and community members working with children and youth. With the exception of the risks associated with smoking and commercial tobacco use, participants felt that there is also not enough information about other risk factors for respiratory disease and asthma triggers available to members at the community level.

Focus group discussions also revealed that information that is available (whether it is printed or comes from verbally through a health professional sometimes is conflicting and not up-to-date, and does not provide manageable actions that individuals and communities can take.

- **Lack of access to knowledgeable health care providers**

A number of discussions revealed that while a relationship with a health care provider that is knowledgeable about respiratory health can play a very positive role in helping individuals understand the risk factors and how to manage their condition, few participants reported this as part of their own experience. Some participants with respiratory conditions suggested that they did not have a regular physician or specialist outside of the community, and when they visited outpatient clinics they would see a different healthcare provider every time. While some participants felt that they did receive information about their asthma from their health care provider, others explained that their health care provider did not have enough time to spend with them to get the full information and support that they needed.

Some participants felt that there was inconsistent and knowledge and insufficient understanding of asthma and respiratory health among the physicians and healthcare providers that they accessed. Some providers seemed to have more knowledge in some areas of respiratory health than others, and/or information that was provided varied among the providers. A number of participants provided examples of receiving, in their opinion, conflicting information from different healthcare providers.

2.4.5. Information needs on chronic respiratory disease

Each focus group identified their needs and pieces of information on chronic respiratory disease that they would like to see in their community (Table 38). In general, all group participants were looking for more information/education on asthma that can lead to a greater community awareness of the disease. The need for asthma resources and materials is so profound that the Inuit community requested to provide them with "*any asthma educational resources available out there*".

In regards to the specific content, for many participants with asthma or who were caring for someone else with asthma (e.g. a child), there was much confusion around the appropriate use of asthma medication. Information and support for using asthma medication was identified as a need by many participants in all of the communities. There is also a need to have general information about proper asthma management and control.

One of the common experiences for many participants with asthma was the struggle to identify asthma triggers that were unique to them. For many, it took living with respiratory problems for a long time (and for some, exposure to multiple sources of information on asthma and other respiratory diseases) before they correctly identified their triggers and understood what steps they needed to take to help themselves (or other family members) manage their respiratory condition properly. Participants agreed that they needed clear and accurate information on what triggers may be present in the community, how to correctly identify them as well as practical and simple steps that they can take to reduce their exposure and manage their symptoms when they appear.

Table 38: Participant-identified information needs on chronic respiratory conditions, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• Educational resources on asthma • Information on asthma/**asthma awareness initiatives**		• **Asthma awareness initiatives**	• **Asthma awareness initiatives** • Information/resources on chronic respiratory disease • Community education on lung health
Content: • **Info on asthma medications** • **Info on asthma management and control** • Info on asthma prevention • Info on asthma triggers and environmental control (cleaning, beddings, etc.)	*Content:* • **Info on asthma medications** • **Info on asthma management and control** • Info on relaxation techniques	*Content:* • **Info on asthma medications**	*Content:* • **Info on asthma management and control** • Info on asthma triggers and allergies (e.g. food, pets, etc.)

*Content highlighted in bold denotes responses that are common across three or more cultural communities

2.4.6. Tools and approaches to communicating information on chronic respiratory conditions

Participants identified the kinds of materials, tools and resources that they would like to see on chronic respiratory disease in their community (Table 39). The responses varied across the focus groups and cultural communities, and included mainly:

- Workshops and group sessions including presentations at Wellness Fairs
- Printed materials (booklets/pamphlets, books for kids, posters, checklists)

Table 39: Participant-identified tools and approaches to receiving information on chronic respiratory conditions, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
Printed • Booklets delivered house to house (or mailbox) • Books for kids • Checklists			*Printed* • Posters • Pamphlets • Asthma Road Map
Group Discussions: • Workshops/**group session** • **Presentations at Wellness fairs**	*Group discussions:* • **Group discussions** • Activities with kids (i.e. drawing activities at primary school)	*Group discussion:* • **Presentations at Wellness fairs** • In person interactions (word of mouth)	*Audio Visual:* • Local radio station • Short videos
Other: • Asthma camp for children	*Other:* • Incentives/prizes • Info sharing associated with other activities (e.g. traditional basket weaving workshops)	*Other* • Resources available at the library • Info provide with the medication renewal	*Other:* • Incorporate into existing programs

*Content highlighted in bold denotes responses that are common across three or more cultural communities

The Inuit community also wants to see audio-visual materials (e.g. short videos, radio based Public Service Announcements). Participants in two communities (the French speaking First Nations and Inuit communities) suggested associating or integrating respiratory health information with existing community activities, such as a Christmas dinner or traditional basket weaving workshops. Participants in the French speaking First Nations community also suggested that incentives, such as prizes, would be a good way of encouraging local participation.

English speaking First Nations communities would like to see more education geared towards kids and suggested organizing Asthma Camps during the summer and having books for kids as possible options. Another specific suggestion that was put forward by the Inuit community is to develop an "Asthma Road Map" of the community identifying various community resources that may help people with asthma successfully manage their disease and provide information on how to access these resources. This tool could help raise awareness about existing services that are available at the community level for people with asthma.

2.5. Community Resources

All group participants were asked to assess the existing resources on risk factors for the development of chronic respiratory disease that are available from disease organizations, the Public Health Agency of Canada and Health Canada. An assessment package was compiled based on the findings from the environmental scan and the results of the "A Shared Voice" project (the Asthma Society of Canada, 2010). A brief description of materials included in the assessment package is presented in Appendix 10. Please see below the list of materials that were highly favored by the focus group participants (Table 40).

Table 40: Participant preferences on the existing materials on respiratory health, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• Booklet "Your Health at Home", Health Canada • Factsheet" Know the Difference", Aboriginal Cancer Care Unit • Booklet "Triggers", Asthma Society of Canada • Flu poster, the Public Health Agency of Canada and the AFN • Poster "Basics of Asthma, Allergies and Anaphylaxis", Ontario Physical and Health Education Association	• Booklet "Your Health at Home", Health Canada • Factsheet" Know the Difference", Aboriginal Cancer Care Unit	• Booklet "Your Health at Home", Health Canada • Booklet "Triggers", Asthma Society of Canada • Poster "Basics of Asthma, Allergies and Anaphylaxis", Ontario Physical and Health Education Association	• Booklet "Your Health at Home", Health Canada • Factsheet" Know the Difference", Aboriginal Cancer Care Unit • "Healthy Environments for Kids", the Pan American Health Organization • Flu poster, the Public Health Agency of Canada and ITK

2.5.1. Tools and approaches to receiving health-related information

At the end of the focus group sessions, participants were asked about their preferences in receiving health-related information and what delivery mechanisms, in their opinion, would work and be more effective in their communities. Participants identified the format of materials and resources that they would like to use to learn about health-related issues (Table 41). The responses varied across the focus groups and cultural communities and presented in the table below.

Table 41: Participant-identified tools and approaches to receiving health-related information, by community

First Nations	First Nations (Francophone)	Métis	Inuit
Format: • **Group sessions/health fairs** • **Printed materials (factsheets, books)** • **Audio-visual materials** (PSAs on TV, radio; video) • Online resources for children and youth • Webinars • Activities with incentives (contests)	*Format:* • **Group discussions** • Video conferences/ webinars • **Video/DVD** with Aboriginal actors • Activities with incentives/prizes (contests)	*Format:* • **Printed materials** (posters) • Workshops • Info available at community settings (e.g. major retailers, etc.)	*Format:* • Websites • **Group discussions** • **Printed materials** (brochures/booklets, coloring books for children, calendars) • **Audio-visual materials** (video/audio files) • Interactive activities (e.g. puzzles, radio quiz shows, trivia games, jeopardy, etc.)

*Content highlighted in bold denotes responses that are common across three or more cultural communities

Participants were also asked who should deliver health-related information and the majority agreed that it should be provided by healthcare professionals (e.g. physicians, nurses, community health representatives, etc.) or guest speakers from the disease organizations (for example, during health fairs or community events). They also saw a greater role for community leaders in delivering health-related information and suggested that they should be trained appropriately in order to be involved in health education/promotion activities. Participants from First Nations communities also would like to see information delivered via tele-health and/or webinars and have an opportunity to participate in support groups. The Inuit community mentioned that it would be beneficial to have one point of contact where they could come and receive health-related information such as a resource center or information kiosk, for example, organized at a local library.

2.5.2. Cultural Relevance of Community Resources

In addition to the information and delivery mechanisms identified throughout this report, participants provided insight into what would make resources targeting the community relevant, and increase a positive response/uptake within the community (Table 42).

Cultural practices are important for Aboriginal community members; therefore, materials that are produced and/or adapted need to respond to the unique cultural diversity and heritage of each of the three cultural communities – First Nations, Inuit and Métis. For example, the imagery that would reflect the cultural practice and history of Inuit communities is different than what would speak to First Nations communities. The Inuit community pointed out that culture is being valued more now and efforts are made to restore what has been lost.

Table 42: Participant identified cultural considerations for the development/adaptation of materials on respiratory health, by community

First Nations (English)	First Nations (Francophone)	Métis	Inuit
• **Advice from Elders** (e.g. experience and wisdom form grandmothers) • **Use of culturally relevant symbols (e.g. the Medicine Wheel)**	• Visibility of **community leaders** on health issues Health Canada • Associate information with traditional activities (e.g. pow wows)	• **Advice from Elders** • Storytelling	• **Advice from Elders** • **Use of culturally relevant symbols (e.g. Inukshuk)** • Use of images of Aboriginal people • No need for translation in some communities • More resources are needed to be translated to Inuktitut for other communities •

*Content highlighted in bold denotes responses that are common across three or more cultural communities

A common theme was the role that Elders and community leaders play in communicating health messaging. Hearing the first hand stories and advice from Elders, grandmothers, and community leaders was identified as an important component in raising awareness of health issues, and of making positive changes in the community.

Participants also identified the use of Aboriginal people images and culturally relevant symbols as potential strategies to make materials more culturally relevant. For example, one participated stated: "*I think if you put an Aboriginal symbol on stuff, it makes people realize that it is going to be something that is relevant to them and their culture. That's beautiful*."

Participants also indicated that different members within a community, as well as between communities, speak different languages. For example, elders in a community may speak a traditional language and may not be comfortable or able to discuss health issues in another language, while youth that did not grow up speaking a traditional language would prefer resources in English or in French.

3. Overall Focus Group Results

The combined findings from the pre-assessment test and focus group discussions revealed consistent themes and results, thereby addressing overall key focus group findings that are summarized as follows:

1. There is a good general understanding about negative effects of poor outdoor air quality to human health including the risk of developing chronic respiratory disease. Project participants felt quite aware of issues related to outdoor air quality in their community, but emphasized a lack of information on outdoor air quality available at the community level. Even if minimal resources exist, there is a low awareness level of available resources amongst community members and how to access these resources and educational materials. There was a strong agreement that more information/education was needed on air quality, including raising awareness of its link to respiratory health, in particular explaining the exact impact of poor air quality on people with asthma and associated allergies. Project participants would like to have information on local air quality conditions available for community residents, as well as have educational materials on idling and grass fires. They also would like to be provided with practical tips on how to manage respiratory disease during periods of poor air quality (e.g. stay indoors, do not open windows, avoid outdoor activities, etc.). Additionally, project participants indicated that more education activities on outdoor air quality should target children at school to ensure their proper understanding about the issue.
2. Project participants showed a good understanding about the possible impact of poor indoor air quality on someone's respiratory health. However, participants indicated that there was little information on indoor air quality, with the exception of a number of resources on mould and how to clean it. They also identified a lack of information on how mould affects respiratory health as a main barrier to address the mould problem in the community. In the existing materials about mould, a link between mould and respiratory health is not emphasized, and there is also not enough information on how to access available resources on mould (56.3% of participants did not know or were not aware of these resources). The number one piece of information about indoor air quality that participants would like to use is on mould and how it affects respiratory health. While providing information, lower cost tools and activities aimed at preventing mould growth in homes would be also well received and may result in some improvements. Practical tips and information on how to clean and maintain a home properly including simple solution on how to deal with mould and dust/dust mites and prevent them from happening were identified as being potentially useful to community members.

3. Participants felt that there was good awareness of the risks of smoking and many sources of information linked smoking to health risk, namely: advertising on cigarette packages and television; awareness raising days such as No Smoking Days and Weedless Wednesdays; wellness fairs at school, printed materials circulated by health care providers, etc. For these participants, what is needed are comprehensive prevention programs that target the reasons that many people take up smoking (e.g. self-esteem issues and/or dealing with trauma), and policies (such as the "no smoking in public places") which had a positive impact on individual and community smoking behaviour. There is also a lack of knowledge about smoking as a leading cause of COPD as half of the participants (59.2%) did not know or were not sure about their casual connection.

   Despite a good general understanding about the impact of second-hand smoke, its detailed effects were not fully understood by everyone. There was also a lack of information on the risks of third hand smoke as only a few participants had heard of the concept of third hand smoke and its potential impact on health. More education/information is needed about the link between second (and third) hand smoke and asthma and associated allergies.

   Participants also identified a lack of resources and support for someone who would like to quit smoking and indicated a need for cessation programs, tools, and support resources. A general focus on education for children and youth was mentioned by all of the communities as many participants felt more information should be available on smoking prevention, especially targeting younger community members.

4. There is a good general understanding of asthma amongst project participants; however, knowledge about specific aspects of asthma management (e.g. proper medication use, trigger avoidance, how to prevent and deal with an asthma attack, etc.) is absent. Participants also demonstrated a lack of knowledge about early signs and symptoms of asthma. Participants agreed that they needed clear and accurate information on practical aspects of asthma management (e.g. how to correctly identify triggers in the community, practical and simple steps to reduce their trigger exposure and manage their disease properly, how to take medication correctly, etc.). There is also a need to have general information about proper asthma control, what it means and how to achieve it.

   The importance of proper community awareness of asthma was emphasized by all project participants as they identified a current lack of community awareness about the disease. Asthma is not perceived as a top health priority compared to other chronic diseases (e.g. diabetes, mental health disorders, etc.), and there is a lack of community-based resources/information on asthma and associated allergies. Therefore, educational resources on asthma should be available at the community level to ensure proper access to up-to-date information and increase community awareness of the disease.

5. Participants identified their general preferences in receiving health-related information as well as specified several formats that should be used when communicating information about various topics (e.g. outdoor and indoor air quality, smoking, asthma, etc.). Suggested delivery methods vary depending on the cultural community (First nations, Inuit and Métis) and are closely related to the existing community traditions, practices and programs. Overall, based on the combined data from the focus group discussions and pre-assessment tests, three methods appear to be top choices for receiving health-related information, such as: (a) printed materials in English/French; (b) audio-visual materials (e.g. radio and TV-based Public Service Announcements, video/DVD in English/French, etc.), and (c) in-person education either delivered individually by health care professionals (e.g. a community health representative or nurse) or in a group setting (e.g. group sessions/workshops). Participants were also expressed interest in incorporating respiratory health education into existing community programs and services and making information available at community events. The latter activities could be conducted by community members who would be properly trained in organizing health promotion/awareness events.

6. Culture plays an essential role in providing health-related information to Aboriginal community members. Project participants identified several strategies that could be used to ensure cultural relevance of educational materials and resources. A common theme was the role that Elders and community leaders play in providing information and communicating health messages. Hearing the first hand stories and advice from Elders, grandmothers, and community leaders was identified as an important component in raising awareness of health issues, and making positive changes in the community. Participants also suggested the use of Aboriginal people's images and culturally relevant symbols as potential strategies to make educational materials more culturally appropriate. Not many participants (7.1%) indicated the necessity of having some materials available in Aboriginal languages; however, it was a consensus during the focus group discussions that some communities (e.g. Inuit) might require materials to be translated in Aboriginal languages, specifically Inuktitut.

4. Community Survey Results

The second activity of the project was to conduct community surveys to complement and expand on the qualitative data collected by means of focus groups. A total of **162** questionnaires were completed and the data was entered into SPSS v.14 for analysis. Closed-ended questions are reported as frequency counts and transformed into percentages. Open-ended responses were counted and grouped with excerpts quoted or paraphrased where appropriate.

The community survey (Appendix 3) was structured the same way as other data collection tools designed for this project. It contains the following sections: A) Demographics, B) Air quality-Outdoor air pollution, C) Housing and Indoor air quality, D) Non-traditional tobacco use (smoking), E) Knowledge of respiratory disease, F) Community resources, and, G) Cultural and traditional aspects. The main findings are summarized below under each of the survey's categories.

