

The Respiratory Health Awareness Community Outreach and Engagement Model in First Nations, Inuit and Métis Communities: Pilot Intervention

# FINAL REPORT

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Asthma Society of Canada

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## **Executive Summary**

It is well-known that respiratory health is an important issue facing First Nations, Inuit and Métis communities in Canada. The risk factors for chronic respiratory disease play a significant role in the development of asthma and associated allergies, as well as other chronic respiratory diseases. The social determinants of health (i.e., indoor and outdoor air quality, environmental tobacco smoke, mould, etc.) have become the subject of much attention by researchers and policy makers given substantial increases in disease prevalence over the past few decades. It has been estimated that the prevalence of asthma is 40% higher in First Nations, and Inuit communities than in the general Canadian population (Life and Breath, 2007). There is no current prevalence data available for Métis communities.

According to the key results of the project "An Exploration of First Nations and Inuit Perspectives on Community Respiratory Health Awareness Initiatives" (Phase I) conducted by the Asthma Society of Canada (ASC) in 2010, it was determined that there was a lack or, indeed, absence of resources on respiratory health at the community level that specifically target First Nations, Inuit and Métis community members. Important findings from this project also revealed that overall there was low level of knowledge on how social determinants of health can affect respiratory health.

The Phase I project showed that there was a high need to bring awareness of risk factors for chronic respiratory disease (namely, outdoor and indoor air quality, mould, second- and thirdhand smoke exposure, etc.) to First Nations, Inuit and Métis communities. The project also helped identify potential educational and awareness strategies to bring the right information and resources to Aboriginal community members and make them more relevant to their cultural and traditional practices. As a main Phase I project outcome, a *Respiratory Health Awareness community outreach and engagement model* (the Model) was developed and recommended for pilot implementation.

The Phase II initiative was built on the key findings of the Phase I project.

## **Project Goals and Objectives**

The main goals of the Phase II project entitled "The Respiratory Health Awareness Community Outreach and Engagement Model in First Nations, Inuit and Métis Communities: Pilot Intervention" were

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- 1) To evaluate the effectiveness of the Model implementation in selected Aboriginal communities by conducting a pilot intervention and to make recommendations for its future application in Aboriginal communities across Canada.
- 2) To empower First Nations, Inuit and Métis communities to create better awareness of lung health, to improve their knowledge about the risk factors for chronic respiratory conditions, and to enable Aboriginal communities to establish community-based resources on respiratory health.

The main objectives of the project were aligned with the overall objectives of the Lung Health Program, the Public Health Agency of Canada and related to the increase in awareness, the prevention of and, the early detection of lung diseases.

## **Project Design**

The Phase II project design was primarily based on the principles of the community-based participatory approach; therefore, Aboriginal communities were engaged and participated in all aspects of Model implementation including the development of educational materials and resources. This pilot intervention was conducted in selected Aboriginal communities from Western and Eastern Canada, as well as one French-speaking First Nations community from Quebec. In total, the project was piloted in **seven** communities including five First Nations, one Inuit and one Métis community:

- Postville, Newfoundland and Labrador (Inuit community)
- Prince George, British Columbia (Métis community)
- Wendake, Quebec City (First Nations French-speaking community)
- Listuguj, Quebec (First Nations community)
- Conne River, Newfoundland and Labrador (First Nations community)
- Saddle Lake, Alberta (First Nations community)
- Enoch, Alberta (First Nations community)

The project was conducted over a period of 13 months and the ASC worked closely with the main project partners (Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK), Métis Nation British Columbia (MNBC), AllerGen NCE Inc., and the Social Support Research Program (SSRP), University of Alberta) to achieve project objectives. A step-by-step approach to the Model implementation was applied to ensure proper community engagement in the project and capacity building within the participating communities on as consistent a basis as possible.

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### **Project Activities**

The main project activities were conducted under four main stages as follows:

- (1) Community Engagement,
- (2) Toolkit Development and Community Training,
- (3) Model Implementation and
- (4) Model Evaluation and Results Dissemination.

Stage 1) The *first stage* of the project consisted of actions aimed at engaging participating communities in the Model implementation process by identifying appropriate resources and appointing community personnel (e.g., Community Outreach Coordinators and Liaisons (COCLs)) to conduct project activities at the community level. Community-based Advisory Groups consisting of the key community stakeholders, community leaders, Elders and/or Knowledge Keepers were also established to oversee the Model implementation at the community level, as well as to ensure that the Model-related activities were appropriately modified according to the community's needs and practices. In all communities combined, **52** individuals were involved in the work of Community Advisory Groups and **30** meetings were held over the course of the project implementation.

To guide the pilot Model implementation on the national level, a National Advisory Committee (NAC) was created and comprised of **26** members who were representatives from the key partner organizations (i.e., AFN, ITK, MNBC, and AllerGen, and SSRP); project supporters (National Collaborating Centre for Aboriginal Health (NCCAH), the Division of e-Learning Innovation, McMaster University, the Canadian Action Network for the Advancement, Dissemination and Adoption of Practice-informed Tobacco Treatment (CAN-ADAPTT), and Healthy Indoors Partnership (HIP)); community representatives; respiratory health experts, and key opinion leaders in the area of First Nations, Inuit and Métis community health.

The development of the *Respiratory Health Awareness Toolkit* (the Toolkit) was conducted during the *second stage* of the project with input from the communities and guidance provided by NAC members. During the development of the Toolkit, special considerations were given to making materials and resources culturally relevant and appropriate by applying strategies identified during the Phase I project (Asthma Society of Canada, 2011). The range of educational materials on respiratory health, and the risk factors for chronic respiratory disease, were developed for the Toolkit, including: **18** printed materials (information cards, posters, and brochures); **21** conversation cards to be used during support circles; **10** digital stories with

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personal messages related to the main environmental factors that can impact respiratory health, and a Master Group Presentation to be used during community events and programs.

Stage 2) Other activities during *Stage 2* included training of communities to prepare them for Model implementation, and recruiting community leaders, Elders and Knowledge keepers to become *Respiratory Health Champions* in their communities. A special instructional web-based training Module (information session) was developed in partnership with the Division of e-Learning Innovation, McMaster University to educate on the main issues related to respiratory health, and **52** Respiratory Health Champions completed the Module.

Stage 3) During the *third stage*, the main Model-related activities were implemented by the COCLs in consultation with the Community Advisory Groups. Respiratory Health Champions delivered the main education messages related to respiratory health to fellow community members by using a "word of mouth" approach. Community members were also informed about the risk factors for chronic respiratory disease through multiple outreach strategies, including participating in health and wellness fairs; conducting presentations at community celebrations and programs, and by providing respiratory health information during social gatherings and cultural events (i.e., BINGO games, powwows, etc.). In total, **44** presentations were delivered with approximately **3157** community members in attendance. The French-speaking First Nations community also organized a radio podcast reaching out to **8,000** individuals.

The materials and resources in the Toolkit were distributed to participating communities in a form of the Master Toolbox (one per each community, **7** in total), **36** Distribution Toolkits to various healthcare and community organizations, as well as **910** Individual Packages to community members. In total, **47** community-based healthcare professionals were involved in the project, and **18** Distribution Toolkits were disseminated to healthcare settings. Additionally, a National Coordination Centre/ online Clearing House (**BREATHE**: *Building Respiratory Education and Awareness for First Nations, Inuit and Métis: Tools for Health Empowerment*) was established at the ASC as a key point of contact for information on respiratory health for First Nations, Inuit and Métis communities.

Stage 4) The *fourth stage* of the project was dedicated to assessing the early effectiveness of the Model implementation at the pilot stage. Using specifically designed project evaluation tools, a post-implementation assessment was completed. The ASC Project Team also summarized feedback on the Toolkit that was received from the participating communities and from the main Project Partners.

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### **Project Results**

The pilot Model implementation worked well in participating communities. The process of implementing the Model incorporated substantial community engagement and capacity building activities. The participating communities showed high interest levels towards the project, were fully engaged in the process, and indicated that Model-related activities were positively received by, and were appealing to, community members. Overall, participating communities experienced increased levels of respiratory health awareness after the Model implementation. In addition, support for, and conversation on, respiratory health increased in most communities. The project results demonstrated improved community members' perceptions of the programs on respiratory health available at the community level, specifically for those with a chronic respiratory condition. Further, after the Model implementation, there was greater awareness and increased perceived availability of community-based materials on respiratory health at a variety of places within the communities. Integration or linkages of respiratory health programs with existing community structures and organizations improved as well.

Participating communities also showed marked progress in the development of capacity to address respiratory health issues. Key findings demonstrated improved perceptions about community commitment and social environment in regard to dealing with issues related to community respiratory health. Community leadership on respiratory health enhanced and there was increased availability and awareness of support and information offered by community leaders. Community members also indicated an increased comfort level in sharing information about their respiratory health and the ability to contact a community member for information and support. Additionally, participating communities showed their increased willingness to help reduce negative effects of open burning and to provide help in improving indoor air quality in homes of community members.

The Toolkit materials and resources were well-received, deemed to be good for educating community members, and were appreciated for the helpful, useful and interesting information; appropriate content and reading level; appealing design; locally and culturally relevant images; and the intergenerational applicability of the materials. The Master Toolbox, Distribution Toolkits and Individual Packages were adapted to the community's needs and were used to improve access to information on respiratory health, potentially overcoming barriers to accessing these types of resources.

#### Recommendations

While culturally appropriate resources in the Toolkit now exist, and the Model has proven to be appropriate and successful in the pilot communities, further work needs to be done on finalizing

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the Toolkit materials and resources based on the feedback obtained during the pilot testing, as well as implementing the Model in other Aboriginal communities. The findings from this project support five key recommendations.

- *1)* It is recommended that modifications be made to the newly-developed Toolkit materials and resources according to the feedback received from community members, as well as the comments provided by the main project partners.
- 2) The second recommendation is to implement the Model and distribute the modified Toolkit in additional Aboriginal communities located close to the initial pilot communities. The communities involved in the initial Model pilot would be used to showcase and introduce the Model and distribute the Toolkit to nearby communities located in the same region. Respiratory Health Champions from the pilot communities and other engaged community leaders would help both promote the Model and assist in Toolkit dissemination to additional communities. This intervention would be associated with a comprehensive, extensive evaluation of the Toolkit in these communities, which is necessary to ensure broader applicability of the Toolkit and its relevance to other Aboriginal communities, and is crucial to support its future use Canada-wide and internationally.
- 3) The *third* recommendation is to make final revision to the Toolkit based on the feedback received during the extended (modified) pilot. In addition, it is suggested to develop a knowledge mobilization package to facilitate further Toolkit dissemination and introduction to other Aboriginal communities across Canada. This package would include the final version of the Toolkit materials and resources, as well as an explanation on how to use the Toolkit at the community level and information on practical approaches that need to be applied to ensure successful and effective Toolkit implementation. The finalized Toolkit and Model-related activities would be available for use in Aboriginal communities across Canada, as well as other vulnerable populations (i.e., communities affected by poverty, poor housing, low socio-economical level, and multicultural communities).
- 4) To ensure the success of the Canada-wide Model implementation, a *fourth* recommendation is to bring together key Aboriginal and provincial health decision and policymakers, and program planners to exchange knowledge and information about the Model and the Toolkit in order to gather insights, share resources, plan effective strategies, and determine next steps for the broader implementation of the Model in

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Aboriginal communities across Canada. This would also help assess the capacity of Aboriginal organizations or regional health authorities to lead future Model implementation through knowledge translation and mobilization.

5) After the Toolkit is finalized, the knowledge mobilization package is prepared, and implementation strategies are defined, a *fifth* recommendation is to implement the Model and distribute the Toolkit in additional Aboriginal communities located in Provinces and Territories other than those involved in the initial or modified pilots, followed by comprehensive evaluation on health outcomes, capacity building and program reach.

### **Conclusion and Next Steps**

*In conclusion*, the ASC and key Project Partners will work collaboratively with First Nations, Inuit, and Métis communities across Canada to create a self-sufficient and sustainable outreach and engagement system that facilitates greater access to community level respiratory health educational materials and resources and improve respiratory health at the population level.

The ASC is planning to seek long-term funding for incorporation of the Model in all interested Aboriginal Communities in Canada, widespread distribution of revised, culturally appropriate materials in the Toolkit among both urban and non-urban Aboriginal people, and a fully functioning National Coordination Centre (Clearing House) **BREATHE** to promote lung health in the Canadian Aboriginal population.

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## **Project Background and Description**

## **Brief Organizational Overview**

<u>Project Title:</u> The Respiratory Health Awareness Community Outreach and Engagement Model in First Nations, Inuit and Métis Communities: Pilot Intervention

<u>Lead organization</u>: The project was conducted and led by the Asthma Society of Canada in cooperation and collaboration with the Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK), the Métis Nation British Columbia (MNBC), and the AllerGen NCE Inc

<u>Main partners</u>: Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK), Métis Nation British Columbia (MNBC), and AllerGen NCE Inc.