4.1. Outdoor Air Pollution

Of all the respondents who answered this section (n=153), slightly more than half (57.5%) were not aware that outdoor air pollution represented an issue in their community. Of the 42.5% of participants who did feel that air pollution was an issue in their community, many provided various reasons including: pulp and paper mills (n=19); road dust (n=9); wood and garbage burning (n=5); and car and truck pollution (n=5). The majority of participants (69.5%) believed that outdoor air quality in their community could affect someone's health and well-being. When asked to choose from a list of options regarding what effects outdoor air quality can have on human health, 'decreased general health' was chosen most often by 38.9% of participants as presented in the Table 43.

Table 43: The effect of outdoor air quality on human health and well being

Decreased general health	**38.9%**
Increased pain/discomfort (i.e. irritated eyes, increased mucus production, etc.)	36.4%
Worsening of chronic cardiac conditions	36.4%
Lost physical activity/energy	31.5%
Loss of desire to work	21.0%
Other (please specify):	8.0%
Breathing problems	2.4%
Allergies and asthma	1.2%
Death	1.2%
Wood smoke from chimneys	1.2%
Stay inside/depression	0.6%
Long term medical problems	0.6%

The similar responses were given by participants in First Nations, and Métis communities where the majority agreed that outdoor air quality could affect someone's health and well-being (Table 44). Participants from the Inuit community were less aware about potential harmful effects of outdoor air pollution as 42.4% of participants did not feel that poor air quality had any impact on someone's health.

Table 44: The effect of outdoor air pollution on human health and well-being

Do you feel that outdoor air quality can affect someone's health and well-being?	**First Nations**	**Inuit**	**Métis**	**Non-Aboriginal**
Yes	**72.0%**	**57.6%**	**83.3%**	**68.2%**
No	28.0%	42.4%	16.7%	31.8%

Further, when asked whether or not outdoor air pollution had an effect on respiratory conditions, the majority of participants (85.4%) agreed. Among respiratory conditions that can be affected by air pollution, asthma and allergies were named more often (by 68.5% of participants) followed by bronchitis (58.0%) and common cold and flu (47.5% and 44.4%, respectively) (Table 45).

Table 45: Participant-identified effect of outdoor air pollution on respiratory conditions

Do you think outdoor air pollution has an effect on respiratory conditions?	**Yes**	**No**
	85.4%	14.6%
If YES, what respiratory conditions are affected by air pollution?		
Common Cold	47.5%	
Bronchitis	58.0%	
Pneumonia	42.6%	
Reactive Airway Disease	34.6%	
Asthma (difficulty breathing, wheezing, etc.)	**68.5%**	
COPD/Emphysema	38.9%	
Allergies	**68.5%**	
Flu	44.4%	

The majority of participants (69.5%) also feel that decreasing outdoor air pollution levels can help decrease the rate of respiratory conditions. Road dust and non-traditional tobacco use (cigarette smoke) were most often identified by project participants as possible sources of air pollution in their community (76.5% and 65.4%, respectively). Approximately half of participants also recognized forest fires, sources of burning coal and wood, and wind bringing pollution from somewhere else as potential causes of poor outdoor air quality (Table 46).

Table 46: Participant-identified possible sources of outdoor air pollution in their community

What are the possible sources of air pollution in your community?	
Road dust	**76.5%**
Cigarette Smoke (non-traditional tobacco use)	**65.4%**
Sources of burning coal and wood	54.3%
Wind (bringing it from somewhere else)	48.1%
Forest fires	46.9%
Industrial pollution	43.2%
Traditional Tobacco	25.9%
Other (please specify):	9.3%
Vehicle exhaust	1.9%
Garbage fires	1.9%
Rotten fish	1.2%
Grass fires	0.6%
Gasoline from tanks	0.6%
Tree pollen	0.6%

Other miscellaneous answers included industrial sources of air pollution such as the mills, the diesel generating plant, and pulp mill that were named by 0.6% of participants each.

When analyzed separately, First Nations, Métis and Inuit community members identified the same two top sources of outdoor air pollution in their respective communities. The majority had chosen cigarettes smoke (70.0% of First Nations participants, 73.7% of Métis participants and 62.2% of Inuit participants) and road dust (65.0%, 89.5%, and 94.6%, respectively) as the main sources of air pollution in their communities.

Half of participants (51.9%) did not know how air quality was currently being reported in their community. Some participants indicated that it was reported by local media, either in a local newspaper or/and on the local weather network channel (23.5% and 22.2% of respondents, respectively). Less frequent choices included: community healthcare centre or community centre, and Internet (e.g. Weather Network, Coalition of air purity) (Table 47).

Only the Métis community was aware where to find information about the local air quality readings as the majority of participants from that community identified 'local newspaper' and the coal weather network channel as the main information sources (73.7% and 52.6%, respectively). Among other communities (First Nations and Inuit), most did not know where to look for this information (57.5% and 62.2%, respectively).

Table 47: Participant identified information sources about air quality in their community

How is air quality being reported in your community?	
Community centre	9.9%
Community healthcare centre	10.5%
Local Newspaper	23.5%
On the local weather network channel	22.2%
Internet (websites)	8.6%
I don't know	**51.9%**
Other	7.4%
Not reported	2.5%
Radio	1.9%
Television	1.2%
Band office	1.2%
Local government	O.6%

The majority of respondents (65.1%) reported that they did not use any of the resources listed in the Table 47 above. Of the 34.9% of participants who did use these resources, 80% found them to be useful. When asked to provide a reason for not using the resources on outdoor air quality, most wrote that they "*weren't aware these resources existed*" (n=6) followed by "*a lack of concern over air quality/health*" (n=4). One respondent wrote that "*no one listens to our concerns*" and another wrote: "*it's not offered here*".

Overall, the majority of participants (81.7%) felt that gaining information about outdoor air quality in their community would be helpful in managing and preventing chronic respiratory conditions (i.e. asthma, associated allergies and/or COPD/emphysema). The similar response was given by each of the Aboriginal communities. The majority of First Nations (85.7%), Métis (66.7%), and Inuit (97.1%) participants agreed that receiving more information would be beneficial for their communities.

Further, those who answered 'Yes' were asked to specify what kind of information on outdoor air quality they would like to receive (Table 48). The top there choices included: information about the air quality index, detailed information on air pollutants, and information on how air pollution can affect respiratory health. The similar topics were chosen by participants in each community. In addition to the topics mentioned above, the majority of First Nations participants would like to learn about potential solutions to improve air quality in their community (62.5%) as well as be provided with practical tips on what to do on 'bad air quality days'. The latter topic was also of potential interest for the Métis community (selected 52.6% of the time). The Inuit community also indicated their need to know about 'who is at risk from air pollution' (chosen by 62.2% of Inuit participants).

Table 48: Participant-identified information preferences on outdoor air quality

	Yes	No
Do you feel that gaining information about outdoor air quality in your community would be helpful in managing and preventing chronic respiratory conditions (i.e. asthma, associated allergies and/or COPD/emphysema)?	**81.7%**	18.3%
If YES, what kind of information on outdoor air quality would you like to receive?		
Information on what air quality index is	**57.4%**	
Information on air pollutants	**56.2%**	
Information on how respiratory health can be affected by air pollution (i.e. Asthma and associated allergies)	**55.6%**	
Information on who is at risk from air pollution (i.e. children, elders, people who have respiratory conditions, etc.)	51.9%	
Information on how to improve the air quality in my community	51.9%	
Information on how the weather can affect the outdoor air quality	51.9%	
Information on health messages (telling me the risks for that day)	51.9%	
Information on the effects of air pollution on someone's health	50.0%	
Information on common sources of these pollutants (i.e. forest fires)	47.5%	
Other (please specify):	1.2%	
"other"	0.6%	
"not sure how"	0.6%	

4.2. Housing and Indoor Air Quality

The majority of project participants (73.9%) reside in houses. An apartment was named as the second most common housing type (chosen by 13.1% of participants) (Table 49). When asked to list all the types of flooring in their home, laminate was the most common answer (in 61.7% of homes), followed by hardwood (34.6%), carpet (32.1%) and tiles (30.2%). Other types of flooring named were 'canvas' (n=12), 'cushion flooring' (n=7), and cement (n=2).

Table 49: Housing type of project participants

What kind of housing facility do you reside in?	
House (includes split levels, four-plexes, single family homes or "home")	**73.9%**
Apartment	13.1%
Tomgat regional housing	6.9%
Trailer	4.8%
Camp work	0.7%
Supportive living	0.7%

Participants were asked whether or not indoor air quality could be poor. Of the 155 who answered this question, 80% agreed that indoor air quality could be poor. When further asked about potential sources that can cause poor air quality in a home, dust accumulation in the vents was chosen more often (by 84.6% of participants) followed by mould (79.0%), cigarette smoke and pet dander (71.0% and 69.8%, respectively) (Table 50).

Table 50: Participant-identified potential sources of indoor air pollution

What are the sources that can cause poor air quality in your homes?	
Dust accumulation in the vents	**84.6%**
Mould	**79.0%**
Carpet	66.0%
Cigarette smoke	**71.0%**
Old furniture	56.2%
Pet dander	**69.8%**
I don't know	4.9%
Other	
Furnace	0.6%
Woodstove	0.6%
Poor air circulation	0.6%
Cleaning chemical	0.6%

The majority of participants (72.4%) reported that their home was not damp. Of those who reported having a damp home, 62.3% noticed condensation on their windows. Further, written responses to the question 'Which room does condensation occur' included: "all rooms" (n=13), bathroom (n=12), basement (n=9), kitchen (n=7), and bedroom (n=7).

Almost all participants (93.6%) reported that it was important for them to remove dust in their home on a regular basis. The frequency of dusting varied with 47.5% of participants reported cleaning the dust once a week, 23.0% dusting every day, 10.8% dusting every two weeks, and 10.1% dusting once a month. The small percentage of participants (2.2%) reported cleaning the dust 3 times per week.

Participants were asked a series of questions to test their knowledge about mould and how to deal with it. Based on the responses provided, participants had a good idea about how recognize mould visually or by smell, and only 7.4% of participants did not know how to answer this question (Table 51).

Table 51: Recognizing mould

What does mould look like? (please check all that apply)	
It is Black, white or any color	76.5%
Can smell musty	68.5%
Looks like a stain or smudge	54.9%
I don't know	7.4%

Participants demonstrated some understanding about the factors that can cause mould growth indicting that it can be caused by moisture or damp areas (chosen by almost all participants- 95.1%). However, they also thought that temperature (identified by 63.0% of participants), light (17.9%) and wind (11.7%) could be reasons for mould to grow. When asked where mould can be found in someone's home, the top three responses were: bathroom (90.1% of participants), bottom edge of the windows (84.0%), and kitchen (74.1%) (Table 52).

Table 52: Participant-identified places of mould growth

Where can you find mould in someone's home? (please check all that apply)	
Bathroom (under the sink or on the wall of the bathtub)	90.1%
Bottom edge of the windows	84.0%
Kitchen (under the sink)	74.1%
Laundry room	71.0%
Closets and bedrooms	65.4%
Potted – Plants	53.7%
Living space (i.e. old furniture or firewood stored in the living space)	46.3%
I don't know	1.2%

When asked if they know how to prevent mould form forming, the majority (65.4%) provided a positive answer. Those who said 'Yes', were also able to name strategies that can be applied to prevent mould from happening with the following three measures being most commonly identified: keeping surfaces clean and dry after showering (60.5% of participants), tuning the bathroom fan on when you shower (59.9%), and taking out the garbage daily (54.3%) (Refer to Table 53 for the complete list of the chosen strategies).

Table 53: Participant-identified strategies to prevent mould from forming

Do you know how to prevent mold from forming?	**Yes**	**No**
	65.4%	34.6%
If YES, how do you prevent mold from forming?		
Keep surfaces clean and dry after showering	60.5%	
Turn the bathroom fan on when you shower	59.9%	
Take out the garbage daily to prevent odors and spoiling	54.3%	
Prevent moisture buildup in the living space	53.7%	
Keep your closets and bedrooms tidy	46.9%	
Vacuum often	46.9%	
Dry your laundry tub and washing machine after you use them	43.8%	
Avoid hanging laundry indoors to dry	42.0%	
Don't store old furniture	41.4%	
Other: Use Dehumidifier	1.2%	

Additionally, participants showed a good understanding about how mould can affect someone's respiratory health. Only 7.4% of participants did not know how to respond to this question. The majority thought that mould could cause asthma flare-ups (82.1%), cough (81.5%), wheezing, and throat irritation (77.2% and 76.5%, respectively). Other frequent responses included: shortness of breath, and sinus congestions (Table 54).

Table 54: Participant-identified effects of mould on someone's respiratory health

How can mould affect someone's respiratory health?	
Asthma flare-ups	**82.1%**
Cough	**81.5%**
Wheezing	77.2%
Throat irritation	76.5%
Shortness of Breath	72.8%
Sinus congestion	71.0%
Lung infections in pre-existing COPD patients	68.5%
I don't know	7.4%
Other "depends on how they react to it"	1.9%

There is a low level of awareness of how to handle mould and where to get help in the community to deal with the mould problem. Only 21.9% of respondents knew who to contact to get rid of mould in their home. Among the written answers of who they would contact, the "*housing manager/office*" was the most common (n=6), followed by "*health department*" (n=4), "*Band Office*" (n=3), "*landlord*" (n=2), and "*neighbour*" (n=2). One person stated: "*We have to help ourselves, no help for us*" and another wrote that "*can't afford this service*". The same tendency was observed in each cultural community where most participants did not know who to contact to deal with mould problems (see Table 55 below for detail).

Table 55: Participant awareness about community resources on mould and its remediation

Do you know who to contact to get rid of mould in your home?	**First Nations**	**Inuit**	**Métis**	**Non-Aboriginal**
Yes	26.3%	14.3%	22.2%	17.4%
No	**73.7%**	**85.7%**	**77.8%**	**82.6%**

When further asked 'Do you have any information available on mould in your community', almost half of participants (45%) responded that they did not know it any information existed. Another 34.4% chose 'No' and 20.5% answered 'Yes'. The similar pattern was determined in each community. The majority of First Nations and Métis participants did not know if the information existed (50.7% and 68.4%, respectively). Amongst non-Aboriginals living in Aboriginal communities, 40.9% did not know if any information was available and another 36.4% thought that no information existed at the community level. In the Inuit community slightly more than one third (38.2%) thought that information on mould was available with another 61.7% of participants responded ‘No’ and ‘I don’t know’.

When asked to choose from a list of options on where to find information on mould, community health care centre was chosen the most often (but still only 9.3% of the time) followed by community centre (6.8% of the time), home owners guide book (6.8%), and local newspaper (2.5%). Other written answers included: “housing authority/Band office” (n=4) and “Google” (n=2). Moreover, the majority of participants (84.4%) reported that they had never used any of the resources identified in this survey. Among those who did, 40% of participants did not find them useful. The reasons provided for not finding these resources useful included: “*an absence of mould problems*” (n=5) and “*do not know the information existed*” (n=3). One person noted: “*I have asked to have it taken care of but I haven’t heard back or got any help*”.

The majority of participants (86.9%) felt that receiving information about housing and indoor air quality would be helpful in managing and preventing chronic respiratory conditions. Further, each Aboriginal community expressed interest in having more information on indoor air quality and respiratory health. Thought, the number of participants who were interested in the topic was lower in the Métis community (Table 56) compared to other groups.

Table 56: Participant-expressed interest in gaining information on indoor air quality

Do you feel that gaining information on indoor air quality would be helpful in managing/preventing chronic respiratory conditions?	**First Nations**	**Inuit**	**Métis**	**Non-Aboriginal**
Yes	**85.7%**	**97.1%**	**66.7%**	**90.5%**
No	14.3%	2.9%	33.3%	9.5%

Among topics of potential interest, information on how to clean mould, prevent it from happening and information on how mould can affect someone’s health were chosen more often (by 74.7%; 73.5%, and 72.8% of participants, respectively) (Refer to Table 57 for the complete list of topics identified by participants). In addition to the topics identified above, First Nations and Métis participants would like to know ‘what mould is’ (chosen by 76.3% and 57.9% of participants, respectively).

Table 57: Participant-identified information preferences on indoor air quality

Do you feel that gaining information about the housing and indoor air quality in your community would be helpful in managing and preventing chronic respiratory conditions (such as asthma, associated allergies and/or COPD)?	Yes	No
	86.9%	13.1%
If YES, what kind of information on housing and indoor air quality would you like to receive?		
Information on how to clean mould	**74.7%**	
Information on how to prevent mould formation in my home	**73.5%**	
Information on how mould can effect someone's health	**72.8%**	
Information on what mould is	70.4%	
Information on how respiratory health can be affected by mould (i.e. asthma and associated allergies)	69.1%	
Information on how to improve the air quality in my house	66.0%	
Information on who is at risk from mould (i.e. children, elders, people who have respiratory conditions, etc.)	63.6%	
Information on how to prevent asthma flare-ups in children	59.9%	
Information on common sources of poor indoor air quality (i.e. burning fire wood)	59.3%	

4.3. Non-traditional Tobacco Use (Smoking)

Almost half of participants (44.0%) identified themselves as current smokers of non–traditional tobacco. When asked to list the products that they smoked, current smokers chose manufactured cigarettes (40.1% of the time), 10.5% hand rolled cigarettes, 1.2% pipe tobacco, and 1.2% marijuana. The number of cigarettes they smoked per day ranged from 2 to 40 per day (with the mean=13.8 per day). The number of years participants spent smoking ranged from 2 to 47 years (with the mean = 21.3 years). When asked about rates of smoking among Aboriginal youth, half of participants (52.2%) thought that the smoking rates among Aboriginal youth 15 -17 year olds were triple compared to those of 15 – 17 year olds in the general Canadian population, however, 41.5% responded 'I don't know' and 6.3% chose 'No'. When further asked to indicate one population group with the highest rate of smoking, 54.4% chose 'men and women' equally', 23.4% chose 'Aboriginal populations in Canada', 15.8% chose 'men' and 6.3% chose 'women'.

Almost third of participants (26.6%) reported being ex-smokers of non-traditional tobacco. Among those who quit smoking, the time when they had stopped smoking ranged from less than a year ago to 21 years ago (responses ranged from 1989 to 2010). When asked to list all the products that ex-smokers had previously used, manufactured cigarettes was chosen most often (32.7% of the time), followed by hand rolled cigarettes (11% of the time), pipe tobacco (1.2%), marijuana (1.2%), and cigars (0.6%).

Among the 156 participants who responded to this section, 42.9% reported that they had a family member or neighbour living with them who used non-traditional tobacco (smoked cigarettes). When asked to list all the places where those people smoke, 'outside the front door of the house' was chosen most often (25.3% of the time) followed by ‘anywhere in the house’ (12.3%), and ‘in a separate room in the house’ (7.4%). Over 50% of participants (56.6%) reported that they were exposed to second hand smoke with ‘public places’ being identified most often as the place of exposure (chosen 36.4% of the time) followed by ‘home’ (29.6%), ‘in your car’ (22.8%), and ‘work ‘ (22.2%). The high level of exposure to second-hand smoke was also reported by each Aboriginal community (Table 58) with ‘public place’ again being named as the most common place of exposure.

Table 58: Participant-identified exposure to second-hand smoke, by community

Are you exposed to second-hand smoke?	First Nations	Inuit	Métis	Non-Aboriginal
Yes	**55.7%**	**52.8%**	**63.2%**	**59.1%**
No	44.3%	47.2%	36.8%	40.9%

When further asked if their children were exposed to second hand smoke, 19.5% chose ‘Yes’, 40.9% chose ‘No’, and 39.6% did not have children in their care. A higher level of exposure to second-hand smoke amongst children was reported by Inuit and Métis participants (28.6% and 21.1%, respectively).

Almost all participants (95.5%) agreed that cigarette smoke is harmful to their health. However, a few wrote: “*it depends on your family background*”, “*it doesn’t have harmful chemicals*”, and “*I really don’t know*”. When asked to identify the ways in which cigarette smoke can harm their health, ‘cancer’ was chosen most frequently (82.7% of the time) followed by ‘heart disease’ (73.5%), ‘stroke’ (69.1%), and ‘emphysema’ (65.4%).

Almost all participants (98.1%) also believed that smoking cigarettes can cause chronic respiratory conditions and there were no significant differences amongst First Nations, Inuit and Métis participants in answering this question. Among respiratory conditions that can be caused by smoking, ‘lung cancer’ was identified the most often (chosen by 88.3% of participants), followed by ‘asthma’ (84%), ‘chronic cough’ (80.9%), ‘bronchitis’ (78.4%), increased respiratory infections (74.1%), and COPD (70.4%). The majority of participants (89.3%) agreed that once a person began smoking cigarettes, it would be difficult for them to quit. Further, the majority of participants (82.6%) believed that stopping smoking cigarettes would reduce the risk of lung damage.

Most participants (96.1%) agreed that exposure to second hand smoke was harmful to their health but some wrote: “*just don’t think so, no real proof*”, and “*I think it’s hereditary*”. Among options on how it affects health, ‘lung cancer’ was chosen most frequently (77.2% of the time) followed by ‘respiratory illness’ (75.9%), and ‘heart disease’ (67.3%). The majority of participants (87.2%)

also felt that exposure to second hand smoke from family and friends was putting Aboriginal youth at risk of developing serious health problems (10.5% answered ‘I don’t know’). Almost all participants (98.1%) believed that children could be affected by second hand smoke with ‘increased asthma symptoms’ being chosen most frequently (84% of the time) followed by ‘increased risk of developing asthma and allergies’, ‘increased respiratory infections’ (83.3% each), ‘common colds’ (66%), ‘ear infections’ (63%), ‘slower growth’ (62.3%), and ‘increased risk of Sudden Infant Death Syndrome’ (58.6%). A similar level of knowledge was demonstrated by each Aboriginal community with the majority of participants agreeing that children could be affected by second hand smoke. Among possible effects, ‘increased symptoms of asthma in children’, ‘increased risk of developing asthma and allergies’ and ‘increased respiratory infections’ were the top three choices in all the communities (First Nations, Inuit, Métis, and non-Aboriginals living in Aboriginal communities).

When asked about a difference between the use of Traditional and non-traditional tobacco, 45% of participants answered that they did not know about it, 31.9% confirmed that there was a difference, and 23.1% said ‘No’ (Table 59). Those who answered ‘Yes’ thought that the main difference was in the use of Traditional tobacco for prayer or ceremonies (chosen by 25.9% of participants), and as a gift (chosen by 24.1% of participants).

Table 59: Traditional Tobacco use

Is there a difference between the use of Traditional Tobacco and Nontraditional tobacco?	**Yes**	**No**	**I don’t know**
	31.9%	23.1%	**45%**
If YES, how is it different? (please check all that apply)			
Traditional tobacco is sacred and used as a daily offering to say prayers and ceremonies			**25.9%**
Offering tobacco to water is an acknowledgement of the lifeblood that sustains us all			12.3%
Sacred Tobacco is used in combination with other plants/herbs to treat some illnesses			14.2%
Offering Sacred Tobacco is a way of giving thanks when request given for guidance, advice or ceremonies			**24.1%**
Other “It is bad for the health”, “to some cultures”, medicinal virtue”, “pipe ceremonies’			3.1%

When asked if they found current heath messages about cigarette smoking (non-traditional tobacco use) to be disrespectful of the spiritual medicinal and traditional use of tobacco, most participants (66.3%) responded ‘I don’t know’ (30.0% chose ‘No’ and 3.8% answered ‘Yes’). There was only one written comment on how the information could be changed: “*How we should use it, how our ancestors used it…”*

The majority of participants (59.9%) reported that they had information available on non-traditional tobacco smoke in their community with 20.4% answered ‘No’ and 19.7% answered ‘I don’t know’. Those who answered positively identified ‘community health centre’ as the most common information source (chosen 44.4% of the time) followed by ‘doctor’s offices’ (35.8%), ‘community centre’ (34.6%), ‘through television commercials’ (34%), and Internet (17.9%).

Specific websites that were listed include: “smoking sucks”, “Google” and “health websites”. However, of all the resources listed above, only 34.4% reported that they had ever used these resources. The majority of participants (91.3%) who used resource on smoking, found them to be useful. To the question why these resources were never used, some written comments include: “*just never bothered*”, “*not smokers*” (n=3), “*never heard of any*”, and “*didn’t think I needed to use them until now*”.

There was a difference in awareness of smoking resources available for each of the Aboriginal communities. The Inuit community reported better availability of information on non-traditional tobacco use (91.7% of participants reported having that information available in their community). Slightly more than half of First Nations participants and non-Aboriginals reported having that information available (51.3% and 56.5%, respectively). However, it was a divide amongst Métis participants where less than half (47.4%) answered ‘Yes’ to this questions with another half (52.7%) being unaware or answering ‘No’. With regard to information sources, ‘doctor’s offices’, ‘community health care centre’ and ‘television commercials’ were the top three choices for each of the cultural communities.

A large majority of participants (75.5%) were aware of community information on helping someone to quit smoking (20% chose ‘I don’t know’ and 4.5% chose ‘No’). That was consistent with answers provided by First Nations (75.3%), Inuit (91.2%) and non-Aboriginals (73.9%) living in Aboriginal communities. However, more than one third of Métis participants did not know if any smoking cessation resources were in existence in their community. Among existing sources, ‘access to nicotine replacement therapy’ was selected most often (64%) followed by ‘access to counseling’ (42.6%), ‘access to prescription medication’ (40.7%), and ‘access to a smoker’s helpline’ (35.8%). Other resource options included “*family and friends*” and “*info from Department of Health and Social Development*” (DHSD). Among available nicotine replacement therapies, participants most often indicated having access to ‘nicotine patch’ (61.1% of the time) followed by ‘nicotine gum’ (53.7%of the time), and ‘nicotine inhalers’ (27.8% of the time).

Most participants (70.5%) agreed that gaining information about non-traditional tobacco (cigarette smoking-including second-hand smoke) in their community would be helpful in managing and preventing chronic respiratory conditions. The same result was observed for each cultural community separately (Table 60). However, Métis participants were less eager to learn about non-traditional tobacco use compared to other communities.

Table 60: Participant-expressed interest in gaining information on non-traditional tobacco use (cigarette smoking and exposure to second-hand smoke)

Do you feel that gaining information on non-traditional tobacco use would be helpful in managing/preventing chronic respiratory conditions?	**First Nations**	**Inuit**	**Métis**	**Non-Aboriginal**
Yes	**87.0%**	**94.6%**	**66.7%**	**91.3%**
No	13.0%	5.4%	33.3%	8.7%

The most popular type of information sought was: 'Information on health risks to non-traditional tobacco use (cigarette smoking)' (59.5%) followed by 'Information on how respiratory health can be affected by the use of non-traditional tobacco (e.g. asthma and associated allergies)' (59.3%); 'Information on how to quit smoking' (58.0%); 'Information on how non-traditional tobacco use (cigarette smoking) can affect someone's health smoking' (57.4%), and 'Information on who is at risk from non-traditional tobacco use (cigarette smoke)' (56.8%). They also would like to receive 'Information on how smoking can affect air pollution' (55.6%); 'Information on non-traditional tobacco products" (52.5%); 'Information on how to prevent asthma flare-ups in children who are around cigarette smoke' (51.9%), and 'Information on non-traditional tobacco vs. traditional tobacco' (51.2%). Under 'Other', written answers included: "*info on third hand smoke*", "*continue youth prevention*", and "*it's basically individuals' choice if they want to smoke or not*". The top three preferences for the information content were quite consistent between First Nations and Inuit participants with most of them wanted to learn about 'health risks to non-traditional tobacco use' (63.8% and 70.3% respectively); 'how smoking can affect respiratory health' (63.% and 70.3%, respectively), and 'how to quit smoking' (61.3% and 70.3%, respectively). Métis participants were mostly interested in knowing 'how smoking can affect air pollution' (chosen 67.6% of the time) and 'who is at risk for non-traditional tobacco use' (47.4% of the time).

4.4. Knowledge of Respiratory Disease

When asked to select from the list of respiratory conditions they have heard about, asthma was chosen most frequently (by 89.5% of participants) followed by the flu (85.2%), common cold and bronchitis (see Table 61 for the complete list). Under 'Other', participant also mentioned: "*TB*", "*smokers cough*" and "*cystic fibrosis*".

Table 61: Participant-identified respiratory conditions

Asthma	**89.5%**
Flu	85.2%
Common Cold	82.1%
Bronchitis	82.1%
Pneumonia	74.7%
COPD/Emphysema	59.3%
Reactive Airway Disease	19.1%

Almost all participants (94.1%) believed that there were ways to prevent chronic respiratory conditions form occurring. Of the options on how respiratory conditions can be prevented, 'quit smoking' was the most popular (chosen 85.8% of the time) followed by 'avoid second hand smoke' (82.7%), maintain a healthy lifestyle (77.2%), maintain house humidity (67.9%), and keep household dry (63.6%). Among additional answers, one person wrote: "*I don't know*" and another mentioned "*clean air and homegrown food*".

The majority of participants (71.7%) reported that that they had received information about asthma/breathing problems or associated allergies. The same result was observed in each cultural community with exception of Métis participants. There was a divide amongst those participants in receiving information about asthma or allergies with 52.6% answered 'Yes' and another 47.4% said 'No'.

In general, among those who answered 'Yes' to the question about receiving asthma-related information, the majority of participants had received it from 'health care professionals' (64.2%), mostly provided by 'doctor' (49.4%), 'nurse' (45.75%) or in a community health centre (38.3%) . The second most popular choice was 'media,' (chosen 45.7% of the time), with 'on television' (42.6%) being the most commonly identified sources. The same main sources were identified by participants in each cultural community. Other identified informational sources included: 'in a community health centre' (38.3%), 'family members' (32.1%), 'school' (27.2%), 'friends' (24.1%), 'in the newspaper' (21.6%), and 'Internet' (13.6%) with the following websites being mentioned: "Quebec food allergy association", "Google", and "MSN". One person indicated "*textbooks*" as a source of information.

Most participants (74%) reported that they knew what can cause asthma/breathing problems and associated allergies. Environmental exposures (e.g. indoor/outdoor air pollution, cigarette smoke, etc.) was identified as the possible cause most often (chosen 66.0% of the time) followed by and 'if my parents have asthma and associated allergies, then I will have it too' (chosen 25.5% of the time). However, the statement 'if my parents have asthma and associated allergies, it doesn't mean that I will have it too" was also chosen 43.2% of the time.

Overall, participants showed a good knowledge about asthma and allergy symptoms. From a list of choices for asthma symptoms, 'shortness of breath' was selected most frequently (by 92.5% of participants) followed by 'wheezing' (88.3%) and 'a feeling of tightness in the chest' (81.5%).

Though, (10.5%) answered ‘I don’t know’ to the question: ‘What are asthma symptoms?’. Additional written answers included: “*gasps of air*” and “*my throat stings*”. From a list of choices for allergy symptoms, ‘sneezing’ was chosen most frequently (93.2% of the time) followed by ‘itchy and runny nose’ (92% of the time), ‘red and watery eyes’ (87.7%), and ‘a feeling of congestion that can lead to a headache’ (67.3%). Only 4.9% of respondents could not answer this question. Additional written answers included: “*stuffy*’, “*swelling of throat*”, “*hives*”, “*swelling*”, and “*tight chest*”.

Among the list of choices for factors that can increase the risk of developing asthma, ’cigarette smoke (including second hand smoke)’ was chosen most frequently (84.0% of the time) followed by ‘pollens and mold’ (82.7%), ‘pet dander’ (79.6%), ‘house dust mites’(77.8%), ‘outdoor air pollution’(76.5%), and ‘carpets and stuffed furniture’(75.9%). Additionally, chemical irritants at home and in the workplace were chosen 67.9% of the time and 69.1% of the time, respectively. A small number of participants (9.3%) did not know how to answer the question.

When asked about factors that can trigger asthma symptoms, ‘smoke’ was selected more often (by 85.8% of participants) followed by ‘pollen and mould’ (80.9%), ‘animals’ (79.0%), ‘strong smelling substances’ (77.8%), ‘dust mites’ (73.5%), ‘cold air’ (67.3%), ‘physical exercise’ (66.7%), and emotional stress (63.0%). Less than half of participants (47.5%), also identified ‘medications’ as a possible asthma trigger. A small number of participants (7.4%) did not know how to answer this question.

Most participants (65.2%) reported that there were educational materials/resources about respiratory conditions (such as asthma, COPD, and associated allergies) available in their community (30.4% answered ‘I don’t know’ and 4.4% said ‘No’). Among those who answered ‘Yes’, 47.5% of participants indicated that the information was available ‘on the Internet’ with the following selected websites: Public Health Agency of Canada (chosen 40.7% of the time), the Asthma Society of Canada (36.4%), the Lung Association (35.8%), the Canadian Cancer Society (31.5%), and COPD Canada (25.3%). Other less popular information sources were: ‘local television commercials’ (chosen by 15.4% of participants), and ‘local radio station’ (chosen by 13.6% of participants). Under ‘Other’, additional responses included: “*Québec food allergy association*”, “*nursing station*”, “*Department of Health and Social Services*” (n=2), “*doctor’s office*”, and “*Division Nunatsiavut*”. However, only third of participants (31.3%) reported ever using any of the above information resources. Of those who did use the resources on chronic respiratory disease, the majority (91.7%) found them useful. Those who never used the resources provided the following reasons for not accessing them: “*I do not have asthma*” (n=2), “*never heard of them*”, “*never thought about it*” (n=2), “*I consult my doctor*”, and “*I feel I know enough*”.