<u>Supporting organizations</u>: National Collaborating Centre for Aboriginal Health (NCCAH), the Division of e-Learning Innovation, McMaster University, the Social Support Research Program, University of Alberta, the Canadian Action Network for the Advancement, Dissemination and Adoption of Practice-informed Tobacco Treatment (CAN-ADAPTT), and Healthy Indoors Partnership (HIP).

#### About the Asthma Society of Canada (ASC)

The 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 38-year reputation of providing health education services to consumers and health care professionals and offers evidence-based and age-appropriate asthma and allergy education, and chronic 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 are the following: 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 ASC has a special interest in helping adults and children, including those from First Nations, Inuit and Métis communities, affected by asthma and associated allergies in vulnerable and remote communities to achieve a symptom-free life by providing them with culturally appropriate up-to-date information about asthma and its management.

## **Project Background and Development**

Asthma and associated allergies represent a significant issue for First Nations and Inuit 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 (Life and Breath, 2007). There is no current prevalence data available for Métis communities. While heredity factors play a very important role in the determination of asthma and allergies, the social determinants of health (i.e., indoor and outdoor air quality, environmental tobacco smoke, mould, etc.) are also significant in the development of chronic respiratory disease amongst First Nations, Inuit and Métis community members. Thus, poor housing conditions such as older dwellings and those with dust, damp and mould have been shown to be associated with chronic respiratory disease, in particular asthma and associated allergies. Overcrowding (15% of the First Nations population and 38% of Inuit communities compared to 3% for the rest of Canada) can also impact health and lead to the increased likelihood of developing chronic respiratory diseases (i.e., asthma), increased incidence of asthma exacerbation and increased allergic sensitization (Health Canada, 2006).

In the context of determinants of health, there are high rates of tobacco use among Aboriginal communities (i.e., the rate of smoking among First Nations and Inuit community members is more than three times the rate of the general Canadian population- 59% and 70%, respectively) (Health Canada, 2004). Smoking while pregnant and early childhood exposure to environmental tobacco smoke have been shown to be the key risk factor for asthma and related allergies; 62% of Inuit women who were pregnant in 2001 reported smoking on a daily basis (Tait et al., 2007). Second-hand smoke is also a problem in Aboriginal households, which is often exacerbated by overcrowding and poor ventilation.

The risk factors for, or determinants of, asthma and related allergies and other chronic respiratory diseases have become the subject of much attention by researchers given substantial increases in disease prevalence over the past few decades. In 2010, the ASC completed a baseline needs assessment of awareness material and resources on respiratory health that were available for First Nations, Inuit, and Métis community members. According to the results of the Phase I project "An Exploration of First Nations and Inuit Perspectives on Community Respiratory Health

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Awareness Initiatives" (Asthma Society of Canada, 2010), there is a high need to bring awareness of risk factors for chronic respiratory disease (namely, outdoor and indoor air quality, mould, second- and third-hand smoke exposure, etc.) to First Nations, Inuit and Métis communities.

It was determined that there was a lack or, indeed, absence of resources on respiratory health at the community level that specifically target First Nations, Inuit and Métis communities and take into consideration their learning preferences and cultural traditions. Important findings from this project also revealed that overall there was low level of knowledge on how social determinants of health can affect respiratory health. In general, there was a strong sense among Phase I project participants that respiratory health was an important issue facing their communities.

These findings of the Phase I project supported the need for the development and/or adaptation of materials and resources on respiratory health that would be relevant for First Nations, Inuit and Métis communities and also helped identify 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 cultural and traditional practices. As a main Phase I 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 was developed and recommended for pilot implementation.

The Phase II project was built on the key findings of the Phase I project, as well as those of other projects conducted by the ASC in Aboriginal communities and supported by the First Nations and Inuit Health Branch (FNIHB), Health Canada: "A Shared Vision", 2009 and "A Shared Voice", 2010.

The Phase II project was aimed to evaluate practical approaches to the *Respiratory Health Awareness Community Outreach and Engagement Model* pilot implementation in selected First Nations, Inuit, and Métis communities. The project was supported by the Public Health Agency of Canada (PHAC) through the National Lung Health Framework Phase II funding. Additional funds were secured from AllerGen NCE Inc. to supplement the funding for two additional pilot communities in the Province of Alberta.

## **Project Goals and Objectives**

The primary goal of the project entitled "The Respiratory Health Awareness Community Outreach and Engagement Model in First Nations, Inuit and Métis Communities: Pilot Intervention" was to evaluate the effectiveness of the model implementation in selected

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Aboriginal communities by conducting a pilot intervention and to make recommendations for its future application in Aboriginal communities across Canada. A secondary goal was to empower First Nations, Inuit and Métis communities to create better awareness of lung health, to improve their knowledge about the risk factors for chronic respiratory conditions and prevention strategies, and to enable these communities to establish community-based resources on respiratory health. Finally the project was also aimed to develop and/or modify educational materials and resources needed to make the model implementation successful and effective.

The main objectives of this project were aligned with the overall objectives of the Lung Health Program (Public Health Agency of Canada, Lung Health Program Phase II, Guidelines for Applicants, 2010) and related to the increase in awareness, the prevention of and, the early detection of lung diseases, including risk factors (social determinants of health) for development of chronic respiratory disease. The stated objectives of the project under description as outlined in the proposal remain unchanged and as follows:

- Engage the selected communities in the model implementation process by identifying appropriate resources and applying strategies to build community capacity
- Develop 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.) based on common learning objectives and key topics identified during the projects conducted by the ASC and its partners
- Develop a comprehensive toolbox/toolkit of tools, resources and materials that offer a variety of communication and learning methods to target different audiences within Aboriginal communities (people directly or indirectly affected by chronic respiratory disease, broader community members and general public)
- Pilot Respiratory Health Awareness community outreach and engagement model (Appendix 1) in selected communities and adapt it to the unique needs and priorities of these communities ensuring their ownership of the process
- Identify and train community leaders in delivering respiratory health education messages and becoming respiratory health "champions/advocates"
- Establish a National Coordination Centre (e.g., National Aboriginal Asthma/Respiratory Health Information Centre) to provide administrative and resource support to the communities involved in the model testing as well as distribute educational materials on respiratory health to Aboriginal communities across Canada

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• Assess the effectiveness of model implementation and determine next steps for broader model application in Aboriginal communities across Canada

The project was also designed to empower communities to have better awareness and information resources, services, and materials on respiratory health and the risk factors for chronic respiratory disease available at the community level. These resources are normally comprised of general practical resources, as well as tips, actions and strategies that could be applied to support actions taken to reduce the risk of chronic respiratory disease, improve overall respiratory health and prevent chronic respiratory disease from occurring. This initiative was conducted in selected First Nations, Inuit and Métis communities targeting the communities as a whole including people directly or indirectly affected by chronic respiratory disease, broader community members, the general public, parents of children affected by asthma and associated allergies and their extended family members as well as community leaders, Elders, and knowledge keepers.

## **Project Activities and Accomplishments**

## A Brief Project Overview

The Phase I project "An Exploration of First Nations and Inuit Perspectives on Community Respiratory Health Awareness Initiatives" (Asthma Society of Canada, 2010) identified the needs of Aboriginal community members in regard to the necessary information and communitybased resources on respiratory health and the risk factors for chronic respiratory disease. Despite cultural differences among individual Aboriginal groups, the gaps in existing resources and educational materials were consistent across all three Aboriginal communities (First Nations, Inuit, and Métis) indicating the need for the development and implementation of the core community outreach and engagement model. During the project under description, *the Respiratory Health Awareness Community Outreach and Engagement Model* (see a brief description of the model activities in Appendix 2) was piloted in selected First Nations, Inuit, and Métis communities in order to create greater access to culturally appropriate and targeted respiratory health educational materials and resources at the community level.

The project design was primarily based on the principles of the community-based participatory approach (Agency for Healthcare Research and Quality, 2004); therefore, Aboriginal communities were engaged and participated in all aspects of model implementation including the development of educational materials and resources. The project also followed the Medical Research Council (MRC) Framework for Design and Evaluation of Complex Interventions

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(Campbell, 2007). The Phase I project (Asthma Society of Canada, 2010) provided information on the gaps, barriers, and preferences in knowledge transfer in Aboriginal communities, as well as created the model for pilot intervention. According to the MRC Framework, the Phase II project represented an exploratory or pilot trial.

This pilot intervention was conducted in selected Aboriginal communities from Western and Eastern Canada, as well as one French-speaking First Nations community from Quebec. In total, the project was piloted in **seven** communities including five First Nations, one Inuit and one Métis community as follows:

- Postville, Newfoundland and Labrador (Inuit community);
- Prince George, British Columbia (Métis urban community);
- Wendake, Quebec City (First Nations French-speaking community);
- Listuguj, Quebec (First Nations community);
- Conne River, Newfoundland and Labrador (First Nations rural community);
- Saddle Lake, Alberta (First Nations community); and
- Enoch, Alberta (First Nations community).

Five pilot communities were involved in the Phase I project while two First Nations communities in Alberta were added during the Phase II project to understand perspectives and experiences related to the model implementation of First Nations community members from Western Canada. The number of communities for the pilot was increased by one due to the additional funding received from AllerGen NCE Inc. The Social Support Research Program (SSRP), University of Alberta led by Dr. Miriam Stewart was commissioned by the ASC to help coordinate the project implementation in these two Alberta communities.

To be compliant with the Canadian Institute of Health Research (CIHR) guidelines for heath research involving Aboriginal people (CIHR, 2007), relevant ethics approval was received prior to the model implementation. An application was submitted to the Research Ethics Board (REB) of Health Canada and the Public Health Agency of Canada (PHAC) in December 2010 followed an oral presentation about the project to the REB panel on January 20, 2011. The presentation was delivered by Dr. Wayne Warry (McMaster University) and Dr. Oxana Latycheva (ASC) via a conference call. An approval (see the approval certificate in Appendix 3) was granted by the REB of Health Canada and the PHAC on February 14, 2011 (Principal Investigator- Dr. Wayne

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Warry, McMaster University) and renewed on February 28, 2012 (see Appendix 4). Additionally, a renewed application was submitted to the Nunatsiavut government to continue conducting the project in Postville, Newfoundland and Labrador with an approval letter received on June 06, 2011 (Appendix 5).

The project was conducted over a period of 13 months, beginning March 07, 2011. The ASC worked closely with the main project partners (the AFN, ITK, MNBC, SSRP, and AllerGen) and applied a step-by-step approach to the model implementation ensuring proper community engagement of community members as well as focusing on capacity building within the participating communities. Thus, the main project activities were conducted under four main stages; 1) Community Engagement (March-May, 2011), 2) Toolkit Development and Community Training (June-September, 2011) 3) Model Implementation (October-December, 2011) and 4) Model Evaluation and Results Dissemination (January-March, 2012).

The *first stage* of the project consisted of actions aimed at engaging participating communities in the model implementation process by identifying appropriate resources and conducting activities to prepare them to implement the project without placing an extra burden on existing community programs and services. The participating communities were contacted in March 2011 by the Project Manager informing communities about the project and its main components and confirming their participation in the project. Once the communities agreed to be involved in the intervention, a formal agreement was signed with each participating community outlining the main community responsibilities in the project (Appendix 6).

As a next step, conference calls were organized with community Health Directors/Managers to discuss activities to be conducted during the first stage of the project. The communities were offered a choice of tailored project activities based on their unique characteristics and practices while following the general guidelines and instructions established for the project. In particular, the communities were provided directions on how to proceed with appointing a Community Outreach Coordinator and Liaison (COCL) for the project, as well as to identify a hub in the community from which the project could be implemented. Each of the communities appointed COCLs using either existing community outreach workers/representatives or by hiring personnel specifically for the purpose of this project. They also established community leaders, Elders and/or knowledge keepers to oversee the model implementation at the community level and ensure the model was appropriately modified according to community needs and practices.

At the same time, a National Advisory Committee (NAC) was established to oversee and guide the project implementation. Representatives from key partner organizations (i.e., AFN, ITK,

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MNBC, and AllerGen), project supporters (NCCAH, SSRP, CAN-ADAPTT, HIP, and the Division of e-learning innovation, McMaster University) as well as community representatives were invited to participate in the work of the NAC. Additionally, respiratory health experts and key opinion leaders in the area of First Nations, Inuit and Métis community health were offered an opportunity to be involved in the work of NAC in an advisory role (refer to Appendix 7 for the list of NAC members).

As communities were developing personalized approaches, they were actively involved in the planning of the model implementation by participating in a project launch meeting, which took place in Toronto on May 17-18, 2011. One or two delegates from each community (i.e., COCLs for the project, Elders and/or community leaders) were invited to participate in the launch meeting, along with the members of the National Advisory Committee. In preparation to the meeting, the ASC completed an assessment of existing materials and resources on respiratory health and the risk factors for chronic respiratory disease that were specific to First Nations, Inuit, and Métis communities. Based on the findings of this environmental scan, a comprehensive list of existing materials was compiled and classified under certain categories (namely outdoor air quality, indoor air quality, non-traditional tobacco use, and information on chronic respiratory disease). This list was discussed by the launch meeting participants and decisions were made on what materials were likely to be included in a Respiratory Health Awareness Toolkit to be developed during the project. The meeting participants also discussed what materials and resources (content, design, and delivery method) needed to be developed to address the current gaps in respiratory heath education for Aboriginal community members and meet their educational and cultural preferences.

Overall, the meeting gave an opportunity for community representatives to comment on the model implementation and be involved in decision support processes from the beginning of the project. It also allowed them to make connections among participating communities facilitating "community to community" advice and engagement, as well as helping establish ongoing communication with the Project Team at the ASC, the main project partners, and NAC members.

At the end of Stage 1, the communities were supplied with a Community Assessment Guide (CAG), a planning tool that was developed for the purpose of this project (Attachment 1). It was used to help create a community profile of the existing respiratory health awareness resources, as well as to define immediate community needs for respiratory health information. The Project Team worked closely with the communities through conference call consultations when applying the CAG and helping them specify priorities for action unique to each community. These consultations helped ensure that communities had adequate support to carry out the model implementation and, as well, provided training for COCLs.

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The development of the *Respiratory Health Awareness Toolkit* (the Toolkit) was conducted during the *second stage* of the project. The Toolkit includes resources and materials that were developed with input from the communities and guidance provided by NAC members. During the development of the Toolkit, special considerations were given to making materials and resources culturally relevant and appropriate by applying strategies identified during the Phase I project (Asthma Society of Canada, 2011). The range of educational materials on respiratory health, and the risk factors for chronic respiratory disease, were adapted and/or developed for the Toolkit such as printed materials (information cards, posters, and brochures); conversation cards to be used during support circles; digital stories with personal messages related to the main issues that can affect respiratory health, and a master group presentation to be used during community events and programs. All materials in the Toolkit were reviewed by the main project partners and expert reviewers from government agencies and other lung health stakeholders (refer to Appendix 8 for the list of expert reviewers).

Other activities during Stage 2 included training of communities to prepare them for model implementation, and recruiting community leaders and Elders to become *Respiratory Health Champions* in their communities. Community leaders, Elders and/or knowledge keepers were either appointed or nominated to be Respiratory Health Champions in their communities. A special instructional web-based training module (information session) was developed in partnership with the Division of e-learning Innovation, McMaster University to educate them on the main issues related to respiratory health.

In the beginning of the *third stage*, a pre-implementation assessment was conducted in the participating communities according to an evaluation plan (Appendix 9) that was developed and approved by the NAC members and by using evaluation tools specifically developed or modified for the purpose of this project. Then, the main model activities were implemented by the COCLs in consultation with the community Advisory Groups. Community leaders, Elders and/or knowledge keepers completed the online information session in order to become Respiratory Health Champions and delivered the main education messages related to respiratory health to their community members by using a "word of mouth" approach. Community members were also informed about the risk factors for chronic respiratory disease through multiple outreach strategies, including participating in health and wellness fairs; conducting presentations at community celebrations, and programs, and providing respiratory health information during social gatherings and cultural events (i.e., Bingo games, powwows), etc. The materials and resources in the toolkit were distributed to various healthcare and community organizations as well as community individuals. Additionally, an online Clearing House (BREATHE: *Building Respiratory Education and Awareness for First Nations, Inuit and Métis: Tools for Health* 

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*Empowerment*) was established at the ASC as a key point of contact for information on respiratory health for First Nations, Inuit and Métis community members.

The *fourth stage* of the project was dedicated to assessing the early effectiveness of the model implementation at the pilot stage. Using specifically designed project evaluation tools, a post-implementation assessment was completed. The Project Team also summarized feedback on the Toolkit that was received from the participating communities, and the main project partners. The communities were responsible for collecting data necessary to perform the model evaluation and were actively involved in coordinating the completion of necessary evaluation forms and surveys.

Throughout the project, updates on model implementation activities were regularly communicated to the participating communities, NAC members, and the main project and communication partners (refer to Appendix 10 for the list of communication partners) by means of conference calls, e-mail correspondence, and via distribution of project facts sheets.

Some preliminary results of the project were presented to the NAC members and discussed during the project evaluation workshop that took place in Toronto on March 19, 2012. Recommendations were developed to inform future implementation/roll-out of the model and compressive evaluation/validation of the toolkit.

## Stage 1: Community Engagement

This stage of the project was completed between March and May 2011. A summary of activities conducted in March 2011 was presented in the ASC Progress Report that was submitted to the PHAC on April 20, 2011 (refer to Appendix 11 for the complete progress report). In summary, in the beginning of Stage 1, after appointing a Project Manager and Project Coordinator, appropriate communication took place to inform potential communities and the main project partners about the project, its main components, and key deliverables. All participating stakeholders (e.g., communities, project partners and NAC members) were provided with an executive summary of the project (Appendix 12) and phone calls were organized when necessary to give detailed explanations about activities to be undertaken to pilot the model. In the beginning of each stage, participating communities and NAC members were also provided with a document that outlined the main activities to be conducted during each stage and subsequent conference calls were organized to discuss project milestones and address any potential issues related to each particular stage of the project.

In the beginning of Stage 1, participating communities were approached and their involvement in the project was confirmed. Selected communities were chosen to reflect the cultural and geographical diversity of Aboriginal communities across Canada allowing for potential knowledge transfer and mobilization opportunities upon the project completion. Community Health Manager/Directors involved in the project (see Table 1 below) played an instrumental role in confirming the project and setting the stage for its implementation at the community level.

Community	Community	Community Outreach Coordinator
	Leaders/Representatives	and Liaison (COCL)
Wendake, QC	Micheline Roy	Marie-Pier D. Coulliard (March - July
First Nations	Health Director	2011)
(French-speaking)		Jeanette Daigle (July – March 2012)
Listuguj, QC	Donna Metallic	Monica Barnaby
First Nations	Director of Health	Patricia Gray
Conne River, NL	Theresa O'Keefe	Elaine Jeddore
First Nations	Director, Health & Social	
	Services	
	Ada Roberts	
	Nurse Practitioner	

Table 1: Participating communities and community leadership, by community

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Prince George, BC	Tom Spence	Kimberly McLeod
Métis	President, Prince George	
	Metis Community	
	Association (PGMCA)	
	(March – May 2011)	
	Patrick Pocha	
	Acting President of	
	PGMCA	
	(May – March 2012)	
Postville, Labrador	Shirley Goudie	Margaret Edmunds
Inuit	Town Clerk	
	Joan Goudie	
	Community Health Nurse,	
	Department of Health and	
	Social Development	
Saddle Lake, AB	Theresa Cardinal	Rosina Stamp (March – December 2011)
First Nations	Health Director, Saddle	Maureen Cardinal (December 2011-
	Lake	March 2012)
	Sharon Anderson	
	Research Associate,	
	Social Support Research	
	Program	
	Roxanne Blood	
	Alberta Coordinator,	
	Saddle Lake	
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Enoch, AB	Ron Morin	Amber Ward
First Nations	Chief, Enoch	
	Elaine Papin	
	Director, Enoch Health	
	Centre	

## **Establishing community involvement**

The ASC, in partnership with the AFN, ITK, MNBC, and SSRP, confirmed the participation of six communities in the project. The participating communities were contacted in March 2011 by the Project Manager and initial conference calls were held with each of the participating communities to discuss activities to be conducted during the project. Formal community agreements outlining community responsibilities within the project were signed (Appendix 6) and each community was provided with a detailed description of the funds available to implement project activities at the community level during each stage. All documents were translated into French for the French speaking First Nations community. The communities were given an opportunity to review and provide feedback on any community-related background documents developed for the project and changes were made where necessary.

Proper community involvement in the project was ensured by maintaining ongoing communication between the participating communities and the ASC Project Team and addressing any community needs and concerns as they arose. Conference calls were held with each participating community to ensure their proper understanding about the project and the scope of activities to be implemented during the first stage (Appendix 13). It was also supported by acknowledging unique individual characteristics of the communities and allowing participating communities to tailor project activities according on their structure and existing healthcare services and resources. The communities were given initial directions on how to proceed with the project in their communities. Before project initiation, they also obtained proper approvals at the community level (e.g., Band Council, Town Council) as required and according to the existing community protocols.

#### Establishing project structure at the community level

### Community outreach coordinator and liaison (COCL)

Participating communities were provided direction on how to proceed with appointing a Community Outreach Coordinator and Liaison (COCL) for the project as outlined in the Project Milestones document, Stage 1 (Appendix 13). COCLs were hired to carry out the project activities at the community level, while receiving guidance from the Project Manager at the ASC. Some communities (Listuguj, Wendake, Conne River, and Enoch) decided to use their existing personnel to conduct project activities and assigned community health workers/representatives to implement the project. Others (Postville, Prince George, and Saddle Lake) hired personnel specifically for the purpose of this initiative with assistance provided by the ASC, ITK, and MNBC as required. Please refer to Table 1 above for the list of COCLs involved in the project (Table 1).

Once each community identified a COCL, initial training was organized and conference calls were held with each of the COCLs to outline what project activities were to be conducted and held during the first project stage (Appendix 13).

#### Community project hub

Each community was also asked to identify a hub, a central location in the community from which project activities would be implemented. In the majority of participating communities, health centres were chosen as the main place to house the project and provide office space for COCLs. In Postville, the Department of Health and Social Services (DHSD) was chosen as the central project location and necessary approvals were obtained from the Nunatsiavut government and the Town Council to allocate office space to the COCL. In Prince George, the Prince George Métis Community Association (PGMCA) took a lead in implementing project activities and provided necessary support to the COCL.

#### Community Advisory group

Each community identified its own community-based Advisory Group consisting of main community stakeholders, community leaders, Elders and/or knowledge keepers to assist in overseeing and guiding the project implementation at the community level. In preparation to establish a community Advisory group, several documents were prepared by the Project Team and distributed to the COCLs via electronic communication and as a hard copy via mail. Mailed documents were organized in folders and contained both hard copies of the documents, as well as their electronic versions in a CD format. As the Project Team was planning to prepare a series of

documents to guide the work of the COCLs, each document folder was colour coded for its easy identification. Thus, a blue folder with documents on how to establish the Community Advisory Group was provided to be used as a reference and kept on file at the community level (Attachment 2).

To facilitate the establishment of Advisory Groups in the communities, the following documents were created: a guide on how to establish a community advisory group and a budget available to complete this activity. All documents were translated in French for the French-speaking First Nations community, presented in Attachment 2, and are described below in detail:

## a) A Guide on how to establish a Community Advisory Group

The guide on how to identify and recruit community advisory group members was developed to assist the COCLs when establishing a Community Advisory Group. The ASC prepared an outline on what an advisory group is, a list of steps to follow when creating an advisory group, and potential group membership. They were also asked to complete a list identifying the names of the community advisory group members and their affiliation in the community, and submit this list back to the ASC.

## b) A Budget for the Community Advisory Group

The COCLs were also provided with a budget outline explaining what funds were available for a maximum of 5 community advisory group meetings. Expense forms were also developed and were required to be completed and returned to the ASC with receipts, if available, for any funds used for refreshments or travel by Community Advisory Group members for the purpose of their meetings. Honoraria were allocated to reimburse an Elder or community leader for their involvement in the Advisory Group. This reimbursement was either provided to Elders and community leaders directly by a cheque after completion of a special invoice or given to the communities as part of their quarterly installments. Some communities felt that the Advisory Group members had equally contributed to the overall guidance of the project and split the honoraria funds available equally among all group members.

All communities were successful in recruiting Community Advisory Groups and their work is described in more details in Chapter 6 of this report (refer to section 6.3. Community Advisory Groups).

#### **Establishing the National Advisory Committee (NAC)**

The National Advisory Committee (NAC) was established based on the Phase I Project Advisory Group (Asthma Society of Canada, 2010). The NAC included key project partners and stakeholders with an aim to guide project implementation and provide input during all the stages of the project development. The NAC also included representation from each of the communities to ensure their full engagement in the project (see Appendix 7 for the complete list of NAC members). The project background documents (e.g. Executive summary; Project Milestones, Stage 1, etc.) were distributed to the NAC members and reviewed as required.