Among Aboriginal communities, better availability of resources had been reported by Inuit participants with less awareness about available resources in First Nations and Métis communities (Table 62). Among those who said ‘Yes’, the Internet was identified as the main source of the available information.

Table 62: Participant-identified availability of community resources on chronic respiratory conditions, by community

Do you feel that gaining information on indoor air quality would be helpful in managing/preventing chronic respiratory conditions?	First Nations	Inuit	Métis	Non-Aboriginal
Yes	57.9%	83.3%	52.6%	69.6%
No	7.9%	0%	5.3%	0%
I don't know	34.2%	16.2%	42.1%	30.4%

Most participants (87.3%) agreed that gaining information on how to manage and prevent chronic respiratory conditions would be helpful for their community. That was consistent across the cultural communities with a slightly less number of Métis participants who indicated a need for more information. Those who answered positively were further asked about what kind of information they would like to receive. The top three choices included: 'information on asthma', 'early signs and symptoms of asthma', and 'information on allergies'. Other common choices are presented in Table 63 below.

Table 63: Participant-identified information needs on chronic respiratory disease

Which areas on asthma and/or allergies would you like to know more information on? (please check all that apply)	
Information on Asthma (What Asthma Is)	**74.7%**
Early Signs and Symptoms of Asthma	**74.7%**
Information on Allergies	**73.5%**
Information on asthma and smoking	67.9%
Information on indoor air quality and asthma	69.1%
Information on outdoor air pollution and asthma	66.7%
Information on asthma and pets	66.7%
Information on asthma and second hand smoke	66.0%
Early Signs and Symptoms of Chronic Obstructive Pulmonary Disease (COPD)	64.2%
Information on how to control my environment	59.9%
Other :"*allergy medicine and natural ways*", "*personal choices*," and "*how to control asthma*"	2.5%

The three top choices identified above were similar for each Aboriginal community. In addition, the Métis community members would like to learn about 'early signs and symptoms of COPD' and non-Aboriginals living in Aboriginal communities were interested in ‘indoor air quality and asthma’.

4.5. Community Resources

The majority of participants (96.3%) identified health care professionals as the most popular way of getting health-related information/heath education. That was also the number one choice for each cultural community. This mostly happened at a community health centre, doctor’s office or by receiving brochures at healthcare clinics/offices (Table 64).

Table 64: Participant-identified community-based health information sources

Where do people in your community get their health information/health education? (please check all that apply)	
Health care professionals	**96.3%**
Community Health Centre	74.7%
Brochures at health care clinics/offices	63.6%
Doctor’s Office	61.7%
Nurse practitioner	56.2%
Health clinics in schools	40.7%
Pharmacy	40.1%
Media	**65.4%**
Commercials on Television	49.4%
Local Newspaper	32.1%
Local Radio Station	24.1%
Schools	44.4%
Family	40.7%
Friends and Neighbors	34.6%
Community Centre	26.5%
Internet : “*Google*” (2),”*Asthma Society of Canada*”, “*Cancer society*”, “*Lung Association*”, “*COPD Canada*”	24.7%
Library	19.1%
Community Leader	16.7%

Local media was the second most popular choice (chosen by 65.4% of participants) followed by schools (44.4%) and family (40.7%). Most respondents (91.0%) reported that they did not find it difficult to receive health information/education in their community. Those who did find it difficult identified the following barriers: “*lack of a resource centre/ information*” (n=5), “*work – resource centres are only open 9-5*” (n=3), “*no computer*” (n=2), “*need support groups*” (n=2), “*more programs*”, and “*travel*”.

When asked how they would like to receive health-related information, slightly more than half of participants (52.5%) would prefer printed materials in English followed by TV in English (45.1%) and in-person education delivered by a nurse of CHR (38.9%). These choices were consistent with results obtained for each Aboriginal community. A small number of participants would like to receive health information in Aboriginal languages (Table 65).

Table 65: Participant-identified approached for receiving health-related information

Pamphlets written in English	**52.5%**
Video/DVD in English	37.0%
Radio in English	34.0%
In English from a CHR or nurse	**38.9%**
TV in English	**45.1%**
Video DVD in my aboriginal language	1.9%
Pamphlets in aboriginal language	3.1%
Radio in my aboriginal language	1.9%
TV in my aboriginal language	1.2%
In my aboriginal language from a CHR or nurse	1.2%
Other:	
"Websites"	0.6%
"French pamphlets"	1.2%
"by a doctor"	1.2%

When further asked, 'How do you find it easiest to learn and remember new health-related information?', the visual learning style (e.g. through pictures/diagrams, Internet, video/DVD) was chosen the most frequently (79.0 % of the time) followed by 'reading' (through written text) (54.3%), and auditory materials (e.g. CDs, lecturing, discussion Groups, the E-Learning Module) (40.%). A quarter of participants (25.9%) also indicated their preferences towards digital/new Technologies. Under 'Other', written comments were: "*word of mouth*", and "*workshops*". When analyzed each Aboriginal community separately, the majority of First Nations and Inuit participants indicated their preferences for visual (chosen by 72.5% of First nations and 86.5% of Inuit participants) and reading materials (chosen by 56.3% of First nations and 62.2% of Inuit participants). Métis participants preferred to learn using visual or auditory methods (78.9% and 47.4%, respectively). Overall, a smaller number of participants (11.0%) thought that material should be available in Native languages (11.1%). This number was higher for Métis participants with 21.1% of them expressing a need to have materials available in Aboriginal languages.

When asked specifically about where they would like to access information on respiratory health, almost all participants (95.1%) had chosen health care professionals with 'nurses' clinics' and 'doctor's offices' being the top two choices (Table 66). In additional, First Nations participants indicated that information should be available in health clinics at schools (chosen 73.8% of the time) while Métis participants named 'pharmacy' (chosen 78.9% of the time) as one of the potential places to receive information on respiratory health. Media was again the number two choice (by 67.3% of participants) followed by community centres (58.0%) and online (websites)

(42.6%). The Métis community was more interested than other communities in receiving information from the media (chosen 89.5% of the time).

Table 66: Participant-identified preferred access to respiratory health information

Where should access to information on respiratory health be found? (please check all that apply)	
Health care professionals	**95.1%**
Health clinics in schools	67.9%
Doctor's offices	72.8%
Nurses clinics	75.9%
Pharmacy	56.8%
Media	**67.3%**
Community TV channels	53.7%
Local Radio channels	41.4%
Community Leader Offices	33.3%
Local libraries	35.2%
Community Centers	**58.0%**
On the internet (websites)	42.6%
Other : "*DHSD*", "*Health Professionals*", "*all Over*", "*schools*"	6.8%

When also asked 'Who should deliver the health information and educational sessions on risk factor for respiratory health', 'health care professional' was the most popular choice (chosen 86.5% of the time) followed by 'community outreach worker' (51.2%), and 'teachers at school' (46.9%). A little bit more than third of participants (37.7%) also indicated that they would like to receive this information from 'peers (individuals with the same disease)', and 'community leaders' (37.0%). Elders were chosen as potential speakers by 24.7% of participants. Additional written answers included: "*DHSD*", "*everyone*" and "*self- interest, really*".

Almost all participants (92.6%) expressed their preference in having printed materials on respiratory health and the risk factor associated with chronic respiratory disease. Among printed materials, posters, brochures and booklets were chosen more often. The second most popular choice was media announcements/publications in the media (chosen by 74.7% of participants) followed by audio-visual materials (69.1%), and educational sessions (67.9%). Refer to Appendix 25 for the complete list of choices on the preferred format. The similar distribution was observed for each Aboriginal community and is presented in Table 67 below.

Table 67: Participant-identified preferences on the format of educational materials on respiratory health and the risk factors associated with respiratory health, by community

Format	First Nations	Inuit	Métis	Non-Aboriginal
Printed materials	92.5%	94.6%	89.5%	95.7%
Media announcements	73.8%	75.7%	78.9%	73.9%
Audio/video materials	65.0%	83.8%	63.2%	60.9%
Educational sessions	67.5%	70.3%	73.7%	60.9%

Accessibility of materials was identified as an important feature by each Aboriginal community (First Nations, Inuit and Métis). When asked further about how materials can be made more accessible, posters in the community was the number one choice followed by community flyers and mailing out information to everyone's home (Appendix 26). Based on the responses provided, language appeared to be also important in receiving information on respiratory health with the majority of participants wanted to have materials in English. Provided answers indicated once again a preference of having information at healthcare centres (77.8%) or delivered via local media (75.3%). This finding was consistent across all cultural groups. The majority of participants (72.8%) also identified community settings as a possible venue of receiving information on respiratory health with group education/discussion in their community being the most popular choice (Appendix 26). With regard to in-person education, group education was favored by all communities over individual education. The Inuit community also expressed interest in having support groups/information nights for parents/grandparents in their community. Audio/video materials were preferred by half of participants (51.9%). In addition, 60.0% of First Nations and 56.5% of non-Aboriginal participants would like to have online resources.

4.6. Cultural and Traditional Aspects

When participants were asked if their cultural and traditional practices were relevant to the awareness and prevention of chronic respiratory diseases, slightly over half thought that it was relevant (with 18.2% answering 'relevant' and 38.5% 'somewhat relevant'). A quarter of participants (25.2%) reported that it was 'not relevant', and another 18.2% chose 'not comfortable to answer'.

When asked 'what tools and methods need to be developed to incorporate Aboriginal culture in learning materials about respiratory health', information about native remedies as the top answer (chosen by 52.5% of participants) followed by advice from Elders (42.0%). Healing circles led by professionals seemed to be also important and was chosen by 37.0% of participants. Table 68 below presents the complete list of methods mentioned.

Table 68: Participants-identified methods to improve cultural relevance of materials on respiratory health

What tools and methods need to be developed to incorporate the knowledge available on respiratory health prevention and care into Aboriginal Culture?	
Storytelling	32.7%
Advice from Elders	**42.0%**
Facilitating interconnectedness with family and community	32.7%
Healing circles led by professionals and Elders	**37.0%**
Ceremonies	24.7%
Information about native remedies and its use in chronic respiratory diseases (i.e. asthma and allergies)	**52.5%**
Information about holistic approach	28.4%

When analyzed by the community, information about native remedies and advice from Elders were in the top three choices for all communities (First Nations, Inuit and Métis). Healing circles led by professionals and Elders was the third choice for First Nations participants. Inuit participants would like to build and facilitate ‘interconnectedness with family and community’ as their third choice. Métis participants would like to incorporate storytelling in their learning about respiratory health and the risk factors for the development of chronic respiratory disease.

Most participants (64.3%) agreed that cultural symbols or schemata from First Nations, Inuit and Métis communities should be incorporated in the materials and resources on respiratory health so “*all Native nations will learn about it*”. Those who agreed provided the following suggestions: “*eagle*” (n=2), “*Inukshuk*” (n=2), “*Medicine Wheel*” (n=2), “*nature and outdoor images*”, “*animals*”, “*show more Inuit involved*”, “*anything that represents clean air*”, “*mother Earth*”, “*healing circles*”, “*opening ceremony*”, and messages such as “*take care of your body as your ancestors*”. It was also suggested to use health–related images as participants wrote: “*no smoking symbols*” (n=2), “*symbol of person with asthma holding their chests*”, “*anything to do with death*”, and “*women who are pregnant and second hand smoke*”. A higher number of Métis participants would like to have cultural symbols incorporated in the materials (60.0% vs. 54.9% of First Nations participants and 45.1% of Inuit participants).

For those who disagreed that cultural symbols were needed, the main reason was that information on respiratory conditions is all about health, not culture; therefore, cultural images are not relevant (n= 7) as one participants stated that “*symbols don’t make a difference*”. Another person also wrote: “*This is a common disease and not associated with one society or the other. It gives the idea of labeling.*” Another popular response was that symbols were not relevant due to lack of knowledge about their culture (n=4). For example, one person mentioned: “*don’t know much about my culture*”.

There was a divide amongst participants over the question about whether or not respiratory health materials could be adapted to suit their cultural needs (57.3% of participants agreed and 42.7% disagreed). For those who agreed, the most common suggestion was to teach their culture (n=8) as one participant wrote: "*Teach our traditional way*" and "*holistic approach*", and "*Teach our culture*". Other popular answers were to get more Elders involved (n=3), and have more in-person teaching by community members (n=5). With regard to the material format, suggestions included: "*not so technical*", "*more colorful, eye catching*" as well as use "*plain regular English*" (n=2) and "*Aboriginal people in visual presentations*". Other comments included: "*make it relevant to children*", "*advertise more*" and "*more often*". Specifically, participants also recommended to put information "*on a t-shirt to spread the message*", have it on "*health centre calendar, booklets and daily planner*", and show support at "*local sporting events*".

For those who disagreed that respiratory health material could be adapted to suit their cultural needs, the main reason provided was a lack of knowledge of one's own culture (n= 6). For example, "*Because I don't know my cultural ways*", and "*our culture is faded, don't really know much about it, first thing we would have to bring our culture back*". Other answers included: "*I don't know*" (n = 4), and "*Not everyone cares about this*".

There was a variety of responses to the question: 'Is there anything else you would like to share?' Some answers included: "*People should come in to talk and give info*" (n=2), "*need info on how asthma runs in the family*", "*everybody should try and stop smoking*", "*air pollution should be told right away not when it is too late and damage is done*". Participants mentioned that education should "*focus on children, more fragile*" (n=2) and "*kids are tech savvy – reach then through media and technology*". Participants expressed a need to be educated and "*think this survey is a positive step*". A specific suggestion was to have "*photo of local person with asthma*" while designing educational materials.

At the end of the survey, participants were asked how they would like their community to address the awareness and prevention of chronic respiratory disease and its risk factors. The majority of participants (69.1%) thought that the community should connect with lung health organizations (e.g. the Asthma Society of Canada). The majority of participants (64.8%) also expressed interest for the youth to be involved in the development of materials followed by engaging neighboring communities (41.4%).

5. Key Results from the Community Surveys

The data from the community surveys (quantitative data) support the trends identified by a means of the focus group discussions and are consistent with the key focus group findings. The key results from the community surveys are as follows:

1. Similar to the focus group results, participants showed a good understanding about the impact of air pollution on human health in general and respiratory conditions in particular. Community survey data also confirmed a lack of awareness of existing

community resources on respiratory health and outdoor air pollution as at least half of the survey participants (51.9%) did not know where to find information about outdoor air quality. Only Métis community members knew where to find information about local air quality readings. Participants also indicated that existing resources were not being used for a variety of reasons, mostly due to their lack of knowledge about them or the absence of resources at the community level.

Overall, participants would like to learn about air pollutants and have information on local air quality readings (e.g. Air Quality Index (AQI) or the Air Quality Health Index (AQHI). They also would like to be provided with detailed information on how air pollution can affect respiratory health. Some additional topics were identified by each cultural community such as: potential solutions to improve air quality in their community (First Nations participants); information on 'who is at risk from air pollution' (Inuit participants), and practical tips on what to do on 'bad air quality days' (First Nations and Métis participants).

2. In general, participants had a good knowledge about potential sources of poor indoor air quality. They also maintained good cleaning practices in their homes when it comes to removing dust. It appeared that participants also had a good idea about where mould could grow in the house and showed some understanding on how to prevent it from happening. However, some misunderstanding existed about what factors could cause mould growth as light, temperature and wind were identified among potential contributors. Further, the knowledge of how to deal with mould problems seems to be rather low.

   The majority of participants (79.4%) also did not know or were not aware of any community-based resources on mould or who to contact in case of mould problems. This finding was similar across all cultural groups. The majority of those who knew about the resources (84.4%) preferred not to use them as well as did not find them useful. With regard to the information needed, consistent with the focus group data, participants would like to have resources on how to clean mould and prevent it from forming. They also would like to learn about how mould affects someone's health including its role as a risk factor for development of chronic respiratory conditions. There was consistency in the topics identified among First Nations, Inuit and Métis communities.

3. There is a high rate of self-reported smoking among project participants as almost half of them (44.0%) reported being current smokers mostly using manufactured cigarettes. There also a high self-reported level of exposure to second-hand smoke (reported by 56.6% of participants) mainly happening outside people's front door. The majority of participants also indicated being exposed to second-hand smoke in public places.

   Consistent with the focus group results, almost all participants (95.5%) knew that smoking was harmful to their health and could cause cancer, heart disease, stroke, and emphysema. They also showed a good awareness of smoking as a risk factor for chronic respiratory disease and understanding about how smoking could cause permanent lung damage. There was also a good general understanding about harmful effects of second-hand smoking including its impact on children. These findings were similar across all cultural communities.