The NAC members also participated in review of the community-related documents and/or guides and provided their input with regard to the preparation of the project launch meeting. Further, NAC members were involved in the development of the evaluation plan to assess the effectiveness of project activities that was finalized by the end of Stage 1 (Appendix 9). Dr. Wayne Warry, Project Principal Investigator and Dr. Oxana Latycheva, Vice-President, ASC Programming, took a lead on conducting a literature review on outcome indicators that could be applied to assess the project effectiveness and initiated the development of data collection tools to be presented to the NAC members for review and approval. NAC members also provided input into the development of a Community Assessment Guide (CAG), a tool to be used to plan the model implementation at the community level (Attachment 1).

The involvement of additional partners (i.e., The Canadian Action Network for the Advancement, Dissemination and Adoption of Practice-informed Tobacco Treatment (CAN ADAPTT); Ontario Physical Health Education Association (Ophea); and Healthy Indoors Partnership (HIP)) in the project was explored and necessary arrangements were made to invite them to be involved in the project. Involvement of the Division of e-learning Innovation, McMaster University was also confirmed. Further, the Project Team developed a list of Communication Partners (Appendix 10) that would be kept informed and updated on project activities throughout the project.

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#### Conducting an Environmental Scan of existing materials and resources on respiratory health

During this stage, a list of current resources and materials on respiratory health and the risk factors for chronic respiratory disease specifically targeting First Nations, Inuit, and Métis communities was compiled by the ASC Project Team. For the purpose of the scan, the risk factors for chronic respiratory disease were divided into three categories, namely (1) outdoor air quality (information on poor outdoor air quality and smog, open or outdoor burning, idling and road dust); (2) indoor air quality (information on mould, radon, formaldehyde, wood burning stoves, and household products), and (3) commercial tobacco use (information on commercial tobacco use, commercial tobacco use and pregnancy, exposure to second-and third-hand smoke, smoking cessations programs). A final category, (4) chronic respiratory disease (asthma, respiratory allergies, and COPD) was added to address the connection between the risk factors and the development of chronic respiratory disease.

The main purpose of the scan was to compile a list of existing awareness and educational resources that are specific to First Nations, Inuit and Métis communities to understand which ones could be potentially included in a *Respiratory Health Awareness Toolkit*. A search for materials was conducted both on a national and international level by reviewing relevant policy documents and existing literature under the above-mentioned categories. The environmental scan also assisted in reviewing existing awareness materials and resources available for First Nations, Inuit, and Métis communities; identifying gaps in available information and/or resources, and evaluating the necessity of developing new materials and services.

#### Scan Methodology

The initial scan involved a broad search for chronic respiratory disease educational materials and resources available provincially and nationally to determine what resources on respiratory health exist that are specific 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 included the words 'Aboriginal' or 'Indigenous', 'First Nations', 'Inuit', 'Métis' along with corresponding terms such as 'asthma', 'COPD', 'allergies' or 'chronic disease', 'chronic respiratory disease' as well as terms used to describe the risk factors such as 'mould', 'radon', 'formaldehyde', 'cleaning and personal products', 'pollution and smog', 'outdoor burning', 'road dust', 'emissions and idling', 'smoking', 'non-traditional tobacco', 'smoking and pregnancy', 'second hand smoke', and 'third hand smoke'. Beyond the key word search, health-related Canadian sites were included, such as the Public Health Agency of Canada (PHAC), Health Canada, Environment Canada, Natural Resources Canada, and non-

governmental organizations such as the Canadian Lung Association and their provincial branches. The search also included the websites and resources of listed communication and project partners, for example: the Assembly of First Nations, Inuit Tapiriit Kanatami, National Indian and Inuit Community Health Representatives Organization, Métis Nation British Columbia, National Aboriginal Health Organization, National Collaborating Centre for Aboriginal Health, Aboriginal Health Research Network, The Canadian Action Network for the Advancement, Dissemination and Adoption of Practice-Informed Tobacco Treatment, National Métis Council, Aboriginal Nurses Association, Indigenous Physicians Association of Canada, etc. The online search was accompanied by a number of phone and e-mail inquiries including some individual contacts with knowledgeable informants.

The list of resources complied as a result of the environmental scan is presented in Attachment 3. The environmental scan also represented a first step in the process of determining major gaps in existing educational material to guide the development of new materials and resources. Information summarized in the scan ultimately served to create the Toolkit, which includes both previously existing materials from several sources and those developed once the gaps in existing educational materials were identified. Additionally, the environmental scan aided in the creation of related materials and resources such as conversation cards for support circles, a master group presentation, and an online information session (training module).

#### **Project Launch Meeting/Workshop**

On May 17<sup>th</sup> and 18<sup>th</sup>, 2011, a one and a half day meeting was organized by the Project Team and held in Toronto to officially launch the project, discuss communities' priorities related to the model implementation, and determine each particular community's involvement in model-related activities. The main project partners, NAC members, and delegates from each participating community were invited to participate in the meeting. Twenty-three individuals representing the key project partners, stakeholders, and community representatives from the participating communities (Prince George, British Columbia (Métis community); Wendake, Quebec (First Nations French-Speaking community); Listuguj, Quebec (First Nations community); Conne River, Newfoundland and Labrador (First Nations community), and Saddle Lake, Alberta (First Nations community)) attended the meeting (refer to Appendix 14 for the workshop participant list). The meeting agenda is presented in Appendix 15 and the main goals of the workshop included the following:

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- Sharing the main accomplishments and key findings from the Phase I project *"Exploration of First Nations and Inuit Perspectives on Community Respiratory Health Awareness Initiatives"* (Asthma Society of Canada, 2010)
- Describing Phase II project objectives: "Respiratory Health Awareness Community Outreach and Engagement Model in First Nations, Inuit and Métis Communities: Pilot Intervention."
- Getting to know our partner communities involved in the Phase II project
- Reviewing and refining a Community Assessment Guide (CAG), a planning tool to create community profile on the existing respiratory health awareness resources and define the initial priorities for action
- Identifying priority resources and materials on respiratory health and the risk factors for chronic respiratory disease (i.e., outdoor and indoor air quality, mould, second and third hand smoke) to be included in the Toolkit
- Refining community engagement strategies based on suggestions expressed by community representatives
- Confirming priorities and an action plan for the next steps in the project

A detailed summary of the launch meeting proceedings was circulated to all meeting participants after the meeting and is submitted as Attachment 4. Overall, the meeting gave an opportunity for community representatives and NAC members to comment on the model implementation and be engaged in the planning of the project activities and the development of educational materials from the beginning of the project. Meeting participants reviewed the package of existing materials and resources on respiratory health and made suggestions on which materials should be included in the Toolkit. As well, decisions were collectively made on the tools and resources (content, design, and delivery method) to be developed for the *Respiratory Health Awareness Toolkit*. Discussions held during the meeting confirmed an overarching need for materials and resources that address the relationship between various indoor and outdoor air quality risk factors and respiratory health. The meeting participants also made recommendation on further revisions that need to be made to a draft Community Assessment Guide (CAG) presented at the meeting.

To facilitate the participation of representatives from the French speaking First Nations community (Wendake), the main meeting materials were made available in French (see the French version of the meeting agenda in Appendix 16). The ASC also provided a French interpreter for simultaneous interpretation during the one and a half day meeting.

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The Postville Inuit community was unable to send a representative to attend the launch meeting. The Project Team followed up with the Postville Inuit community and a separate meeting was organized and conducted in Postville, Newfoundland and Labrador on August 29, 2011. The Project Manager traveled to the community to discuss the Inuit-specific aspects of the project as well as to meet with a representative from the Nunatsiavut government. The agenda for the meeting in Postville is presented in Appendix 17 and the meeting was attended by the following community representatives: a community Elder, the community Town Clerk, the community Public Health Nurse and the Team Leader at the Department of Health and Social Development (DHSD).

During the meeting, the Project Manager provided a brief overview of the Phase II launch meeting, a summary of the Phase I project Inuit-specific results, as well as Phase II Project activities. The list of existing materials and resources on respiratory health was also presented and reviewed focusing on the materials targeted to Inuit community members. Community representatives provided feedback on which Inuit-specific materials should be included in the Toolkit. They also commented on the fact that some of the existing materials were available in an Inuktitut dialect that was not used in Postville or any other communities in the Nunatsiavut area, and said that these resources would not be well-received by community members. Community representatives expressed an interest in having activity booklets for children that could be used during group educational sessions with children or in the school environment.

The list of suggested materials and resources to be developed for the Toolkit (Appendix 18) was also reviewed during the meeting and suggestion were made on the desirable content and images. For example, community members felt that a postcard on mould would be of great use in the community. The community participants at the meeting stated that not enough information on mould was present in the community and that community members were not aware of new recommendations on mould cleaning. They also support an idea of developing materials on second and third hand smoke exposure as the majority of community members was not aware of how this exposure could impact respiratory health. When discussing materials and resources to be developed on chronic respiratory disease, the community representatives looked forward to having materials on asthma triggers. They also liked an idea of developing conversational cards that could be used during community events and programs. During the meeting in Postville, participants also provided feedback on the draft Community Assessment Guide.

Furthermore, a social networking event was held on the same day at the community centre, where community members were invited to attend and get more information about the project activities that would be conducted in the community. Refreshments were provided and approximately 20 community members came to learn about the project.

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#### **Development of the Community Assessment Guide (CAG)**

The Community Assessment Guide (CAG) is a planning tool aimed to help communities create a community profile of existing respiratory health awareness recourses and to identify community priorities for model implementation. It was developed by the Project Team with guidance from NAC members and the main partners (AFN, ITK and MNBC) to assist each community in the planning of model implementation and tailoring model activities according to individual community needs, preferences for education, and cultural characteristics. The guide was also used as a training tool for COCLs.

Prior to the development of the first draft, the Project Team conducted initial research on types and formats of community assessment tools available. A draft of the CAG was developed with guidance from the Aboriginal project partners (AFN, ITK and MNBC), presented and discussed at the launch meeting. At the meeting, a recommendation was made to develop three versions of the guide specific to each Aboriginal community (First Nations, Inuit, and Métis). After the launch meeting, three community assessment guides were developed in order to reflect cultural differences among Aboriginal communities and are presented in Attachment 1. Currently, the CAG is available only in English and the French-speaking First Nations community (Wendake) completed the English version of the guide with help from its bilingual members.

The guide includes seven sections as follows:

- Section 1: Community Demographics
- Section 2: Community Structures
- Section 3: Sense of Community
- Section 4: Community Capacity and Leadership Building
- Section 5: Community Needs and Priorities of Action
- Section 6: Knowledge Transfer and Mobilization
- Section 7: Initiatives to Implement under the Model Components

The Project Team worked closely with the communities through conference call consultations when applying the CAG and helping them develop a community profile of the existing respiratory health awareness resources and to define initial priorities for action. These consultations helped ensure that communities had a good understanding of the project activities to be conducted and to identify community resources to be used during the project implementation.

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#### **Description of the Communities involved (Community profiles)**

Community profiles were compiled based on the completed Community Assessment guides provide by the participating communities and are presented below. While the communities participating in the project did not represent all Canadian provinces and territories, the results of the project may certainly be used as a starting point (exploratory pilot) and then can be adapted to meet the needs of other First Nations, Inuit, and Métis communities across Canada.

#### First Nations Communities

#### Listuguj, Quebec

Listuguj is a Mi'gmaq community situated on the border of Quebec and New Brunswick with a population of 3,000 members. It falls within the tribal district of Gespe'gewa'gi, and 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.

This reserve community is 80% First Nations and 20% non-Aboriginal. The population is comprised of 40% children (ages < 18), 30% youth (ages 8-25), 20% adults, and 10% seniors. Roughly 60% of the population is female, while 40% is male.

Members of this community get primary health care through community health centres/clinics, and family physicians' offices which are staffed with nurses (n=5) who work 5 days a week and 7 hours per day. Specialty care from healthcare professionals or related services (e.g., respirologists, Certified Asthma/Respiratory Educators, asthma education clinics, pulmonary function labs) are available in a nearby community which is 5 kilometers away. To see an allergist they must travel 90 kilometers. The wait time to see one of these specialists (e.g., a respirologist or allergist) is from several months to a year. One of the barriers faced by community members in accessing hospital care is transportation/distance to the nearest hospital.

Three types of community centres are available in Listuguj: a community culture centre; recreational centre; and an Elder lodge. The community holds various events and gatherings such as smudging and powwows, and information on respiratory health and chronic respiratory disease was provided during the events before the model implementation. Some resources on respiratory health are available in nursing stations, community health centres, and physicians' offices. These resources and materials are mainly on commercial tobacco use (cigarette smoking), mould, radon, and COPD. Individual health education is done during sweet grass and

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traditional prayer ceremonies. The three languages used by community members are English, French and Micmac, which are also taught in the school system. Another part of traditional culture that is preserved is the passing of knowledge by Elders.

The community's main priorities on respiratory health and risk factors for chronic respiratory disease were ranked as follows: 1) chronic respiratory disease (e.g., asthma, COPD, allergies); 2) outdoor air quality (e.g., outdoor burning, industrial pollution, road dust); 3) indoor air quality (e.g., mould, dust mites, sprays and aerosols, household cleaners, woodstove burning, radon, air filters, furnaces/ventilation systems, humidifiers/dehumidifiers, formaldehyde in carpets); 4) smoking (e.g., second and third hand smoke, smoking cessation, and the effects of cigarette smoke on individual health). Resources and materials accessible to this community did not match their first three priorities. Resources and materials on cigarette smoke exposure are available in many formats; however, information on asthma and COPD is not available. Further, information on outdoor and indoor air quality is limited and only available in select formats.

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

Wendake is the current name for the Huron-Wendat Reserve, an enclave near the 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, which is urban and non-remote, is 1,347 persons with a land area of only 1.46 km<sup>2</sup> (about 360 acres).

Members of this community get primary health care through community health centres/clinics and nursing centres, which are staffed with nurses and community health care workers. Specialty care from healthcare professionals or related services (e.g., respirologists, allergists, Certified Asthma/Respiratory Educators) are not available in the community, but can be accessed in a nearby city. The wait time to see one of these specialists (e.g., a respirologist or allergist) is approximately 6 months.

Two types of community centres are available in Wendake such as: a community culture centre and a friendship centre, which offer various community services and programs. The community holds various events and gatherings, such as health and wellness fairs, with information on respiratory health and chronic respiratory disease not being well covered during the events. Some resources on respiratory health are available in nursing stations and community health centres. These resources and materials are mainly on cigarette smoking, mould, radon, and COPD. Individual health education is done during traditional prayer ceremonies. Members are involved in cultural activities such as traditional tobacco ceremonies and powwows. The
traditional languages of Innu and Atikamekw are not used by many. Another part of traditional culture that is preserved is the passing of knowledge by knowledge keepers, spiritual and community leaders. The community-based Huron-Wendat museum of First Nations culture also plays an important role in passing on traditional knowledge to the community.

The community's main priorities on respiratory health and risk factors for chronic respiratory disease were ranked as follows: 1) chronic respiratory disease (e.g., asthma, COPD, allergies); 2) smoking (e.g., second and third hand smoke, smoking cessation, and the effects of cigarette smoke on individual health); 3) indoor air quality (e.g., mould, dust mites); 4) outdoor air quality (e.g., burning of coal and wood, and industrial pollution).

Resources and materials are accessible to this community for all categories listed above. However, they are available in one format: pamphlet/brochure except seniors' education groups, which are available for education on how to avoid cigarette smoke exposure.

## Conne River, Newfoundland and Labrador

Miawpukek is the traditional Mi'kmaw name for the community, while "Conne River" (meaning "Middle River") is the more popularly 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 with a population of 1123.

This reserve community is 95% First Nations and 5% non-Aboriginal. The population is comprised of 24% children (ages < 18), 12% youth (ages 8-25), 57% adults, and 7% seniors. Roughly 60% of the population is female, while 40% is male.

Members of this community get primary health care through community health centres/clinics which are staffed with nurses and nurse practitioners that are on call 24 hours a day and 7 days a week. Specialty care from healthcare professionals or related services (e.g., respirologists, allergists, Certified Asthma/respiratory Educators, asthma education clinics, pulmonary function labs) are available in a nearby community two hours away (by car). The wait-time to see one of these specialists (e.g., a respirologist or allergist) is approximately 4 to 6 months. On a related note, there are several barriers or problems faced by community members in accessing or seeking hospital and/or primary care. Barriers include the distance it takes to travel, the long wait-times, and the limited availability of specialists.

Two types of community centres are available in Conne River: a youth centre, which offer services such as an after school program, and an Elders centre. The community holds various events and gatherings, and information on respiratory health and chronic respiratory disease are

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covered during the events. In particular, the topics of asthma, mould, and indoor and outdoor air quality have been discussed during these events and healthcare professionals and traditional teachers/healers have spoken at them. On average, once or twice a year, these individuals are invited to come to the community to discuss health related issues. Some resources on respiratory health are available in nursing stations and community health centres. These materials are mainly on cigarette smoking, mould, radon, and COPD. Individual health education is delivered during traditional prayer ceremonies. Members are involved in cultural activities; however, the traditional language is not used by many and the Micmac language is just starting to be reintegrated into the school system. Another part of traditional culture that is preserved is the passing of knowledge by Chiefs and Elders.

The community's main priorities on respiratory health and risk factors for chronic respiratory disease were ranked as follows: 1) chronic respiratory disease (e.g., asthma, COPD, allergies); 2) indoor air quality (e.g., mould, household cleaners, radon); 3) outdoor air quality (e.g., outdoor burning and forest fires); 4) smoking (e.g., second and third hand smoke exposure, smoking cessation, and the effects of cigarette smoke on individual health).

Some resources and materials on respiratory health are accessible to this community. However, they are available in limited formats (pamphlets/brochures mostly) except telephone support lines and oral presentations provided on topics of cigarette smoke exposure and indoor air quality.

### Saddle Lake, Alberta

Saddle Lake is a settlement in central Alberta, situated on Saddle Lake 125 Indian Reserve where it is governed by the Saddle Lake Cree Nation. The Saddle Lake Nation is a Treaty 6 Nation, from the Cree language group created in 1953 by merging the former Little Hunter (Saddle Lake), James Seenum, and Blue Quill Bands. The Saddle Lake reserve is located on Highway 652, approximately 180 km northeast of Edmonton, 26 km west of the Town of St. Paul and 105 km north of the Town of Vegreville.

This reserve community of 6,000 is 90% First Nations and 10% non-Aboriginal. The population is comprised of 10% children (ages < 18), 60% youth (ages 8-25), 20% adults, and 10% seniors. Roughly 45% of the population is female, while 55% is male.

Members of this community get primary health care through community health centres/clinics, family physicians' offices, and nursing stations which are staffed with physicians, registered nurses, nurse practitioners, and community health outreach workers/representatives. Specialty care from healthcare professionals or related services (e.g., respirologists, allergists, Certified Asthma/Respiratory Educators, asthma education clinics, pulmonary function labs) are not

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available in the community. The wait-time to see one of these specialists in a neighbouring community (e.g., a respirologist or allergist) can be anywhere from a few weeks to several months. On a related note, there are several barriers or problems faced by community members in accessing or seeking hospital and/or primary care. These consist of the distance it takes to travel, transportation, access to phones, and possession of an Alberta Health Care number. Unwillingness to seek help until a condition is unbearable also plays an important barrier in accessing proper care.

Three types of community centres are available in Saddle Lake: a community culture centre, a recreational centre, and a seniors' lodge. There are also various youth programs that are run from other community-based centres. The community holds various events and gatherings, and health-related issues are discussed at them by healthcare professionals and traditional teachers/healers. However, information on respiratory health and chronic respiratory diseases are not covered during the events. Members are involved in cultural activities such as powwows, round-dances, sweats, feasts and hand games, though the traditional language is not used. Traditional culture is preserved in the passing of knowledge by Elders.

The community's main priorities on respiratory health and risk factors for chronic respiratory disease were ranked as follows: 1) indoor air quality (e.g., mould, dust mites, sprays and aerosols, household cleaners, radon, furnaces/ventilation systems, etc. ); 2) smoking (e.g., second and third hand smoke exposure, and the effects of cigarette smoke on individual health); 3) chronic respiratory disease (e.g., asthma, allergies, and allergic skin conditions); 4) outdoor air quality (e.g., industrial pollution, and road dust).

Some resources and materials are accessible to this community for all of the general categories listed above. However, they are available only in two formats, namely pamphlets/brochures and posters.

### Enoch, Alberta

This reserve, non-remote, suburban community of 2,211 is 98% First Nations and 2% non-Aboriginal. The population is comprised of 28% children (ages < 18), 30% youth (ages 8-25), 40% adults, and 2% seniors. Roughly 65% of the population is female, while 35% is male.

Members of this community get primary health care through community health centres/clinics which are staffed with physicians, registered nurses, and community health outreach workers/representatives. Specialty care from healthcare professionals or related services (e.g., respirologists, allergists, Certified Asthma/Respiratory Educators, asthma education clinics, pulmonary function labs) are not available in the community, but can be accessed in the nearest major city, 33 kilometers away. The wait-time to see one of these specialists in a neighbouring

community (e.g., a respirologist or allergist) can be approximately 3 to 6 months. There are several barriers or problems faced by community members in accessing or seeking hospital and/or primary care. These barriers include poverty, transportation to and from healthcare facilities, and limited access to specialists.

Two types of community centres are available in Enoch: a recreational centre and an Elder centre that host many programs and services. The community holds various events and gatherings, and health- related issues are discussed by healthcare professionals quite frequently (for example, once-a-week discussions about diabetes). However, information on respiratory health and chronic respiratory disease is not provided during these events. Members are involved in cultural activities such as round-dances and the traditional language, Cree, is used often. Traditional culture is also preserved in the passing of knowledge by Elders and knowledge keepers.

The community's main priorities on respiratory health and risk factors for chronic respiratory disease were ranked as follows: 1) chronic respiratory disease (e.g., asthma, COPD, allergies and allergic skin conditions); 2) indoor air quality (e.g., mould, dust mites, sprays and aerosols, household cleaners, woodstove burning, radon, air filters, furnaces/ventilation systems, humidifiers/dehumidifiers, etc.); 3) smoking (e.g., second and third hand smoke exposure, and the effects of cigarette smoke on the individual health, information about smoking cessation programs and traditional tobacco use); 4) outdoor air quality (e.g., smog, outdoor burning, industrial pollution, road sanding, and road dust).

### Inuit Community

### Postville, Newfoundland and Labrador

Postville began as a trading post and was originally called 'the Post.' The community of 197 people is located 25 - 30 km into Kaipokok Bay, 110 air miles north-northeast of Goose Bay and is a rural, remote community. 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. 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.

This rural, remote community is 87% Inuit and 13% non-Aboriginal. The population is comprised of 27% children (ages < 18), 6% youth (ages 8-25), 54% adults, and 14% seniors. Roughly 56% of the population is male, while 44% is female.

Members of this community get primary health care through nursing stations with one nurse who works 7 hours per day and is on call 24 hours a day, seven days a week. Specialty care from healthcare professionals or related services (e.g., respirologists, allergists, Certified Asthma/Respiratory Educators, asthma education clinics, pulmonary function labs) are available in St. John's, Newfoundland which is a 2.45 hour non-stop flight away. The wait time to see one of these specialists (e.g., a respirologist or allergist) is approximately six months to a year. There are several barriers or problems faced by community members in accessing or seeking hospital and/or primary care, including getting referrals from local physicians who travel from Goose Bay every 2 months to Postville. If community members are referred to a physician they either have to wait for the physician's visit or they have to fly to Goose Bay. Getting care in Goose Bay is associated with some difficulties for community members such as culture shock (e.g., language), illiteracy, and financial constraints (flight costs).

Two types of community centres are available in Postville, a recreational centre and the Department of Health and Social Development (DHSD) which offers many programs and various types of support. The community holds various events and gatherings; however, no information on respiratory health is shared during them. Some resources on respiratory health are available in nursing stations and community health centres, but none elsewhere in the community. These materials are mainly on cigarette smoking and smoke exposure. Very little information and fewer varieties of it exist on outdoor and indoor air quality, COPD, and asthma. General health education is delivered as a part of community feasts with traditional food and prayer involved. Members of Postville are largely (90%) involved in traditional activities such as hunting, fishing, berry picking, traditional crafts, and firewood gathering. However, the traditional language is not used by many; Inuktitut is spoken fluently by only one person in the community. Traditional culture is preserved in the passing of knowledge by knowledge keepers.

The community's main priorities on respiratory health and risk factors for chronic respiratory disease were ranked as follows: 1) smoking (e.g., second and third hand smoke exposure, smoking cessation programs and the effects of cigarette smoke on the individual health); 2) chronic respiratory disease (e.g., asthma, COPD, allergies); 3) indoor air quality (e.g., mould, dust mites, radon), and 4) outdoor air quality (e.g., outdoor burning, forest fires, road dust, burning garbage at dumpsite, and smoke pots for smoking fish).