There was a high level of awareness about smoking cessation resources available at the community level with the majority of participants (75.5%) indicating some knowledge about these resources. However, 40.1% of participants did not know if information on smoking and respiratory health existed in their community or thought that there was none available. Further, those participants reported not widely using the existing resources. It appeared that Inuit participants were more knowledgeable about community-based smoking cessation resources while Métis participants demonstrated less awareness about these types of resources.

Similar to the focus group participants, community survey participants would like to learn about health risks associated with tobacco use, how smoking affects respiratory and general health, and how to quit smoking (what steps to follow). They would also like to learn how to prevent asthma flare-ups in children who expose to second-hand smoke. There is also a need to understand how cigarette smoke influences overall air pollution, and have information about the difference between traditional and non-traditional tobacco as the majority of participants (68.1%) were not able to identify the difference between traditional and non-traditional tobacco or believed that there was not any.

4. The majority of participants received information about asthma either from health care professionals or local media. Overall, participants revealed a good understanding about ways to prevent chronic respiratory disease from occurring and showed a good knowledge of asthma and allergy symptoms as well as asthma triggers. However, 10.5% of participants still could not identify asthma symptoms from the list provided. Some misinformation also exists about possible causes of asthma and allergies as some participants (43.2%) did not know that asthma had a hereditary nature and could run in the family.

Participants believed that information on chronic respiratory disease was available in the community; however, they identified the Internet as the most popular source. Further, only third of participants ever accessed the informational resources available in their community. The Inuit community demonstrated a better awareness level about community resources on asthma compared to other cultural groups. The Métis community showed less knowledge about asthma resources available in their community.

There was a consensus (87.3%) that more information on management/prevention of chronic respiratory disease would be needed in their communities. The top three topics that they would like to learn about are: information on asthma, early signs and symptoms of asthma, and information on allergies. In addition, the Métis community expressed interest in learning about early signs of COPD.

5. The community survey results confirmed the top three preferences in receiving health-related information that came out the focus group discussions and the pre-assessment test results. Participants would like to learn using printed materials, having information available on TV, and have access to in-person education. Healthcare professionals were named as the most valued source of health information with local media being in the second place. Schools and family are also important in providing health-related information and were chosen almost by half of participants. Most participants reported having good access to health information/education in their communities; however, some indicated a lack of resources and a need for more programs (e.g. support groups).

The visual learning style was selected as a method of preference for health educational materials followed by written text and audio materials. A quarter of participants would also like to see the utilization of digital/new technologies.

When it comes to education on respiratory health, participants indicated that respiratory health information should be available from healthcare professionals (e.g. nurse stations, physicians), local media, and community centres. It was suggested that education on chronic respiratory disease and the risk factors for its development should be available in a form of printed materials, media announcements/publications, and/or be delivered via educational sessions preferably in a group setting within the community. Healthcare professionals, community outreach workers, and teachers were the top there choices for delivering educational sessions. Peers and community leaders were also rated quite high with a quarter of participants looking to receive information from Elders.

6. The quantitative data confirmed that cultural aspects and elements that are relevant for providing education on respiratory health and the risk factors for chronic respiratory disease. Similar to the focus group results, participants would like to see more involvement of community leaders and have advice from Elders as well as have appropriate symbols/cultural images being embedded into educational materials. However, it was also suggested to be cautious using the culture symbols/images to avoid "*labeling*". Participants also would like to learn their traditional way and culture by having information about native remedies, and learning about respiratory health in healing circles. Interconnectedness with family and community was emphasized by a third of participants as an important element to ensure proper community participation and engagement. All cultural communities had chosen information about native remedies and their role in management of chronic respiratory disease as well as advice from Elders amongst their top three strategies to improve cultural relevance of materials and resources. As in the focus groups, not many participants required materials available in Aboriginal languages and indicated English/French as a language of choice. Among Aboriginal groups, a higher number of Métis participants indicated a need to have materials available in Native languages.

As a way of moving forward, it was recommended to work with lung health organizations (e.g. the Asthma Society of Canada), engage communities and involve youth in the development of any new materials/programs.

7. There was much consistency in results obtained for each Aboriginal group. They all would like to learn about health-related issues by having visual, text or auditory materials. They preferred to receive health-related information by using printed materials, through the local media and in-person from healthcare professionals. The top two sources for receiving information on respiratory health and risk factors for chronic respiratory disease were also healthcare professionals and the local media. In addition, group sessions at a community setting were one of the most common choices amongst all cultural communities.

These findings demonstrate that despite some cultural differences, a common model of community outreach and engagement could be designed to be piloted in First Nations, Inuit and Métis communities. As well, general educational strategies and materials could be designed and then tailored to the needs of each Aboriginal community.

6. Development of the Community Outreach and Engagement Model

As the main outcome of the project, the Community outreach and engagement model was developed to be piloted and implemented into First Nations, Inuit, and Métis communities throughout Canada. The main goal of the model is to increase respiratory health awareness, in particular, knowledge and understanding of chronic respiratory disease and the risk factors of its development. It was also designed to empower communities to create a self-sufficient community outreach/awareness system and to have greater access to resources on respiratory health. The model was created to provide information and awareness to communities about the risk factors for chronic respiratory disease (e.g. asthma and associated allergies) as it relates to the social determinants of health.

Based on the findings of all project activities (e.g. the environmental scan, the focus group data including the results of the pre-assessment test, and the community survey findings) as well as the examples of existing community outreach and chronic disease management models (e.g. the "Chronic Care (Wagner) Model" (1998), the "Integrated Life course and Social Determinants Model of Aboriginal Health"(2009), and the "Social Ecological Model of Health" (2008)), the draft main components of the model were developed by the project team. The proposed components of the model were then discussed and reviewed during the Advisory Group/focus group meeting, further identifying what was necessary to include in the community outreach and engagement model.

All partner organizations were involved in designing the outreach model and making recommendations for future development of public information/educational materials to be used under each of the model components. Additionally, the draft model was presented at the AllerGen results dissemination/grant writing workshop to solicit further feedback and suggestions on how to modify the model components and awareness/educations strategies under each of them. The workshop was jointly organized by the ASC and AllerGen and will be discussed in detail in the Results Dissemination section of this report. The final draft was developed based on all the feedback provided and two graphical models were presented to the Advisory Group members for final review and approval. One of the final draft models was favourably received by all the Advisory Group members and considered for future implementation (Appendix 17). The agreed community outreach and engagement model and its components are described below in detail.

6.1. The Main Model Components

In general, the model components outline ways of outreaching to communities not only on a community level but also on an individual and family level. The model has been designed to conduct public awareness campaigns and disseminate educational materials related to respiratory health in Aboriginal communities using a variety of means such as community workshops/public forum, health/information fairs, community programs, and social events. As well, the purpose of the model is to ensure the adequacy and cultural appropriateness of promotional/awareness programs related to chronic respiratory conditions, and their risk factors.

The central part of the model (Appendix 17) represents the idea of self-management and self-education and serves to empower community members on the individual level (child, youth and/or adult) and then expanding and reaching out to incorporate the family and the community as the whole (First Nations, Inuit and Métis). The model core is further linked to the social determinants of health showing how the individual and community involvement could lead to potential improvement in health outcomes. Here are the **five** key components of the program aimed to provide awareness and education on social determinants of health as well as chronic respiratory disease:

6) Community education
7) Community awareness
8) Community participation
9) Community leadership
10) Community health care delivery

Community Education encompasses respiratory health education provided to Aboriginal community members focusing on education for children and youth and their families including foster parents and family Elders. Potential strategies to be considered for implementation under this model component include but are not limited to the following: group educational sessions and support groups for parents/grandparents; provision of printed educational materials (booklets, pamphlets, checklists, books for children) audio and video resources to individuals directly affected by the chronic respiratory disease and/or caregivers; and materials/resources aimed to support the delivery of self-management education. In addition, opportunities for peer-to-peer support and education should be considered given that younger generations prefer to connect with one another and create awareness amongst their peers.

Overall, activities to be implemented under this model component will teach community members including children and youth about the risks factors of chronic respiratory conditions, how these factors affect someone's health, prevention strategies, and provide information on how to manage these conditions properly, mostly for individuals directly affected by the disease. Some activities should directly target the younger population as, based on the project findings, there is a significant concern about the health of the younger population in Aboriginal communities. For example, the youth have begun smoking at a much younger age not knowing the health risks involved in their actions. It is, therefore, critical that educational activities and materials can be readily accessed by the children and youth in Aboriginal communities.

The second model component, ***Community Awareness,*** is aimed to increase the level of awareness about respiratory health and chronic respiratory conditions targeting broader community members. That could be achieved by the use of a combination of active and passive (push and pull) outreach strategies. By implementing this component, the outreach will be conducted to the community as the whole including both individuals directly affected and not affected by chronic respiratory disease (e.g. children, youth, adults, Elders, general public, etc.).

Potential push or "active" outreach strategies will include involving the local media as well as providing respiratory health information at community events and celebrations. Based on the project findings, the development of public service announcements for local television and radio programming was one of the top preferences in creating awareness in the broader community. Further, interactive activities such as a radio quiz show on respiratory health accompanied by prizes and awards will not only encourage more people to participate, but also provide an opportunity to raise awareness of the issues related to chronic respiratory disease and the risk factors for its development.

Already established wide-ranging (e.g. social event for Elders, etc.) and health-related community events (e.g. Wellness Weekends and Wellness Fairs) could also provide a great opportunity to outreach to the community as the whole and make community members being aware of the issues. Community events can be a place to invite healthcare professionals to speak about the issues and to distribute educational materials about chronic respiratory conditions to further educate and publicize the importance of respiratory health awareness. Additionally, well-established community celebrations (e.g. Canada Day, Christmas, etc.) when the entire communities gather together can be used to voice concerns about respiratory health in the community and make the community as the whole aware of the risks for the development of chronic respiratory disease.

With regards to the pull or more “passive” outreach strategies, respiratory health information should be available at community health centres, community centres and other community settings for community members to access. Community representatives trained in delivering respiratory health messages should be also available in the community to answer any questions of community members when needed.

To create a greater involvement of community members in respiratory health awareness initiatives, the third main component, ***Community Participation***, includes strategies that will empower various community members to participate in creating a community that is concerned and well-aware of issues related to respiratory health. As existing housing conditions are strongly related to the rising rate of people with respiratory conditions, housing officials such as housing coordinators from the Band Council, housing inspectors, environmental health officers, and landlords should be approached and informed about the issue.

Involvement of schools, workplaces, local businesses, and various community facilities (e.g. community grocery stores, culture and friendship centres, libraries, major retailers, fitness centres, etc.) in raising awareness of respiratory health is shown to be important according to the project results. For example, local businesses involved in residential development and construction (e.g. carpenters) should be made aware of proper methods of building and renovating housing facilities so the risks such as mould can be minimized and/or prevented.

Further, community organizations and programs (e.g. faith-based groups, after school programs, Elder monthly sessions, youth education programs, etc.) that are well-attended by community members should be included in dissemination of respiratory health information so that awareness can be created among a wider range of community members. Community programs for children, youth, adults, parents, and Elders should include topics on respiratory health from learning about chronic respiratory conditions to easy practical steps to prevent the risks of their development.

Without broader and adequate community participation, the community will not be able to succeed in creating awareness on respiratory health and becoming self-sufficient in delivering respiratory health information and education. The initial model implementation will help initiate these strategies as well as train the communities in delivering programs and activities related to respiratory health education with the ultimate goal of the community being able to sustain these initiatives on its own.

The next component***, Community Leadership*** is a vital element in the development of a self-reliant and well-aware community. As community leaders play a cornerstone role in any community functions and practices and often are community knowledge keepers, they should be involved in delivering respiratory health messages and creating community awareness of the issues related to chronic respiratory disease and the risk factors for its development. Community leaders should be properly trained to become community champions/advocates on respiratory health issues and lead the community in implementing the main model components. For example, the Chief, the Band Council, and community Elders can use their knowledge, significance and authority to make changes in the awareness of respiratory health. They could deliver main respiratory health messages and lead group discussions at community workshops and other events. Because the bond between the community's leaders and members is already strong and reliable, community members will tend to listen and trust them. Therefore, it is very important to have buy-in from community leaders and have them on board during the model implementation.

The Chief and Band Councils also have the authority to implement appropriate by-laws and policies aimed to mitigate the risks of developing chronic respiratory disease. Special considerations should be given to the development of the tools that could help the Band Councils develop appropriate policies as well as to reinforce the existing ones.

The components mentioned above provide guidance on how awareness and educational activities and strategies could be implemented in communities. The fifth component, ***Community Healthcare Delivery***¸ plays a slightly different role in the model and its implementation. According to the project results and findings from other reports prepared by the ASC (e.g. "A Shared Vision", 2009; "A Shared Voice", 2010), many communities have very limited access to healthcare professionals for a variety of reasons and the existing healthcare resources are rather scarce. Therefore, the model requires limited active participation of healthcare providers working in the communities (e.g. physicians, etc.) except community health representatives/workers and/or nurses. The latter should be given an opportunity to get properly educated on respiratory health issues and be available to participate in community-based awareness activities.

By having more healthcare workers/representatives trained in delivering respiratory health education, the community will become more self-sufficient in sustaining the issue and provide opportunities for community members to find respiratory health information in their communities. In some communities, information and education could also be made available through tele-health or other web-based methods (e.g. webinars).

The main goal of this model component is also to establish a connection between community-based initiatives and healthcare delivery. For example, materials to be developed and/or adapted for model implementation should be readily available in all healthcare facilities within and outside the community. Information should not only include educational resources on respiratory health and chronic respiratory conditions, but also provide advice on how to navigate the healthcare system and where to access resources on respiratory health.

6.2. Additional Model Elements

Other components of the model (Appendix 17) such as Community Coordination, and Community Empowerment and Capacity Building are connected to the five components presented above and aimed to empower communities in model implementation by enabling them to modify the model based on their unique needs and circumstances; participate actively in creating materials and resources, and establishing community policies; and sustain model activities beyond the initial pilot.

Proper ***Community Coordination*** is essential in implementing any community-based initiatives. To make the model implementation successful, many activities and initiatives should be well-coordinated at the community level and involve main community stakeholders by, for example, establishing a community advisory group. Communities could also choose a hub to coordinate all the activities and serve as a resource centre. In some communities, this role could be fulfilled by a health centre or the Department of Health and Social Development that could be a point of primary access to educational materials and other resources. Having the resource centre will help ensure that all community members are aware of how and where to find the needed information about respiratory health. Community Coordination is also crucial to establishing a community that can carry on the model activities and be able to coordinate further awareness initiatives on its own.

Community Empowerment and Capacity Building represents the ultimate outcome of the implementation of the main model components and outlines additional strategies to be applied to build a community that could independently sustain the model and related activities. Community capacity could serve as a measure of how well the community can create and maintain proper respiratory health awareness with available resources. With the limited resources that some Aboriginal communities have, communities should apply a step-by-step approach to the model implementation and build slowly the community capacity while ensuring proper engagement of all community members. To help build the capacity of the community, thorough and continuous analysis is also needed. For example, community profiles and scans and ongoing community surveillance are recommended to be conducted prior and/or during the model implementation. Ongoing evaluation of outcomes will help community leaders to create different sustainable methods and approaches and understand which areas need special attention. The community must wok slowly and steadily on building this capacity by using a step-by-step approach and identifying priorities for action. As communities gain more knowledge and resources, their capacity will grow empowering community leaders to implement more strategies and activities towards better awareness of respiratory health and improved knowledge on chronic respiratory conditions including self-management approaches and prevention strategies.

This component also speaks about the use of cultural practices (e.g. traditions, languages, images, etc.) in delivering respiratory health messages. The degree of cultural relevance and how culture should be incorporated in awareness activities should be largely determined by the actual community and based on the existing traditions and practices.

The final model component is the ***National Aboriginal Asthma/Respiratory Health Information Centre****,* which acts as a clearing house for educational resources on asthma and other chronic respiratory diseases as well as the risk factor of their development for First Nations, Inuit and Métis communities from across Canada. Based on the project findings, it is recommended to establish one central point in Canada to access and distribute educational materials and resources on respiratory health. This Centre could also coordinate the model implementation on a national level and serve as the support resources for participating communities. Further, the Centre will not only provide a database of existing materials and resources, but it will also establish a "community of practice". Discussion forums, e-newsletters, success stories, and ongoing feedback and suggestions for improvement obtained from Aboriginal communities are potential ways to keep communities engaged and share experience and lessons learned from the model implementation.