Resources and materials accessible to this community match their first priority but not the others. Materials on cigarette smoke exposure are available in many formats (e.g., pamphlets, brochures,

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posters, telephone support lines, children/youth education groups, and oral presentations).; however, there are few resources on asthma and COPD, or outdoor and indoor air quality.

### Métis Community

### Prince George, British Columbia

Prince George, with a Métis population of 4,000 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 community also holds several community celebrations and works closely with the several groups within the PGMCA such as the Nechako Métis Elders, Prince George Métis Children & Family Services, in the areas of health and family wellbeing.

Members of this urban, non-reserve community get primary health care through community health care centres/clinics, family physicians' offices, community-based hospitals, drop-in or walk-in clinics. Emergency after hours care is also provided within the community. Specialty care from healthcare professionals or related services (e.g., respirologists, allergists) is only available in Vancouver (775 km away). Certified Asthma/Respiratory Educators, asthma education clinics, and pulmonary function labs are also not available in the community. The wait time to see one of these specialists (e.g., a respirologist or allergist) is approximately six months to a year. There are several barriers or problems faced by community members in accessing or seeking hospital and/or primary care. The Prince George Metis community expressed some concerns about discrimination based on race, a shortage of physicians, low literacy level of community members, and health care-related costs (e.g., medication cost).

Two types of community centres are available in the Prince George Metis community: a friendship centre that offers several types of programs; and a family support centre that offers parenting and cultural support. The community holds various events and gatherings, and information on respiratory health and risk factors for chronic respiratory disease (e.g., indoor and outdoor air quality, smoking) is shared during them. Some resources on smoking are available in schools, community health centres, and physicians' offices, but not on other topics. Very little information, and fewer varieties of it, exists on outdoor and indoor air quality, COPD, and asthma. The delivery of general health education is carried out during traditional activities such

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as potlucks, and other community gatherings. Michif and Cree are languages that are spoken in the community and there are Cree language classes available to children. As well, Elders are a cornerstone of the community and often interact with children in schools.

The community's main priorities on respiratory health and risk factors for chronic respiratory disease were ranked as follows: 1) chronic respiratory disease (e.g., asthma, COPD, allergies); 2) outdoor air quality (e.g., forest fires, industrial pollution, road dust); 3) indoor air quality (e.g., perfumes and scents, mould), 4) smoking (e.g., second-hand smoke exposure, smoking cessation).

Resources and materials accessible to this community match their first, but not their second and third priorities. Resources and materials on asthma, COPD, and cigarette smoke exposure are available in many formats (e.g., pamphlets, brochures, posters, television announcements, books/booklets and the Internet); however, there are next-to-no resources on outdoor and indoor air quality.

## Key findings from community profiles

In summary, every participating community is distinct, having a variety of healthcare resources at their disposal and facing their own set of problems and barriers related to health care. Nonetheless, commonalities exist in how health care is delivered in these communities and the types of other community resources that can provide additional supports.

Among all communities, nurses provide primary care through community health centres and clinics, with physicians being available most often in only a neighbouring community or city. The wait-time to see a specialist (i.e., a respirologist or allergist) is approximately 6 months to a year. Barriers facing most communities are the limited primary care services available in their own community. This provides a myriad of challenges for community members who have to either wait for a visiting physician, delaying their care, or they are forced to travel to neighbouring communities and cities. The latter presents other problems such as culture "shock", limited access to transportation, and financial constraints (travel costs).

Almost all communities hold various events and gatherings and, at most of them, health-related issues are discussed in these contexts. Although Aboriginal languages are not used widely, or used at all, community members are still well-engaged in traditional ceremonies and draw on Elders and/or knowledge keepers for the passing of traditional knowledge.

Sometimes during community events, health-related topics are presented by community or visiting healthcare professionals. However, issues related to respiratory health and risk factors of chronic respiratory disease are not well covered during these gatherings. Printed materials on

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smoking in the forms of pamphlets or booklets are quite common in communities, while information on other risk factors is not widely available. For a minority of communities, there are also booklets and pamphlets with information on chronic respiratory diseases and indoor air quality.

Lack of educational programs and resources on respiratory health is an obvious concern given that the communities identify availability of information on chronic respiratory disease as one of their main priorities. Indoor air quality and smoking are also named as top priorities by the majority of communities involved in the project with outdoor air quality identified as the lowest ranked priority of the three main categories of risk factors for chronic respiratory disease.

# Stage 2: Toolkit Development and Community training

The main objectives for this stage of the project (June - September 2011) were the development of a comprehensive *Respiratory Health Awareness Toolkit* (Toolkit) and preparation of participating communities for Model implementation. A summary of project activities to be conducted during this stage was prepared by the ASC Project Team (see "Project Milestones, Stage 2" in Appendix 19) and distributed to all participating communities and NAC member at the beginning of the stage. This document was also translated into French (Appendix 20) to facilitate project implementation in Wendake, the French-speaking First Nations community involved in the project. Subsequent conference calls were conducted with the COCLs and NAC members to discuss these activities in detail.

The Toolkit materials were planned to be used under the main model components and be adapted based on community's specific needs and priorities. The Toolkit was designed to contain educational materials and resources related to chronic respiratory disease, as well as health promotional and awareness materials on respiratory health and the risk factors for chronic respiratory disease for broader community audiences. All materials were available and/or developed in English and French. Specific materials were translated into Cree for participating First Nations communities in the Province of Alberta.

### Development and compilation of the Respiratory Health Awareness Toolkit

The *Respiratory Health Awareness Toolkit* (the Toolkit) was compiled based on the Phase I project findings (Asthma Society of Canada, 2010). According to its results, four main topics related to respiratory health were shown to be of the greater interest to First Nations, Inuit and

Métis community members: outdoor air quality; indoor air quality including information about mould; exposure to second- and third-hand smoke, and information about early signs and symptoms of chronic respiratory disease. Based on the results of the environmental scan conducted during Stage 1 of the project, there were some existing materials that provided information on these topics. After the project launch meeting in May 2011, a decision was made by the main project partners and participating communities on which existing materials were to be included in the Toolkit (Appendix 21). At the same time, a list of materials to be developed was composed (Appendix 22) and agreed upon by project partners, participating communities, and NAC members. The existing and newly developed materials were compiled under six major categories as follows:

- 1) Outdoor air quality
- 2) Indoor air quality
- 3) Traditional and commercial tobacco use (smoking)
- 4) Exposure to second- and third-hand smoke
- 5) Smoking Cessation
- 6) Knowledge on Chronic Respiratory Disease

Each category was further divided into three main sections: a) *Main resources*: educational materials for broader community members; b) *Additional resources*: educational materials for specific groups (e.g., children, youth, smokers, etc.), and c) *Reference resources*: educational materials to be used by community health workers and other health care professionals as a reference.

According to the needs and preferences for respiratory health information identified during the Phase I project (Asthma Society of Canada, 2010) and confirmed at the project launch meeting, a range of educational tools identified by means of the environmental scan was adapted for the Toolkit from the existing resources that were previously developed by other government and non-governmental organizations (refer to Appendix 21 for the list of existing educational materials included in the Toolkit). Those materials were assigned under the above categories, as well as the three main sections (i.e., main, additional, and reference resources). The ASC connected with those organizations to obtain hard copies of the selected materials or printed them from appropriate website if hard copies were not available. In the latter scenario, organizations were informed that their materials would be used in the Toolkit via e-mail communications and permissions were obtained as necessary.

New materials and resources for the Toolkit were developed according to the list that was prepared during the previous stage of the project (Appendix 18) and within the established

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categories (as described above). All newly developed materials were geared to adult audiences, but could be potentially used at intergenerational learning opportunities (e.g., community gatherings and celebrations). Community representatives, the main project partners, and NAC experts were actively involved in the development of new materials and provided their input along the way on their content, design, and cultural aspects. While developing the Toolkit, special consideration was given to making materials and resources culturally relevant and appropriate by applying strategies identified during the Phase I project (Asthma Society of Canada, 2010), such as: a) ensuring proper community involvement; b) including visual images that contain traditional and cultural symbols and photos of Aboriginal people; and c) involving Elders. The latter was achieved by involving Elders in the work of Community Advisory Groups and gathering their feedback during the Toolkit development process.

To meet diverse educational learning needs of First Nations, Inuit, and Metis communities, a variety of materials on respiratory health and the risk factors for chronic respiratory disease were designed. Printed materials were developed in different formats such as information cards, posters, and brochures. Conversation cards were designed to be used during support circles and other community-based programs to maintain the oral style of learning that is common in Aboriginal communities. A Master Group Presentation was also prepared to provide information on respiratory health during community events, programs, and gatherings. In addition, Digital Stories with personal messages related to the main risk factors that can affect respiratory health were recorded in participating communities to be used by local media and be posted on community websites. The development of these resources is described below in detail by the type of material developed.

### Printed Materials

According to the key finding of the Phase I project (Asthma Society of Canada, 2010), printed materials are still considered a mainstream educational format in Aboriginal communities. Where there were some gaps in existing materials, the ASC Project Team worked on developing new resources. Based on existing literature, the Project Team prepared the main content which was reviewed by experts from the NAC Committee and expert reviewers (Appendix 8), and then worked with a First Nations designer to develop new resources. While key messages and core information about the risk factors for chronic respiratory disease were consistent across First Nations, Inuit and Métis communities, the style of the information provided and additional issues identified by communities were tailored based on the needs and preferences of each Aboriginal group (First Nations, Inuit, and Metis).

In regard to the content, new materials were developed to provide key messages about the risk factors of chronic respiratory disease and to deliver information that is simple and easy to read

and understand. They were also aimed to provide practical tips and low cost or no-cost solutions that could be implemented by the majority of individuals in these communities to deal with issues potentially affecting their respiratory health. Further, focus was given to developing materials on early signs of chronic respiratory disease by explaining common symptoms to look for and by providing details on where to access additional information and help if required.

In terms of design, newly developed materials were developed taking into consideration cultural characteristics of images from First Nations, Inuit and Métis communities. Where possible, these features were incorporated in one item that could be used in all three Aboriginal communities. In this case, cultural symbols and images representing all Aboriginal groups (First Nations, Inuit and Métis) were incorporated into the overall design of the resource. However, for some items, three versions of material were designed and tailored specifically for First Nations, Inuit or Métis communities. That approach was chosen due to the differences in content on some topics (e.g., community-based sources of outdoor air pollution, community contacts for mould cleaning, etc.), as well as challenges related to the inclusion of all three cultural images in materials with a small format (e.g., information cards). When three versions of materials were developed, featured content, images, cultural symbols, and photos relevant to each specific community were used. Some images were provided by communities involved in the project.

The newly developed printed materials were designed under the categories described above and the following resources were developed to fill existing gaps in information on respiratory health and the risk factors for chronic respiratory disease:

### 1) Outdoor air quality

Two types of materials were developed to bring attention to issues related to outdoor air quality and respiratory health, and provide information on potential health effects of poor outdoor air quality (Attachment 5). A summary fact sheet (Outdoor Air Quality Factsheet) was developed and presents information on potential sources of bad outdoor air quality, its impact on respiratory health, and simple measures that can be applied to minimize the health risks of poor outdoor air quality exposure (Attachment 5a). Due to different sources of poor outdoor air quality in Aboriginal communities, three versions of the fact sheet were designed for First Nations, Inuit, or Metis community members.

The second material in this category was related to the use of the Air Quality Health Index (AQHI) in Aboriginal communities and aimed to present this new tool to community members, explaining its potential application for planning of outdoor activities (Attachment 5b). Two version of the AQHI Fact Sheet were developed for First Nations and Métis community members. A version for Inuit community members was not designed as the Inuit community in

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Postville does not yet have access to the AQHI. Both fact sheets were reviewed by representatives from Environment Canada and the Air Health Effects Division, Health Canada.

### 2) Indoor air quality

According to the findings of the Phase I project (Asthma Society of Canada, 2010), many community members did not know that mould exposure could affect respiratory health. Therefore, a simple information card was designed to bring attention to potential health effects of mould exposure including appearance of respiratory symptoms (Attachment 6a). Due to the small size of the material and differences in contact information for additional help related to mould removal, three versions of the card were developed.

The second resource in this category was a poster presenting information, simple tips, and solutions on how to maintain a healthy home environment (Attachment 6b) targeting First Nations, Inuit and Métis community members. Icons identifying main elements of healthy home maintenance (e.g., Purchase Right, etc.) were designed by a First Nations artist specifically for this material. Feedback on both the Mould Card and the Healthy Home Poster was provided by representatives from the Environmental Health Program, Ontario Division, Health Canada, and the Environmental Public Health Division, First Nations and Inuit Health Branch, Health Canada. The Mould Card was also reviewed by a representative from the Canadian Mortgage and Housing Corporation (CMHC).