In summary, each model component focuses on various strategies and activities to enable First Nations, Inuit and Métis communities to create better awareness of lung health, to improve their knowledge about chronic respiratory conditions and their management, and to be able to establish more resources on respiratory health. Based on the project results, it is demonstrated that the need for information and preferred delivery methods are consistent across the cultural communities; therefore, justifying the creation of one single community outreach and engagement model that can be further modified to each particular community (First Nations, Inuit and Métis) depending on its unique needs and characteristics and taking into consideration any differences that might exist in each of the communities. The community outreach and engagement model can be adapted based on each and every community and tailored to their needs for respiratory health education and information. The next step will be to implement this model by presenting the model to the communities for their feedback and piloting it in selected communities from across Canada prior to make it available nationally.

7. Major Project Accomplishments

According to the project activities described previously in detail and based on the project's main goals and objectives, there are five major accomplishments of the project implementation as follows:

1) Completed the environmental scan

- Provided a better understanding on current existing successful health promotion and chronic disease prevention programming and materials specific to First Nations, Inuit and Métis communities
- Provided initial understanding on the current existing awareness materials and resources on respiratory health and the risk factors for the development of chronic respiratory disease and helped identify gaps in the information/resources available for First Nations, Inuit and Métis communities
- Provided initial understanding on what needs to be developed with regards to new materials and resources on respiratory health for First Nations, Inuit and Métis communities

2) **Completed the baseline-needs assessment**

- Provided a better understanding of the different kinds of information and awareness initiatives that need to be developed and could be effective in First Nations, Inuit, and Métis communities in order to increase their awareness about the risk factors for chronic respiratory disease (e.g. asthma and associated allergies) as it relates to the social determinants of health

- Gained a better understanding on the commonalities and differences amongst First Nations, Inuit and Métis communities in preferences for receiving respiratory health information and education

- Obtained a better understanding on the preferred delivery methods, format and content of materials and resources related to respiratory health that could be beneficial and useful for creating awareness surrounding respiratory health in First Nations, Inuit and Métis communities

- Gained a better understanding of what materials and resources need to be developed that are culturally appropriate and relevant to First Nations, Inuit and Métis communities

3) **Developed the community outreach and engagement model**

- Designed the community outreach and engagement model based on the data and results obtained from the project activities conducted

- Gained a better understanding on what methods of community outreach will be appropriate to implement in First Nations, Inuit and Métis communities

4) **Built on the existing partnerships and established new collaborations with the key project partners and supporters as well as participating communities**

- The partnerships developed with the communities involved in the project are one of the biggest project accomplishments. These partnerships assisted in reaching the goals and objectives of the project and will continue to provide support during results dissemination activities and the potential implementation of the model as well any future projects conducted by the ASC

- The communities have shown a great interest in continuing their participation in future projects conducted by the ASC as well as made a commitment to be involved in piloting the community outreach and engagement model designed as part of this project

- Existing and newly established partnerships with the key partners and project supported were crucial for the overall success of the project

5) **Gained a better understanding about elements/indicators of cultural relevance of educational materials and resources**

   - Identified what elements should be incorporated in future awareness activities and educational materials to ensure their adequacy and cultural appropriateness for Aboriginal communities

8. Results Dissemination/Communication plan

One of the main activities to be continued after the project is dissemination of the project results to participating communities as well as through key project partners and supporters. All key partner organizations (the Asthma Society of Canada (ASC), the Assembly of First Nations (AFN), the Inuit Tapiriit Kanatami (ITK), Métis Nation British Columbia (MNBC), AllerGen NCE Inc. and the National Collaborating Centre for Aboriginal Health (NCCAH) will actively participate in dissemination of the results using their respective networks and channels. A communication plan (Appendix 27) was developed with input from the Advisory Group members, and reviewed and agreed upon by all key project partners.

AllerGen NCE Inc. in partnership with the Asthma Society of Canada organized and co-sponsored results dissemination/grant writing workshop to discuss the results of the phase I project and explore ideas that could be put forward when applying for phase II NLHF funding. The workshops took place in Toronto on August 9 and 10, 2010. Key AllerGen researchers and key opinion leaders working in the area of respiratory health and Aboriginal communities were invited to participate in the workshop. Researchers with expertise in respiratory health as well as knowledge transfer were also invited to attend the workshop. For the complete list of workshop participants, please refer to Appendix 16. From AllerGen, the following researchers attend the workshop in person: Dr. Malcolm King, Dr. Anthony Levinson, and Shawna McGhan with Dr. Miriam Stewart joining via a conference call. Dr. Louise Giles joined the workshop bringing her expertise in respiratory health and as a member of the Advisory Group. Two AllerGen trainees who are implementing AllerGen-funded projects in Aboriginal communities in Alberta, Amber Ward and Roxanna Blood also attended the workshop bringing some perspectives of First Nations communities from the West Canada. The key program partners either joined the workshop via a conference call (Joni Boyd, ITK) or provided their input on the documents developed after the workshop (Dr. Kim Barker, the AFN and Tanya Davoren, the MNBC).

The full workshop agenda is presented in Appendix 28. During the workshop, the ASC project team presented the preliminary results from the current (phase I) project soliciting participants opinions and thoughts about them. The draft community outreach and engagement model was also presented and participants were asked for their feedback and suggestions on the changes that could be made to the model. The first day concluded with identifying top ten priorities for action based on the preliminary results of the project that should be put forward and included in project recommendations. These ten priorities further served as a base of a discussion about potential ideas to be included in phase II application for the NLHF funding. The discussion about the next steps in the phase II application process took place during the second day of the workshop.

With regards to the communication plan (Appendix 27), the following strategies have been proposed and will be implemented in accordance with the plan as outlined below:

8.1. Dissemination of Project Findings and Results to the participating communities

If the opportunity presents itself, the ASC will go back to the selected First Nations, Métis, and Inuit communities and present the overall project findings from the community surveys and the focus group discussions. To choose the most suitable method of delivering project results to the communities involved in the project, the ASC looked at the results from the community surveys and the focus group sessions to find out preferences in receiving information as indicated by community members in each participating community. The top three communication methods identified were considered as a way of disseminating the project results back to the community. Before finalizing the communication methods for each particular community, the ASC conversed with each community leader/Health Director to confirm the preferred method of presenting the findings from the project. Potential methods of dissemination include but are not limited to: presentation of results at community-based workshops and/or at scholarly meetings; developing factsheets/posters to be presented in public health units and/or offices of healthcare professionals (including specialists such as respirologists, allergists, etc.), and presentation of results to community leaders and government officials where applicable.

The ASC will prepare a master presentation that can be tailored to present the results that are relevant for individual communities (First Nations, Inuit, and Métis) so the community can relate better to the information presented. When preparing a presentation, the following elements will also be taken into consideration:

- The presentation will focus on information that is relevant to the specific community and how their results are compared to the other communities involved in the project. The general findings among all the communities participated in the project will be also described briefly;
- The presentation will have recommendations that communities can follow based on results and findings of the project; and
- The presentation will not only include the project results, but also include information about our future plans and goals heading towards Phase II of the project.

The ASC will maintain the strong relationship with each community and keep a good liaison with a community leader to report back to the community as the project evolves. The ASC will also offer resources, materials and services available from the ASC. The ASC will continue building a foundation of trust with each community and treat each relationship as a partnership; therefore, the ASC will share the power in decision making with the involved communities and inform them of possible future steps if any.

The ASC will also offer similar support and disseminate educational materials other Aboriginal communities from across Canada upon request from them and/or the partner organizations.

8.2. Results Dissemination through partners networks

The final report will be disseminated to all partner organizations and project supporters and be also available on the organizations' websites which are a popular link for accessing health-related information for people working with Aboriginal communities. Further, community health personnel working in Aboriginal communities will be informed about project findings and recommendations through the partners' respective networks and channels. Disseminations strategies and methods to be applied are presented in the Communication plan (Appendix 27) and the main ones can be summarized as follows:

- The final report will be presented to the National Inuit Committee on Health (NICoH), and ITK. ITK will also assist, where necessary in presenting it through the Inuit Nunangaat. Moreover, the report will be disseminated through the ITK magazine and knowledge networks.
- The AFN will ensure that each AFN Regional Health Technician will have access to the entire project report and highlights of the project findings will be presented to them at one of the quarterly meetings. Additionally, project results will be presented at an annual meeting of the First Nations health managers with 900 nurses and health managers from First Nations communities in attendance. An option to present the results to First Nations health personnel at regional meetings will also be considered as one of the possible dissemination strategies.
- The strong working relationship between the AFN and ITK and the First Nations and Inuit Health Branch (FNIHB), Health Canada will ensure that important study finding can be discussed with officials with a view of potential program and policy changes to meet the identified needs. The ASC will be responsible for disseminating the final report to the First Nations and Inuit Health Branch, Health Canada (FNIHB), Health Canada.
- MNBC will send out the final report to their large distribution list of Métis people including every Métis Chartered Community so the results can be seen by Métis people all over British Columbia. The results will also be posted on o the Health page of MNBC's website for additional dissemination. MNBC will be also responsible for submitting the final report to the Métis National Council (MNC) to make it available for all provincial Health Directors of the Governing Member Organizations.

- AllerGen will distribute the final report to its partners, researchers and trainees as well as individuals who participated in the AllerGen results dissemination/grant writing workshop.
- The NCCAH will disseminate the report by placing it on their website as well as featuring it as a topic in their E-Bulletin.

The ASC will be responsible for disseminating the report to the Canadian Lung Association and the National Lung Health Framework (NLHF) Secretariat. The ASC will also participate in distributing the report using a variety of existing communication channels such as: preparing a news release about the project and its key findings; posting the final report on the ASC main website and Asthma Today Widget; providing information about the project and its main results in one of the ASC E-Newsletters, and informing the ASC main partners who might be interested in project results and recommendations.

8.3. Results Presentation at conferences and manuscript preparation

The ASC will take a lead in manuscript preparation by drafting papers and getting feedback from all the partners involved before submitting them. The following journals will be considered for manuscript submission: (1) Canadian Journal of Public Health, (2) Journal of Aboriginal Health, (3) Health and Place, and (4) American Journal of Public Health.

VII. Project Evaluation

The overall success of the project was evaluated through participation in the focus groups as well as the quality of data collected through the pre-assessment questionnaire/test and focus group discussions. The success of the project was also assessed by the number of community surveys completed by community residents and the quality of the responses that were provided. By analyzing each of these activities, the ASC were able to design a community outreach and engagement model and identify the key elements of awareness initiatives on respiratory health that could be beneficial for First Nations, Inuit and Métis communities. We also gained a better understanding of the type of educational materials and resources on respiratory health and risk factors for chronic respiratory disease that could be suitable and culturally relevant for First Nations, Inuit and Métis communities.

The main project outcomes were assessed by applying the ***outcome indicators*** developed in the initial project proposal as follows:

1) Better understanding and knowledge of the resources and materials related to risk factors for asthma and associated allergies available for First Nations, Inuit and Métis communities

This project enabled us to gain a better understanding about existing resources on respiratory health that are available for Aboriginal community members. An environmental scan (Appendix 6) was conducted as one of the project activities and helped gather information about resources on respiratory health that is currently available for Aboriginal community members. It has been determined that there is a lack of resources on respiratory health and the risk factors for chronic respiratory disease that specifically target First Nations, Inuit and Métis communities. Based on the focus group findings and the community survey results, there is also a low level of awareness about existing materials and resources amongst community members and how to access them. Many project participants indicated that the existing resources were not being used mostly due to the lack of knowledge about them or the absence of resources at the community level.

Furthermore, there is also a lack of knowledge about the risk factors for chronic respiratory disease (i.e. indoor/outdoor air quality, housing and smoking) and their connection to respiratory health. For example, there are many existing materials about mould, how to prevent it and to clean it; however, there appear to be limited resources on how mould affects respiratory health.

2) Better understanding of gaps in the existing resources and the need for the development of new materials and resources

The findings of the project support the need for the development and/or adaptation of materials and resources that will be relevant for First Nations, Inuit and Métis communities based on their identified needs. It has been demonstrated that one of the main gaps in the existing resources is their absence at the community level. Further, the existing materials do not provide information on the topics of interest for Aboriginal community members (e.g. how mould affects respiratory health, how to identify asthma triggers and minimize exposure to them, how to take asthma medications properly, etc.).

As well, there is a lack of awareness materials on asthma and understanding about the disease amongst broader community members. Asthma is not perceived as a top health priority compared to other chronic diseases (e.g. diabetes, mental health disorders, etc.), and there is a lack of community-based resources/information on asthma and associated allergies. Therefore, there is a needed to develop and/or adapt materials about asthma to be broadly available in Aboriginal communities to ensure proper access to up-to-date information and increase community awareness of the disease.

3) Better understanding about facilitators and barriers that are faced by Aboriginal communities in accessing information and resources on respiratory health

The project provided a better understanding of the barriers in accessing the existing resources. One of the main barriers identified is a lack of knowledge/awareness about the materials and resources because the availability of resources is not being promoted within the communities. One exception is information on smoking which is broadly advertised in many communities. In many cases, community members did not know where to go to access proper information and support and were using the Internet as the most popular sources of information.

One of the main facilitators identified is the ability to access information at the community level as more information and educational materials on management/prevention of chronic respiratory disease are needed, especially materials on asthma, its early signs and symptoms of asthma, and information on allergies. As well, there is a need to have community champions (e.g. community leaders and/or community health representatives) being trained in delivering main messages on respiratory heath and reaching out to individual community members.

4) Improved knowledge about indicators of culturally appropriate public awareness resources and materials on respiratory health

A better understanding was obtained on how cultural relevance of educational materials could be achieved and what elements could make educational material more culturally appropriate for Aboriginal community members. Based on the project findings, several strategies were identified that could be used to improve cultural relevance of educational materials and resources. For example, involvement of Elders and community leaders in awareness activities and their participation in communicating health messages was named one of the core strategies to ensure proper engagement of community members and their adequate participation in awareness initiatives. Hearing the first hand stories and advice from Elders, grandmothers, and community leaders was identified as an important component in raising awareness of respiratory health issues, and making positive changes in the community.

The use of Aboriginal peoples' images and culturally relevant symbols was also suggested as a potential strategy to make educational materials more culturally appropriate. Not many participants indicated the necessity of having some materials available in Aboriginal languages; however, the consensus during the focus group discussions was that some communities (e.g. Inuit) might require materials to be translated in Aboriginal languages, specifically Inuktitut.

According to the project results, there is also a need to learn their traditional way and culture by having information about Native remedies, and/or learning about respiratory health in healing circles lead by Elders or healthcare professionals. Additionally, interconnectedness with family and community as well as proper community engagement was identified as an important element to ensure proper community participation in awareness activities.

5) Improved knowledge about characteristics of effective awareness resources for First Nations, Inuit and Métis community members

As mentioned previously, in order for the awareness resources to be effective in First Nations, Inuit and Métis communities, the information should be provided at a community level and be culturally relevant for First Nations, Inuit and Métis communities. According to the project findings, incorporating cultural and traditional aspects of the communities is shown to be an essential way of providing health-related information to First Nations, Inuit and Métis communities. Further, participation of highly respected community members such as the Elders and community leaders in any awareness and outreach activities will play an important role in providing health education and ensuring proper attention to the information provided. Using local media such as local TV channels and radio stations was identified as another way of creating effective awareness campaigns that could be beneficial and effective in First Nations, Inuit and Métis communities.

6) Better understanding of the current level of awareness of respiratory health and how it is affected by risk factors, including the social determinants of health (e.g. tobacco use, housing, and indoor/outdoor air quality)

The project helped determined the current level of knowledge about chronic respiratory disease and the risk factor for its development amongst Aboriginal community members. Overall, participants revealed a good understanding about ways to prevent chronic respiratory disease from occurring and showed a good knowledge of asthma and allergy symptoms as well as asthma triggers. However, the project data revealed that there was not enough awareness and knowledge about the social determinants of health and how they affect someone's respiratory health. It was also found that knowledge about specific aspects of asthma management (e.g. proper medication use, trigger avoidance, how to prevent and deal with an asthma attack, etc.) is missing. As well, there is a lack of understanding about early signs and symptoms of chronic respiratory disease, in particular asthma and COPD.

Project participants showed a good understanding about smoking and its effects on health, however, the majority did not know that smoking could lead to COPD development. Despite a good general understanding about the impact of second-hand smoke, its detailed effects were not fully understood by everyone. Thus, it was not enough knowledge about second- and third-hand smoke and their potential negative effects especially on children.

7) Better understanding of what materials and resources are necessary for First Nations, Inuit, and Métis communities

The project helped gained a better understanding on the types, content, format and style of educational materials that could be useful and effective in First Nations, Inuit and Métis communities. The project also helped identified general preferences in receiving health-related information (e.g. printed material, public services announcements/video materials, and group educational sessions) as well as specified several formats that should be used when communicating information on various topics (e.g. outdoor and indoor air quality, smoking, asthma, etc.).