The last resource developed in this category was a brochure on radon (Attachment 6c). It was designed for all three communities and contains simple information about radon, its health effects, and how to detect it in one's home. Brochure pictures were prepared by Tannis Nielson, a Metis artist and educator specifically for this resource. The brochure was reviewed by a representative of the Radiation Health Assessment Division, Health Canada, as well as submitted for feedback to Lung Cancer Canada (still under review).

# 3) Traditional and commercial tobacco use (smoking)

Based on request from participating communities, a poster on the Seven Sacred Teachings and their application to traditional tobacco use was developed (Attachment 7). To develop this poster, the ASC project team consulted with Lisa Meeches, Executive Producer of the Sharing Circle, Canada's longest-running Aboriginal documentary series. The Seven Teachings were adopted from the Long Plains First Nations community, Manitoba and were provided by Lisa's grandfather and spiritual leader, Don Daniels. The ASC Project Team obtained formal permission to use these teachings. Illustrations for the poster were provided by Robert Rice, a First Nations artist from Wasauksing First Nation, and the ASC acquired full rights to use them in the poster.

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The Seven Sacred Teachings provided by Lisa Meeches are tied to seven sacred beings: Eagle, Turtle, Sabe, Wolf, Beaver, Bear, and Buffalo. The teachings were described and then linked to the topic of commercial tobacco use by the ASC Project Team, providing reasons to make homes smoke-free and to protect others from tobacco smoke exposure.

All tobacco-related materials were reviewed by Dr. Peter Selby and members of his team at the Centre for Addiction and Mental Health (CAMH), Toronto, and shared with representatives from the Tobacco Control Program, Health Canada.

## 4) Exposure to second- and third-hand smoke

According to the needs identified during the Phase 1 project (Asthma Society of Canada, 2010), communities wanted to receive information on health effects of exposure to second-hand smoke. They also expressed interest in learning about potential danger of third-hand smoke exposure as this information was not available in their communities. A magazine, BREATHE, was developed to talk about health impacts of exposure to second- and third-hand smoke (Attachment 8a). This resource was reviewed by the team at the CAMH and shared with representatives from the Tobacco Control Program, Health Canada.

The BREATHE magazine was translated into Cree (Attachment 8b) and a Cree language specialist from Alberta worked closely with Elders to ensure, not only proper translation, but appropriate cultural interpretation and adaptation of the material as well.

### 5) Smoking Cessation

No materials were developed in this category as a new smoking cessation resource was recently developed and launched by the CAMH as part of the TEACH project and the STOP program in collaboration with an Engagement Circle of Indigenous community workers, practitioners and Elders. The program "IT'S TIME - Indigenous Tools and Strategies on Tobacco: Interventions, Medicines & Education" is a toolkit that provides community workers, community members and others with culturally relevant commercial tobacco cessation materials and resources in Aboriginal communities. The toolkit includes: teaching circle guides, First Nations art, interactive group activities, craft-making, traditional tobacco teachings and audio recordings of collected quit journey stories (refer to Appendix 23 for the flyer describing the program).

# 6) Knowledge on Chronic Respiratory Disease

During the Phase 1 project, it was identified that community members had a lack of understanding about the connection between commercial tobacco use (smoking) and the development of chronic obstructive pulmonary disease (COPD). Therefore, an information card was developed to explain this connection and inform community members that COPD is primarily caused by smoking (Attachment 9a). Due to the size of the card, it was difficult to

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incorporate images representing First Nations, Inuit and Métis communities in one resource and three versions of the card were developed. As with other smoking-related materials, the COPD card was reviewed by the team at the CAMH, as well as submitted to the Canadian Lung Association (still under review).

The Asthma Triggers Poster (Attachment 9b) was designed to provide simple information on asthma triggers. Its content was mostly based on the ASC educational resource, Asthma Booklet Series, Booklet #2: Triggers<sup>1</sup>. Icons illustrating asthma triggers were designed by a First Nations artist specifically for this material. Another asthma-related resource was adapted from the material that was initially developed by the Ontario Physical Education Association (Ophea) and aimed to present information on asthma, allergies and anaphylaxis in a chart format. The content of the initial chart was jointly revised by the ASC and Ophea (Dr. Lisa Cicutto), and included in a new Asthma, Allergies and Anaphylaxis chart developed for First Nations, Inuit and Metis communities (Attachment 9c). All clinically related materials in this category were reviewed by expert physicians involved in the NAC, particularly, Dr. Susan Waserman and Dr. Louise B. Giles.

## **Conversational Cards**

As part of the Toolkit, conversational cards on respiratory health and the risk factors for chronic respiratory disease were developed to be used during support circles, and other community-based programs (Attachment 10). They were intended for the use by the COCLs, community health representatives/outreach workers, and other community-based professionals. The cards could also be utilized by Respiratory Health Champions to help convey key messages related to respiratory health during their individual interactions and/or group conversations with community members. The card topics are consistent with the categories of materials in the Toolkit and cover the following information:

- The respiratory system and how it functions
- Potential health effects of open/outdoor burning, idling, and road dust exposure
- Indoor air quality, in particular mould, radon , formaldehyde, wood burning stoves, and household products
- Traditional tobacco use (optional card for First Nations and Metis communities)
- How commercial tobacco use (smoking) can affect someone's lungs
- Exposure to second- and third-hand smoke
- Commercial tobacco use (smoking) during pregnancy

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<sup>&</sup>lt;sup>1</sup> Asthma Basics Booklet Series, Triggers- available at <u>http://www.asthma.ca/corp/services/publications.php</u>

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• Chronic respiratory diseases, in particular asthma, respiratory allergies, and chronic obstructive pulmonary disease (COPD)

Each card has an image on the front of the card and information related to the image on the back. The cards were planned to be used to guide a conversation about the topic presented on the card. The cards were also developed to be used in informal settings where community members could discuss the topics in their own language (e.g., Cree or Inuktitut) or apply the language level that could be better understood by community members (e.g., seniors or teenagers).

Further, this set of Conversational Cards was designed to allow communities to discuss the topics that they felt were relevant and appropriate for particular audiences and programs by choosing certain cards for discussion. An order in which cards would be presented could also be defined according to the community's needs and preferences.

Conversational Cards were packaged in small colored boxes, specific for each community. In total, **21** cards were included in each box. The package sent to the Inuit community was modified and did not contain the "Traditional Tobacco" card as traditional tobacco use is not practiced in Inuit communities. Participating communities were also provided with a brief overview of what the Conversational Cards were and a guide on how to use the cards at the community level (Appendix 24).

During the development process, the Conversational Cards were reviewed and feedback was provided by NAC members and main project partners. In addition, the cards were reviewed and revised by a literacy expert to ensure their appropriate language level. A copy of the Conversational Cards was made available in French for the French-speaking First Nations community (Attachment 11).

### Master Group Presentation

According to the recommendations of the Phase I project (Asthma Society of Canada, 2010), a Master Group Presentation on the risk factors for chronic respiratory disease was developed to be used during existing group activities, community gatherings, and community-based programs. Information in the presentation was compiled in such a way that it could be presented by the COCLs, other healthcare professionals (e.g., community health representatives/outreach workers, nurses, etc.), as well as Respiratory Health Champions.

The Master Group Presentation was designed as a short PowerPoint presentation outlining information according to the Toolkit categories (e.g., outdoor air quality, indoor air quality, etc.) (refer to Attachment 12 for a hard copy of the Master Group Presentation). It also contains images, tables, and photos to make it appealing to the target audience. The Master Group Presentation was translated into French for the French-speaking First Nations community in

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Wendake (Attachment 12). As part of the Toolkit, each community was provided with an electronic copy of the Master Group Presentation on a CD (refer to the USB key submitted along with the final report).

Participating communities were provided with the opportunity to modify the Master Group Presentation according to their needs by: adding cultural symbols; including community images and/or photos; choosing which information/slides to present, and by supplementing it with community-specific information if applicable. The presentation was modified by the COCLs as necessary and participating communities were asked to provide the ASC with a revised copy. Some communities went further and developed their own presentations based on the content of the Master Group Presentation provided. For example, the COCL in the French-speaking First Nations community (Wendake) developed a PowerPoint presentation on common causes of chronic respiratory diseases (i.e., asthma, allergies and COPD) and main prevention strategies. This presentation was planned to be conducted during the Model implementation (stage 3 of the project) at the Centre for Training and Workforce Development (CDFM). Pilot communities were also encouraged to develop interactive activities (e.g., trivia games) to be delivered along with the Master Group Presentation during community celebrations and/or events.

### **Digital Stories**

The ASC Project Team worked closely with the communities to develop a selection of personal stories to be included in the Toolkit to be used at a variety of places at the community level (i.e., local media, community and Clearing House websites, Facebook pages, etc.). The development process started during the second stage and continued throughout the project. A selection of short digital video or audio stories was developed based on personal experiences of community members from each Aboriginal community (First Nations, Inuit, and Metis).

This development provided an opportunity for community members to share their experiences of living with a chronic respiratory condition with their fellow members and telling them how various factors (i.e., outdoor or indoor air quality, mould, traditional and commercial tobacco use, second- and third-hand smoke exposure, etc.) could affect their respiratory health. The digital stories were intended to be used to educate community members and served as reminders on how various environmental risk factors could influence the development and management of chronic respiratory disease.

To assist with the development of digital stories in the communities, several documents were prepared by the ASC Project Team and disseminated to the COCLs. These documents were reviewed by NAC members and further guidance and expertise was provided by Dr. Heather Castleden, Assistant Professor at the School for Resource and Environmental Studies, Dalhousie

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University. Dr. Castleden provided two documents that were previously prepared by her and could be applied as a reference while developing digital stories.

A folder (Attachment 13: orange folder) was created and contained several documents (as hard and electronic CD copies) outlining the necessary steps to be undertaken while developing digital stories. The documents that were included in the folder are described in detail below. All documents were translated for the use in the French-speaking First Nations community (Wendake).

## a) A Guide on how to develop a digital story

To assist the COCLs in conducting this project activity, the guide on how to recruit community members to be involved in the development of digital stories, and how to record their stories, was prepared. The ASC Project Team provided an outline on what digital stories are, what topics to consider when choosing a story, steps to take when writing a story before recording, and the optimal number of participants required for one story. The COCLs were also asked to complete a list of potential topics of interest for digital stories identified by their community and submit it to the ASC.

# b) A Budget for the development of digital stories

The COCLs were also provided with a budget outline explaining honoraria available to each community based on the number of digital stories to be developed. The honoraria (\$250 for each digital story developed) were generally provided directly to the communities to be distributed to digital stories participants under the discretion of the community. In some communities, the honoraria were provided directly to the individuals who developed and participated in the digital stories.

### c) A Consent Form for audio/video recordings

A consent form for audio/video recordings during the development of digital stories was developed based on the consent form provided by the CIHR Institute of Aboriginal People's Health. The consent from was accompanied by a Letter of Information (LOI), which provided information about the following: project investigators; the title of the project and its purpose; potential results of the proposed project interventions and processes; a summary of desired participant involvement; participant rights; potential risks; potential uses for the developed digital stories; privacy and confidentiality; products to be derived at the end of the development process, and benefit sharing. At the end of the form, participants were asked to provide their mailing address only for the purpose of sending an honorarium for their participation in this activity. This method of reimbursement was used in a few communities which requested sending the honoraria directly to the participants.

#### d) Seven Elements of Stories and storyboarding for digital stories

The Seven Elements of Stories document (Lambert J, 2008) was provided by Dr. Heather Castleden and presents an outline on the seven important things to keep in mind when developing a digital story such as: (1) Point of view; (2) Dramatic Question; (3) Emotional content; (4) Gift of your voice; (5) Soundtrack; (6) Keep it simple, and (7) Pacing. This outline was distributed to pilot communities (Attachment 13) to assist with preparation of participants for the development of digital stories. The second document included in the package was developed by Dr. Heather Castleden describing how to work on a digital story and take apart the script and the story, and then insert images and music where appropriate.

The COCLs were advised to contact the ASC Project Team if they had any question about the development of digital stories after receiving the package. Subsequent conference calls were organized with the COCLs to discuss package documents if required.

### **Recruiting and training Community Respiratory Health Champions**

Based on the findings of the Phase I project (Asthma Society of Canada, 2010), it was shown that community leaders and Elders could play a crucial role in delivering health-related messages and should be actively involved in health awareness and educational activities. This suggestion was further supported during the project launch meeting/workshop in May 2011 when project partners, NAC members, and community representatives provided ideas on how to identify and train community leaders and Elders to become Respiratory Health Champions. The overall recommendation made was to identify community champions through a nomination process or contest and recruit them from specific age groups (e.g., youth, seniors, etc.). The ASC Project Team worked with the COCLs to conduct this activity and proceeded according to the workshop recommendation.