With regards to the preferred content, several topics were identified as being of a greater interest for Aboriginal community members such as the following:

- Outdoor Air Quality: more information on local air quality conditions; materials on how poor air quality can affect respiratory health and people with chronic respiratory disease; educational materials on idling and grass fires, and practical tips on how to manage respiratory disease during periods of poor air quality (e.g. stay indoors, do not open windows, avoid outdoor activities, etc.).

- Indoor Air Quality: information on mould affects respiratory health (asthma and associated allergies); practical tips on how to deal with mould and clean the home properly; and information on other factors that can cause poor indoor air quality and simple solutions on how to prevent them.

- Non-traditional tobacco use**:** information about the link between second (and third) hand smoke and the development of asthma and associated allergies; support resources for someone who would like to quit smoking; more detailed education on how smoking affects respiratory and general health; information about the difference between traditional and non-traditional, and comprehensive prevention programs that target the reasons that many people take up smoking.

- Chronic respiratory disease: more information on asthma and associated allergies at the community level, specifically on its management and prevention; early signs and symptoms of asthma; information on asthma triggers, in particular allergies; information about proper asthma control and practical aspects of asthma management (e.g. how to reduce exposure to asthma triggers, how to manage asthma properly, how to take medication correctly, etc.).

8) Better understanding about outreach methods/strategies that will be suitable and effective in First Nations, Inuit, and Métis communities

The main focus of this project was on the development of a community outreach and engagement model (Appendix 17) including recommendations on key elements of awareness materials and activities that will be appropriate for First Nations, Inuit and Métis communities. The project results indicated that the preferred method of information delivery is consistent across the communities; therefore, justifying the need to create one model that can be adapted and modified to each community's basic needs and priorities.

The model and accompanying educational strategies have been designed and are presented in detail in the "Recommendations" section of this report. In brief, the suggested delivery methods and outreach strategies vary depending on the individual Aboriginal community (First Nations, Inuit and Métis) and are closely related to the existing community traditions, practices and programs. Overall, based on the combined results, three methods appear to be the top choices for receiving health-related information: (1) printed materials in English/French; (2) audio-visual materials (e.g. radio and TV-based Public Service Announcements, video/DVD in English/French, etc.), and (3) in-person education either delivered individually by health care professionals (e.g. a community health representative or nurse) or in a group setting (e.g. group sessions/workshops). Healthcare professionals, community outreach workers, and teachers were the top there choices for delivering educational sessions. Peers, Elders and community leaders were also rated quite high as many participants indicated a preference of receiving information from them.

Despite overall positive outcomes, the project had ***several limitations***. First, the project findings are limited in regards to the geographical location of First Nations, Inuit and Métis communities that were involved in this project. Most project activities were conducted in Eastern Canada except activities undertaken by the Métis community in Prince George, BC. Although the needs and gaps identified through the project are consistent amongst Aboriginal communities (First Nations, Inuit, and Métis), it is not clear whether this would apply to Aboriginal community members in Western Canada (e.g. the province of Alberta, Manitoba, etc.). This limitation was mitigated somewhat by obtaining feedback on the project results from two AllerGen trainees who attended the AllerGen results dissemination/grant writing workshop. They work with First Nations communities in Alberta on implementing AllerGen-funded projects and provided their perspectives on the project findings and how they could be applied to Aboriginal communities in the West. Further, the majority of AllerGen researchers attending the workshop (Appendix 16) were from Alberta, so they were able to provide comments on how the results could be extrapolated to communities in the West. They also advised on what specific issues would need to be addressed in the community outreach and engagement model when piloting it in Aboriginal communities from across Canada, including Western provinces. If the model is to be piloted, at least one of the communities selected for the pilot implementation should be from the Western Canada.

Second, the majority of project participants were mature adults and the project findings are lacking the perspectives of a younger generation. Indirectly, the needs of the younger generation were identified by their parents and other community members and could be further verified during the pilot testing of the model. Proper engagement of youth should be also ensured if any materials are to be developed during the model implementation. Additionally, the data obtained during this project could be complemented by the results of other projects conducted by the ASC. For example, the recent report "A Shared Voice" (Asthma Society of Canada, 2010) identified the needs of Aboriginal children and youth in regards to asthma educational materials and resources.

Third, participation of community leaders and Elders in the project was limited; therefore, any further steps need to ensure their proper engagement in the development of any educational and awareness activities as knowledge keepers and potential community advocates on the issues related to respiratory health and chronic respiratory disease.

VIII. Recommendations

While First Nations, Inuit, and Métis as individual Aboriginal groups raised information needs and delivery mechanisms specific to their community, overall project participants expressed the need for more tools and information that would empower individuals and the community as the whole to take charge of their respiratory health. Suggestions were provided by participants for tools and specific information that would equip both individuals and the community to better understand the risk factors for chronic respiratory disease, and what actions could be taken to prevent and manage chronic respiratory disease throughout their community.

With regard to an awareness-raising approach that could be suitable for First Nations, Inuit and Métis communities, there are enough common gaps in information on respiratory disease prevention and management that a single core community outreach and engagement model has been developed with a series of common learning objectives and components. This core model could then be tailored and adapted to the unique needs and priorities of local cultural and geographic communities. The following section outlines some specific approaches, tools, strategies, considerations, as well as target groups to be addressed while creating/implementing a model to build awareness of respiratory health issues.

Proposed recommendations presented below are related to the potential implementation of the community outreach and engagement model designed during this project as well as to the development/adaptation of educational materials on respiratory health and the risk factors for chronic respiratory disease to be used during the model pilot implementation. These proposed recommendations are informed by both the suggestions and ideas directly identified by participants and through analysis of their discussions as well as are based on the findings of the community survey. As well, they were finalized according to the feedback provided by the Advisory Group members and participants of the AllerGen results dissemination/grant writing workshop (August 09/10, 2010).

There are **six** core recommendations and subsequent strategies as follows:

1. Pilot the designed community outreach and engagement model

It is recommended that the single core outreach model that has been designed during this project (Appendix 17) be piloted in selected communities and tailored/adapted to the unique needs and priorities of these communities.

1.1. Key components of the community outreach and engagement model

The main components of the community outreach model and engagement are described in details in Project Results section of this report. These components need to be verified by the communities that will be involved in the pilot implementation. As well, graphical changes are required to make the model more appealing and relevant to each of the Aboriginal communities.

For example, the background image could be developed to reflect the unique cultural traditions/images of each cultural group (First Nations, Inuit, and Métis).

1.2. Establish proper community infrastructure to support model implementation

Community Coordination is one of the important support/additional elements of the community outreach model. It is necessary to work closely with the communities selected for the pilot to identify a hub (e.g. health centre, Department of Health and Social Services, etc.) to coordinate all awareness/outreach activities as well as the model implementation. Special considerations should be given to ensure that the community has adequate resources to carry out the model implementation. Further, an Advisory Group consisting of main community stakeholders and leaders including knowledge keepers and Elders should be established to guide and oversee the model implementation and make sure that the model is properly modified according to the community needs and practices.

1.3. Establish a Clearing House (e.g. National Aboriginal Asthma/Respiratory Health Information Centre)

To coordinate the model implementation nationally and provide adequate support to the communities involved in the pilot, it is recommended to establish a National Coordination Centre (e.g. National Aboriginal Asthma/Respiratory Health Information Centre). The main objective of this centre will be to provide administrative and resource support to the communities involved in the model testing. The centre would also work with other Aboriginal communities across Canada to provide them with the existing educational materials on respiratory health and the risk factors for chronic respiratory disease. While providing educational materials for Aboriginal communities from across Canada, the Clearing House would also have sufficient information on respiratory health available for each individual Aboriginal group (First Nations, Inuit and Métis).

The Centre would also help create “community of practice” by maintaining ongoing communication with communities, giving them necessary resources, obtaining their feedback on activities conducted, sharing experiences and lessons learned, etc. These objectives could be achieved by a variety of means such as: establishing and promoting one point of contact (e.g. toll-free number, website); developing communication tools (e.g. e-newsletter, discussion forum), and obtaining ongoing feedback/suggestions for improvement.

1.4. Develop tools and outcome measures to assess the effectiveness of the model

The National Coordination Centre would also be responsible for developing outcome indicators to measure success and effectiveness of the model implementation. The actual outcome measurements to be determined during a pre-implementation phase by the coordination team in consultation with a team of experts in program outcome evaluation.

2. Develop core materials and resources to be used under the main model components

Another recommendation that is based on the findings of the project is the **development of the core content for awareness and educational materials** that will be used to implement various model components (e.g. Community Education, Community Participation, Community Awareness, etc.). This content should be based on common learning objectives/key topics identified during this project with a focus on practical tips and solutions for individuals and communities. Based on the project's main findings, a number of general guidelines and issues should be considered when developing information for these communities. These guidelines and strategies can be applied to all types of awareness building tools (printed materials, group educational sessions/workshops, etc.), all identified topics (risk factors, avoidance strategies, etc.), and all three cultural communities (First Nations, Inuit and Métis) as follows:

2.1. Information should be culturally relevant and appropriate

According to the project findings, the identified strategies to make materials and resources more culturally relevant should be applied while developing/adapting any materials. The main strategies to consider include the following:

- Provide visual information that contains traditional and cultural symbols, images, and photos of First Nations, Inuit and Métis community members;
- Involve Elders in providing education and information by including their advice and storytelling (especially in Métis communities), having them share their experience during healing circles (especially in First Nations communities), and involving Elders in community events (especially in Inuit communities);
- Provide information on Native remedies and traditional holistic approaches and how they could be incorporated with conventional medicine;
- Ensure community involvement, connectedness, and proper engagement while implementing/developing any awareness activities;
- Have core materials and group workshop modules reviewed by an Advisory Committee which consists of members from each cultural community to ensure that the visual representation and approach to marketing and implementing materials/resources in communities are relevant and endorsed by each cultural group.

While key activities and core information about risk factors, triggers, prevention and disease management may be consistent for First Nations, Inuit and Métis communities, the style of the information provided should be further tailored for each community. Materials that target Inuit communities need to feature the images, photos, stories, and languages that are relevant to Inuit communities. Similarly, materials targeting Métis communities should feature the unique cultural identifiers of the Métis community, and First Nations materials should have symbols and images that are relevant to them.

Most materials should be available in English and French. Translation into Aboriginal languages is not widely recommended based on the needs identified during this project; however, it should be considered for each individual community if the target population numbers warrant it. Under the guidance of particular communities, primary consideration should be given to spoken or oral-based tools and materials to ensure that a wider audience of community members is engaged including community Elders and grandparents.

Specifically, it is recommended to develop a selection of personal stories from each of the three cultural communities that can be inserted into materials targeting each group (First Nations, Inuit and Métis) and be widely used at the community level (e.g. digital stories could be available in waiting rooms, played by the local TV channels or/and used by other local media, posted on community websites, etc.).

2.2. Information is tailored to different audiences in the community

Because each community is diverse (e.g. Elders, youth, parents, etc.), and everyone has a different preference for and access to information (i.e. print material, Internet, media, group discussions, one-on-one interaction, etc.), a range of information-sharing tools needs to be developed. Tailoring tools and information to specific audiences is important to ensure that they see themselves in the information that is being provided to them. Further, this also could minimize information overload by prioritizing the messaging and making the information most relevant to their personal/professional experience.

The findings of the project indicate the **development of a comprehensive toolbox/toolkit of tools, resources and materials** that offer a variety of communication and learning methods to target different audiences. Special considerations should also be given to developing/adapting materials for community members who are not currently personally affected by chronic respiratory disease to increase broader community awareness about the issues related to respiratory health (e.g. asthma awareness). For example, there is a need expressed by community members to have materials explaining what to do if a child around them is having an asthma attack or breathing problems. This was perceived as valuable information for many community members since not all children with asthma are consistently carrying their medication with them, yet a wide range of triggers throughout the community put many children at risk of having an attack.

2.3. Tools and key messages focus on the family

Key messages and tools will reach more people in the community and have a stronger impact if they include a strong family component. Key messages and tools should be developed to focus on multi-generational and family-based learning. This could translate into workshops and group discussions that involve multiple generations in the same room, having older generations speak to younger generations (i.e. storytelling and sharing personal experiences), having some awareness initiative delivered at schools, and finding ways of sharing information in different ways to different family members (e.g. creating opportunities to discuss issues in the family through activities led by children). According to the project findings, when children and youth participate in awareness-raising activities at school (particularly when they are involved in the development of materials), they bring these messages home, and create a learning opportunity for parents, grandparents and other family members. Further, special consideration should be given to engaging youth in awareness activities by using a diverse approach that includes both peer interaction and intergenerational communication (e.g. engaging Elders). For example, initiatives could be developed to allow youth to hear information about the risks of smoking from Elders.

Based on the project findings, it is also very important to target parents and families (and in particular young mothers) and ensure that they get the information and tools that they need to have a healthy home and healthy children. Therefore, **the development of materials/resources is recommended to address gaps in basic information for parents** about what needs to be done in their home on a regular basis to prevent chronic respiratory disease as well as how to manage asthma properly and prevent asthma attacks (e.g. regular dusting and eliminating allergy-related triggers and risk factors, taking medications properly, etc.). In particular, young mothers need more support both for preventing and managing respiratory conditions for themselves as well as for their children.

2.4. Information is available in the preferred format identified during the project

Printed materials

Printed and written information (booklets, posters, and brochures) were identified as good ways of communicating information about the various components of achieving and maintaining respiratory health. The existing printed materials that were rated favorably by participants should be adapted where necessary and be available for wide distribution. They should be categorized for the potential use under each of the model components (e.g. community education, community awareness, community healthcare delivery, etc.). The list of the materials should be finalized by working with a particular community and be based on its unique learning needs.

On topics where printed materials do not currently exist, this study recommends **the development of new print materials with practical, action-oriented solutions** (including pamphlets, checklists, action items, magnets, posters, etc.) to make them available throughout the community. If new materials are to be developed, they should be compliant with a list of parameters developed based on the project findings to improve material uptake:

- Develop simple, quick to read, and easily displayed information tools such as fridge magnets and posters that contain a few key messages, reminders, etc.;

- Make information and materials practical and grounded in real-life experience, with easy steps to follow (for example, checklists or short lists of action items instead of lengthy and technical information booklets);
- Provide examples of simple, easy, low cost or no-cost actions (e.g. practical tips) that individuals can do themselves without having to rely on an expert, landlord or community official;
- Rely on strong, culturally relevant and explanatory visuals to reduce reading;
- Include a local contact person (name, phone, location where they can be found, and what information they can provide) to be reached if more information is needed on all materials or other contacts where relevant (e.g. the Asthma Society of Canada).

Group discussions

According to the project findings, any kind of facilitated group discussion (e.g. workshops, educational sessions, support groups, healing circles, etc) would be an important and useful way of communicating information and creating community awareness on respiratory health and the risk factors for chronic respiratory disease.

Based on the project results, another recommendation is to **develop a series of learning modules on respiratory health topics** that can be offered by both trained healthcare professionals (e.g. community health representatives, nurses, etc.) and community leaders, and/or which can be also integrated into existing group activities in the community according to the community outreach model components. The exact group format and how it is executed in a community would have to be explored by members of that community before model implementation. Group discussions would give a community an opportunity to:

- Bring the issue to the community and keep it alive (especially if they were held regularly or seasonally);
- Allow community members to share knowledge and personal experiences (as well as tips and tricks that they use) with each other;
- Demonstrate practical tips and techniques for prevention and management;
- Ask questions about their unique circumstances, allowing others experiencing a similar situation to benefit from the response; and receive personal support and encouragement;
- Be a way of bringing in a respiratory or environmental health professional (as internal and external guest speakers) and their expertise to the community if necessary;
- Meet local community officials (and other leaders) and better understand what services and information they can access at the community level;
- Distribute targeted, printed reference materials (e.g. healthy indoor air themed information at a healthy home themed workshop).

Workshop modules could include, but not be limited to:

- Presentation/storytelling from Elders and other community members;
- Visual demonstrations and hands-on practice opportunities (e.g. changing air conditioner and dehumidifier filters);
- Examples of simple, easy, low cost or no-cost actions that individuals can do themselves without having to rely on an expert, landlord or community official;
- Engaging games (i.e. trivia games) and incentives/prizes for participants.

Public service announcements for local media (radio and television)

Public Service Announcements on the radio and television could alert community members to the current (i.e. seasonal) environmental risk factors, and provide reminders and tips on what they need to do to monitor and self-manage their chronic respiratory condition. They can also serve to educate and raise awareness among other community members about things that they can do to improve the air quality of their community (e.g. raise awareness about the impact of local activities such as garbage burning and grass fires on the respiratory health of community members, especially those with asthma, etc.). Therefore, another recommended strategy is the **development of public service announcements (PSAs),** which will be used on local media and themed and timed to the seasons.

2.5. Information is available on the preferred topics identified during the project

According to the project findings, several topics are of a greater interest for Aboriginal community members. A recommended activity is to **develop the content based on the topics identified and according to the gaps in the materials/resource that are currently available**. Specifically, focus should be given to materials on risk factors and early signs of chronic respiratory conditions explaining common symptoms to look for and providing details on where to go for more information in their community (including the name, location, phone number, and brief description of services and support that is available).

Further, community members with the existing disease should be provided with materials/tools to improve their understanding of the disease and strategies for effective self-management (including information on how to use medications properly, trigger avoidance strategies, information on what to do during asthma attack, etc.). Because of the barriers to accessing health care providers for some individuals, community members diagnosed with chronic respiratory disease are seeking more support and information for managing their condition in their community. Practical information on several topics (e.g. information about common triggers and the steps they can take to help identify the triggers that are unique to them; practical measures for reducing exposure to triggers at home, at work, outdoors, and in the community; etc.) should be made available using the existing materials/resources available from the lung health organizations or developing new materials if required. Specifically, one of the key tools that should be adapted is an asthma action/COPD management plan. It would support people with the disease and would facilitate sharing information with the different health care providers. It would also provide clear instructions on what to do during an asthma attack/COPD exacerbation.

In addition, information on where to access resources on chronic respiratory disease in their community (including the name, location, phone number, and brief description of services and support that is available) should be compiled for each community based on the template developed as part of the model implementation process (e.g. an asthma road map).

3. Develop a comprehensive dissemination network for materials and resources on respiratory health

To increase community members' awareness and knowledge about materials/resources available in their communities, it is important to inform community members and the community as the whole about these resources. It is suggested that the **development of a comprehensive distribution network for printed and other materials** should be undertaken to make them available in both health-focused areas (such as health centres, pharmacies, nursing stations, health fairs, etc.) as well as in the wider community (such as cultural centres, community centres, bingo halls, community stores, etc.). Several distribution strategies should be developed to ensure better uptake and use of the materials and will depend on the community's practices and traditions. These methods should be established by working with a particular community based on the preferences of community members (e.g. some communities prefer getting information in the mail while others ask to not widely distribute unsolicited materials that risk getting lost in the junk mail). Workshops and group discussions as well as existing community events/celebrations should be also considered as important mechanisms to distribute targeted, reference materials.

Based on the project findings, the level of access to the Internet, awareness of and comfort with web-based tools (including online information, video-conferencing and webinars) is inconsistent. For those individuals and communities that do have access and confidence in using new technologies, the web-based education could be a good source of information, but would need to be accompanied by more traditional written, radio, television, or oral means of communication for maximum reach. If web-based tools are to be developed in order to maximize dissemination of the information to various community audiences, online information would need to follow the same guidelines of ensuring that information is simple, action oriented, and relies heavily on strong, culturally relevant visuals, and is engaging/has an interactive component.

It is recommended that **information, tools and educational materials are to be developed/adapted should also be available online for communities that have access to the Internet**. It is necessary to ensure that online tools are interactive, and have a strong visual learning component rather than simply sharing long, detailed text. Before implementing any web-based tools in the actual community, the level of access to the Internet, the quality of the connection, and interest among community members in accessing a web-based tool would need to be assessed to ensure adequate uptake.

4. Develop tools to engage, train and support community leaders in delivering respiratory health education messages

One of the key outreach model components is Community leadership, which calls for buy-in from community leaders in order to be effective in bringing respiratory health awareness to Aboriginal communities. The project data indicates that the best way to mobilize a community to pay attention to the issue and attend community discussions is to have community leaders and Elders providing personal invitations and promote the event personally. Based on the project findings, it is also evident that community leaders could play a crucial role in delivering health-related messages. Therefore, a further recommendation is to **develop tools to train and support community leaders in becoming respiratory health "champions/advocates".** Proper engagement of community leaders would help inspire and motivate other community members to take notice of the issues related to chronic respiratory disease and participate in community awareness activities (e.g. workshops, group discussions, etc.).

5. Develop strategies/tools to ensure adequate participation of community-based healthcare providers/representatives

Under the Community healthcare delivery component of the model, a proper liaison should be established with healthcare professionals working in the community and nearby healthcare facilities. According to the project findings, healthcare providers, both within the community and in the hospitals/healthcare facilities outside of the community, are identified as important sources of information on chronic respiratory conditions for community members. It is important to ensure that the healthcare professionals working outside of the community, but who treat community members, have information about the common risk factors and unique issues that are present in the homes and around the community (e.g. mould, road dust, industrial-based pollutants, etc.).

Based on the project findings, the **development of tools/strategies to establish a connection between community-based awareness activities/resources and healthcare professionals** is recommended in order to raise awareness among health professionals of the risk factors that are prevalent in the local environment. As well, providing health care professionals with information tools that they can share with Aboriginal patients would help ensure that information circulating in the community is consistent and that patients and community members are knowledgeable about the risk factors and management approaches. Specifically, one of the possible strategies could be providing tools and information that are developed as part of the outreach model to various healthcare settings such as community health centres, health clinics, doctor's offices, nursing stations, pharmacies, etc. It is also necessary to make sure that information and management tools that healthcare providers use for Aboriginal community members reflect the cultural values and community circumstances. Community members also need to be well equipped and educated on how to effectively communicate/work with their healthcare provider. Additionally, materials and information provided should reflect the healthcare resources available for each particular community.

Information that is tailored to an individual's needs and environment is the most effective way of ensuring that information is accessed and understood. Community members need to be aware of who can provide this type of service and know how and when they can be contacted. Community health representatives/workers should be trained to provide one-on-one support and education on disease management and risk factors for chronic respiratory disease. Another strategy that is recommended for implementation is the **identification and promotion of individuals in the community that can provide one-on-one education** (e.g. community health representatives, nurse, etc.) and answer questions on different risk factors and disease management.

6. Develop tools and resources to ensure broader community involvement in awareness initiatives

The Community participation component of the model (Appendix 17) encourages outreach to various community organizations and resources in order to increase awareness of respiratory health amongst broader community members as well as explain their potential role in bringing this awareness to the community. Potential organizations and agencies to be included in the outreach are the following: workplaces; local business; housing officials including landlords; community facilities (e.g. Culture centre, community halls, libraries, fitness centres, the friendship centre, etc.); community/grocery stores; foster agencies; major retailers (e.g. Home Depot), and existing community programs (e.g. youth education, Elder monthly sessions/social events). The exact list of community facilities and organizations should be determined in consultation with the community before the model pilot.

Another suggestion is to **develop tools and materials/resources that could facilitate the engagement process for various community organizations**.

Specifically, given the prevalence of mould problems in both on- and off-reserve buildings/houses in First Nations, Inuit and Métis communities, resources/materials are needed to communicate the magnitude of the problem and provide information about indoor air quality risk factors and solutions to building owners/managers.

Examples of developed materials/resources could include but not be limited to:

- Posters and other promotional/awareness materials to highlight the issue to individuals not aware of mould and indoor air quality issues;

- Workshops/community information nights on the sources and causes of mould, the risks of living in a home with mould and symptoms of exposure to mould, mould effects on respiratory health, no-cost and low-cost steps that they can take to improve air circulation and prevent mould, and steps for safe clean-up of mould;

- Workshops/materials targeting building owners and managers (i.e. community leaders on reserve and landlords off reserve) on the sources and causes of mould, the risks of living in a home with mould, the responsibilities that building owners have for maintaining and repairing homes to prevent mould and cleaning mould, no-cost and low-cost steps that they can take to improve air circulation and prevent mould, steps for safe clean-up of mould, and resources (government funding opportunities and tax rebates) that are available to them for clean-up and remediation.

In conclusion, during this project Aboriginal community members have identified their needs in regards to the information and community-based resources on respiratory health and the risk factors for chronic respiratory disease. Despite cultural differences amongst individual Aboriginal groups, the gaps in existing resources and educational materials are consistent across the Aboriginal communities indicating the development of the core community outreach and engagement model. The findings of this project support the need for a community outreach and engagement model to be developed, implemented and piloted into First Nations, Inuit, and Métis communities throughout Canada. Aboriginal community members should be properly engaged and participate in all aspects of the model implementation as well as be involved in the development and/or adaptation of any educational materials. The model should be modified and adjusted to address the unique needs of each particular community allowing for community capacity building and empowerment. As resources are limited, each particular community should define their immediate needs and specify priorities for action and appropriate strategies within the model. The ASC will be applying to the NLHF phase II funding for support to pilot the model in selected Aboriginal communities in order to increase respiratory health awareness, in particular, asthma prevention and management, improve community understanding and knowledge of the risk factors for chronic respiratory disease, and empower communities to create a self-sufficient community outreach and engagement system to have greater access to respiratory health resources at the community level. The ASC will also seek other opportunities to continue its work in Aboriginal communities across Canada.

IX. References

Advisory Group meeting minutes and correspondence, the Asthma Society of Canada, internal communication, July 2010

Asthma Society of Canada (2009) “A Shared Vision: Ensuring quality of life for adults and children with asthma and allergies in First Nations and Inuit communities in Canada”, Final Report. Available at http://www.asthma.ca/adults/Shared_Vision_English.pdf

Asthma Society of Canada (2010) “A Shared Voice: Engaging First Nations and Inuit communities in the development of asthma and allergy education materials and resources for youth and their families”, Summary report.) Available at http://asthma.ca/adults/SR%20-%20Shared%20Voice%20(August%202010).pdf

Asthma in Australia (2008) “Asthma in Aboriginal and Torres Strait Islander Australians”, Australian Department of Health and Aging Accessed at http://www.aihw.gov.au/publications/acm/aia08/aia08-c02.pdf

Atkinson D.L. (2008). Aboriginal Health Promotion – A Literature Review and Environmental Scan, National Collaborating Centre for Aboriginal Health, Ministry of Healthy Living and Sport and Act Now BC.

Australian Department of Health and Aging, Remote Indigenous Australian Asthma Action Plan, February 2008 Accessed at http://www.nationalasthma.org.au/images/stories/manage/pdf/remote_indig_aust_asthma_action_plan_jan08.pdf

Canadian Mortgage and Housing Corporation (CMHC) “Mold Maters: A Resource Guide for First Nations Housing Providers” Available at http://www.cmhc.ca/en/ab/noho/noho_024.cfm

Cancer Care Ontario (CCO), Aboriginal Tobacco Program Accessed at http://www.cancercare.on.ca/cms/one.aspx?pageId=9322

Chase, Dr. Claudette, personal communication with the Asthma Society of Canada, March 2010

Dolan, A.H., and Ommer, R. (2008). Climate Change and Community Health: Lessons from Canada’s East and West Coasts. *Journal of Rural and Community Development,3(2),* 27-46.

Gittlesohn J. et al. (1995) Developing Diabetes Interventions in an Ojibwa-Cree Community in Northern Ontario: Linking Qualitative and Quantitative Data, Chronic Diseases in Canada, Vol. 16, No.4. Available at http://www.phac-aspc.gc.ca/publicat/cdic-mcc/16-4/e_e.html

Hill, Dawn Martin (2009) “Traditional Medicine and Restoration of Wellness Strategies”, Journal of Aboriginal Health, Accessed at http://www.naho.ca/jah/english/jah05_01/V5_I1_Restoration_02.pdf

Jeffery B. et al. (2006) Engaging Numbers: Developing Health Indicators that Matter for First Nations and Inuit People, Journal of Aboriginal Health, p. 44-52 Accessed at http://www.naho.ca/jah/english/journal_V03_01.php

Health Canada, First Nations Occupants' Guide to Mold, Brochure Available at http://www.hc-sc.gc.ca/fniah-spnia/pubs/aborig-autoch/mold-mefaits_guide/index-eng.php

Health Canada "Your Health at Home: What you can do!" (2010) Available at http://www.hc-sc.gc.ca/fniah-spnia/promotion/public-publique/home-maison/index-eng.php

Heart and Stroke Foundation, First Nations, Inuit and Métis Resources, "Let's put our Hearts into it! " Poster Available at http://www.heartandstroke.com/site/pp.aspx?c=ikIQLcMWJtE&b=3479041&printmode=1

Heart and Stroke Foundation, First Nations, Inuit and Métis Resources, "Heartbeat of the Anishnawbe Nation" Video Available at http://www.heartandstroke.com/site/pp.aspx?c=ikIQLcMWJtE&b=3479041&printmode=1

Heart and Stoke Foundation, First Nations, Inuit and Métis Resources, Taking Control: Lower Your Risk of Heart Disease and Stroke. A Guide for Aboriginal peoples Available at http://www.heartandstroke.ab.ca/site/c.lqIRL1PJJtH/b.3650783/k.F4/First_Nations_Inuit__M233tis_Resources.htm

Heart and Stroke Foundation, First Nations, Inuit and Métis Resources, Your Heart - It's in your Hands, Video. Available at http://www.heartandstroke.com/site/pp.aspx?c=ikIQLcMWJtE&b=3479041&printmode=1

Métis Nation – Saskatchewan: Morin, J.M. and M. Oladele (2009). No Judgments. Just facts! Newsletter. 1(1): 1-4.

Ministry of Health and Long-Term Care (MOHLTC), Ontario Diabetes Strategy, Fact Sheets: Diabetes, Alcohol and Diabetes, Diabetes - An Introduction, Foot Care, Health Coverage, Healthy Eating - The Basics, Physical Activity, Maintaining a Healthy Weight, Managing Blood Glucose Levels, Managing Your Cholesterol, Staying Healthy - Managing Type 2 Diabetes, Using Insulin. Available in Cree, Ojibway and Ojicree at http://health.gov.on.ca/en/ms/diabetes/en/fact_sheets.html

Minore B., "Not Just an Aboriginal Face on the Cover: Making Asthma Education Relevant for First Nations, Métis and Inuit communities". Presentation given on behalf of the Centre for Rural and Northern Research, Lakehead University at the Ontario Lung Association, 2010

Mundel E., Chapman G.E. (2010). A decolonizing approach to health promotion in Canada: the case of the Urban Aboriginal Community Kitchen Garden Project., *Health Promotion International, 25 (2)*, 166-172.

National Aboriginal Diabetes Association (NADA), online resources Available at http://www.nada.ca

National Collaborating Centre for Aboriginal Health, “Culture and Language as Social Determinants of First Nations, Inuit and Métis Health”, 2009/10 http://www.nccah-ccnsa.ca/en

National Indian & Inuit Community Health Representatives Organization (NIICHRO), “Taking the Lead for Change- Smoke-free Home Campaign” Accessed at http://www.niichro.com/2004/?page=resources&lang=en

Neganegijig, T. “First Nations Asthma Education Research” Report, Northwestern Ontario Asthma Clinic & the Ontario Lung Association, Prepared by October 2006 (unpublished, provided by the Ontario Lung Association)

Public Health Agency of Canada, H1N1 Flu Virus, Materials for First Nations and Inuit http://www.phac-aspc.gc.ca/alert-alerte/h1n1/tools_outils-eng.php#fn

Reading C. L., and Wein, F. (2009). Health Inequalities and Social Determinants of Aboriginal Peoples’ Health, National Collaborating Centre for Aboriginal Health.

Smylie, J., Anderson, M. Understanding the health of Indigenous peoples in Canada: key methodological and conceptual challenges, CMAJ, September 12, 2006; 175 (6) Accessed at http://www.cmaj.ca/cgi/content/full/175/6/602

Sue M. (2007). Tobacco Cessation Strategies for First Nations, Inuit and Métis: Environmental Scan and Annotated Bibliography, National Collaborating Centre for Aboriginal Health, Ministry of Healthy Living and Sport and Act Now BC.

Tobaccowise.com, the Aboriginal Tobacco Program, Population Health Unit, Prevention and Screening, Cancer Care Ontario http://www.tobaccowise.com/cms

Thunder Bay Regional Health Science Centre, NWO Regional Stroke Program - Video Resources “As the Rivers Flow: Brain Attack” Available at http://www.tbrhsc.net/clinical_partners/regional_stroke_program/video_resources/as_the_river_flows.asp

Varcoe C. et al. (2010). Wisdom and Influence of Elders: Possibilities for Health Promotion and Decreasing Tobacco Exposure in First Nations Communities, Canadian Journal Public Health, 101 (2): 154-58.

Wilson, K., Young TK (2008). An overview of Aboriginal health research in the social sciences: current trends and future directions, International Journal of Circumpolar Health 67(2-3):179-89. Review. Pub Med PMID: 18767338.

Wagner E.H., Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice*. 1998;1(1):2-4.

Zizman, Paani (2009) “Inuit Wellness Fact Sheets: Finding the Right Tools for Effective Knowledge Translation”, presentation at NAHO 2009 National Conference. Accessed at http://www.naho.ca/conference/presentations/B4-ST-O-Zizman.pdf