#### Recruitment/Nomination Process

In order for the communities to conduct a nomination process at the community level, a series of documents were prepared and distributed to the COCLs. A folder was created and contained documents on how to identify and recruit Respiratory Health Champions. All documents were provided in a hard copy, as well as electronically on a CD (Attachment 14: purple folder). The developed documents were reviewed by NAC members, translated into French, and are described below:

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#### a) A Guide on how to identify Respiratory Health Champions

The Guide on how to identify Respiratory Health Champions was developed by the ASC Project Team and included an outline on who Respiratory Health Champions could be, what role they could play, who should be nominated, steps for recruiting, how to make a final selection of candidates, and timelines for their recruitment and training. Additionally, a template was provided to be completed by the COCLs with the names of Respiratory Health Champions recruited and their role in the community.

### b) A Nomination Form and a Ballot Box

As part of the package, a nomination form was given to the COCLs to distribute to community members so they could nominate their fellow members to be Respiratory Health Champions. The COCLs were also provided with a ballot box to be placed at a central location in the community where community members would be able to submit their ballots. The nomination form included an outline on who could be nominated, steps to follow when nominating a community member, as well as a nomination slip to be completed.

### c) A Promotional flyer

A promotional flyer was created to assist the COCLs with informing community members about the nomination process. The flyer included basic information about this project activity, details on how to nominate community members to become a champion, as well as provided contact information in case community members had any questions.

### d) A Budget for training of Respiratory Health Champions

The COCLs were also provided with a budget outline explaining who would receive honoraria for their participation in the training process. Honoraria of \$100 each were allocated to one Elder and one community leader in participating communities to be given after training completion. In some communities, honoraria were given to Respiratory Health Champions directly upon submission of an appropriate form (provided as part of the package). Other communities felt that the total honoraria should be divided among all community Respiratory Health Champions and, in this case, the ASC provided the full amount to the community to distribute under their own discretion.

The budget outline also had information about prizes that would be available to community members participating in the nomination process. All nomination process participants would be entered in a draw to be conducted by the Community Advisory groups and first three winners would be given a prize. Prizes were to be provided by the ASC as in-kind contribution to the project and were given to winners at the end of the project.

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After reviewing the documents provided, the majority of participating communities (Listuguj, Wendake, Conne River, Postville, and Prince George) had decided to go with the nomination process, while two (Saddle Lake and Enoch) asked members of their Community Advisory Groups to identify and recruit community members to become Respiratory Health Champions. In total, **138** nomination forms were submitted (see Table 2 below for a community breakdown).

Community	Number of nomination forms submitted	Number of champions identified
Listuguj, QC	105	10
Wendake, QC (French-speaking)	5	4
Conne River, NL	10	9
Postville, NL	10	4
Prince George, BC	8	7
Saddle Lake, AB	n/a	15
Enoch, AB	n/a	7
Grand Total	138	56

Table 2: The number of Respiratory Health Champions identified and recruited, by community

Based on the results of the nomination process, as well as decisions made by Community Advisory Groups, **56** Respiratory Health Champions were recruited and their breakdown by community is presented in Table 2 above. Community champions hold various roles in their communities, including Elders, community leaders, teachers or school personnel (i.e., retired or assistant, school secretary), students (i.e., nursing or Health Science), Church Board members, community healthcare professionals (i.e., community nurse, community healthcare worker), as well as representatives from community-based organization (i.e., housing, Justice Manager). All community Respiratory Health Champions are trusted members in the community and perceived to be able to deliver key messages on respiratory health and risk factors for chronic respiratory disease.

Development of the Train-the-Trainer Module (information session)

The Train-the-Trainer Module, an interactive, online information session on respiratory health and the risk factors for chronic respiratory disease, was developed by the ASC to train

Respiratory Health Champions. It was designed to equip them with knowledge that they could bring to their communities and educate community members using a "word-of-mouth" approach. This approach was aimed to help motivate community members to make positive changes in their lifestyles, as well as to implement simple measures to prevent the development of chronic respiratory disease.

The content of the Module was developed by the ASC Project Team in consultation with expert reviewers (Appendix 8) and NAC members (Appendix 7). The Division of e-Learning Innovation, McMaster University<sup>2</sup> used the provided content to develop an instructional, online information session (can be accessed at <u>www.respiratoryhealthchampions.ca</u>). The development team at the Division of e-Learning Innovation brings expertise in instructional design, problembased learning, evidence-based medicine, multi-media development, and computer-based learning technologies to create a high quality and enjoyable learning experience.

To be consistent with the materials developed for broader community members, the module was structured around the same categories as in the Toolkit, namely: 1) Outdoor air quality; 2) Indoor air quality; 3) Traditional and commercial tobacco use; 4) Second- and third-hand exposure, and 4) Knowledge on chronic respiratory disease. The module did not contain any detailed information about smoking cessation programs as this information was provided through another resource (Appendix 23). To make the learning experiences complete, an overview of the respiratory system was included in the beginning of the session. Further, to highlight the connection between risk factors for chronic respiratory diseases and the development of these conditions, information on early signs and symptoms of asthma, respiratory allergies, and COPD was added at the end of the module.

This 60 minute information session contains text-based information which is accompanied by an audio voiceover to ensure the content is understood and retained. Interactive features give participants the ability to pause in certain sections and review them again if necessary. Visual pop up messages help reinforce information provided and bring focus to the main points to take away and remember. As well, a "Take away" messages slide appears after each major section or subsection to reaffirm the information provided. Culturally appropriate images and community photos that were obtained from participating communities help participants to relate to the information session. Further, the three cultural symbols representing each community (e.g., feather, infinity, and Inuksuk) were incorporated into the module.

<sup>&</sup>lt;sup>2</sup> The Division of e-Learning Innovation is an educational research and development group within the Michael G DeGroote School of Medicine, McMaster University: <u>www.machealth.ca</u>

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#### **Organizing an Artwork Contest**

During the project launch meeting/workshop, several recommendations were made about strategies that could be applied to ensure full community engagement in the Model implementation. One of the suggestions was to organize an Art Contest in participating communities and to invite young aspiring artists to submit their work. These creative submissions could be used later for the background design of the Model, the front page of Community Assessment Guide, and/or the development of other educational materials. This would make the newly developed resources more community specific and give an opportunity to community youth to be inspired and involved in some meaningful activities representing their communities. At the end of the project, the ASC provided prizes to the youth whose work was chosen as the winning design by members of the Community Advisory Groups.

To assist with organizing the Artwork Contest at the community level, several documents were prepared by the ASC Project Team and disseminated to the COCLs. A folder (Attachment 15: green folder) was compiled and contained all relevant documents on how to conduct the Artwork Contest (hard and electronic copies of the documents were provided). The provided documents were available in English and French, and are described in detail below:

### a) A Guide on how to conduct an Artwork Contest

The guide on how to conduct the Artwork Contest was prepared to assist the COCLs with organizing the contest at the community level and recruiting participants. The ASC provided an outline on what the purpose of the contest was, what steps to follow when organizing it, who could participate, how to submit the artwork, and how the winning artwork design would be selected. It also outlined confidentiality and copyright arrangements related to the artwork submitted. The package contained a form to be completed by participants to describe what the artwork represents and means to them.

#### b) Promotional flyers

Two promotional flyers were developed to inform community members about the contest and placed around the community to invite community members to participate in this activity. Flyers included basic information about the contest, contact details, and explanation on when and where to submit the artwork.

The COCLs were responsible for artwork collection and for organizing meetings of the Community Advisory Groups to review the artwork submitted and select winning pieces.

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### **Stage 3: Model Implementation**

During this stage of the project various model-related activities were conducted in participating communities. A summary outlining the main project milestones for Stage 3 was prepared and circulated to the communities, project partners and NAC members (Appendix 25). The Model implementation activities were conducted by the COCLs working closely with the members of the Community Advisory Groups and community stakeholders involved in the project. The main activities conducted during this stage are described below in detail and included the following: (1) Distributing the Toolkit to community members and organizations; (2) Participating in community events and programs; (3) Completing the training of Respiratory Health Champions; (4) Completing the development of digital stories; (5) Working with community-based healthcare professionals, and (6) Establishing a National Coordination Centre/Clearing house. Participating communities took a lead on all the mentioned above activities except the creation of the Clearing house, which was executed by the ASC Project Team.

#### Distributing the Respiratory Health Awareness Toolkit (Toolkit)

To undertake Model implementation activities and distribute materials and resources from the Toolkit, the ASC Project Team created three types of packages for community distribution: a Master Toolbox with all the materials and resources; distribution Toolkits containing selected materials; and individual packages with the Toolkit newly developed materials for distribution to community members (refer to Appendix 26 for the visual presentation/image of the toolkits). All toolkits were disseminated to participating communities as follows:

#### Master Toolkit (Toolbox)

One Master Toolbox was provided to each participating community to keep in a central location at the community level. A total of **seven** Toolboxes were distributed during the project. The Master Toolbox contained all the newly developed materials and resources, as well as all existing materials selected for the Toolkit. It is a portable file cabinet (Appendix 26) with internal dividers and files containing specific materials. The Toolbox was customized based on the Aboriginal community (First Nations, Inuit, and Métis) and community-specific materials were included as required. All Master Toolboxes were supplied with an introduction (Appendix 27) that outlined what was included in the Toolbox, as well as with a list of all Toolkit materials and resources (Appendix 28). Each Master Toolbox also contained a CD with the Master Group

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Presentation (refer to the USB key submitted along with the final report). The Conversational Cards were also included in the Master Toolbox and were provided in a separate box.

The materials and resources in the Master Toolkit were organized under the six major Toolkit categories (e.g., outdoor air quality, indoor air quality, etc.) and then further divided into three sections, namely : (1) *Main Resources* for wider community distribution during the Model implementation; 2) *Additional Resources* to be used for specific groups (e.g., children and/or youth, community members with asthma, allergies, or COPD, community organizations/businesses, etc.); 3) *Reference Resources* to be used by community outreach workers/health representatives or other health care professionals as a reference.

The communities kept the Master Toolbox at a central location in the community (i.e., the main project hub) so that the Toolkit materials and resources could be easily accessible and retrievable by the COCLs, and other community-based professionals. A box chosen for the Master Toolkit also allowed the COCLs to carry it around the community and display the Toolkit during community events and/or programs. All materials and resources as well as supporting documents provided in the Toolkit were translated into French for the French-speaking First Nations community involved in this project.

### **Distribution Toolkits**

Distribution Toolkits were created and provided to participating communities to be distributed to a variety of places within communities, including healthcare settings (e.g., health centres, pharmacies, nursing stations, etc.) and community organizations (e.g., cultural centres, community centres, bingo halls, fitness centres, etc.). It is a plastic folder with multiple file slots that can be hung down open on a door or any other display area. The material and resources in the distribution Toolkits were organized under the same main categories and included only the *main* resources (Appendix 29). The Distribution Toolkits were also developed specifically for First Nations, Inuit and Métis communities. The French-speaking First Nations community in Wendake was provided with Distribution Toolkits containing materials in French.

A total of **36** Distribution Toolkits were sent out to participating communities during Model implementation. Each participating community received **five** Distribution Toolkits, with the exception of the Métis community in Prince George who requested an additional Toolkit and were provide with a total of **six** Distribution Toolkits. The COCLs were instructed on how to distribute these Toolkits to healthcare settings and/or local community organizations/businesses. An exact list of places for Toolkit distribution was compiled by each community based on their specific needs and existing community structures. Table 3 below shows the places and the number of Toolkits distributed by community.

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Participating communities were also advised that they could add any additional resources to the Distribution Toolkits from the Master Toolbox depending on where those Toolkits would be distributed within the community (e.g., schools, businesses, etc.). For example, if the Toolkit was being distributed to a business, any additional resources that were listed for businesses could be included in the Distribution Toolkit, or if the Toolkit was going to a school, all additional resources listed for children and youth in the Master Toolbox could be included in the Distribution Toolkit.

Community	Number of Distribution Toolkits distributed	Places of distribution
Listuguj, QC	5	<ol> <li>Listuguj Mi'gmaq Development Centre (L.M.D.C.)</li> <li>Alaqsite'w Gitpu School (A.G.S.)</li> <li>Listuguj Band Office</li> <li>Police Station</li> <li>Daycare Education Centre</li> </ol>
Wendake, QC (French-speaking)	5	1. Marie-Paule-Sioui-Vincent Health Centre (community physician)
		<ol> <li>Marie-Paule-Sioui-Vincent Health Centre (nurses)</li> <li>Marie-Paule-Sioui-Vincent Health Centre (Ciga- Stop smoking cessation program)</li> <li>Native Friendship Centre (Puniku Program)</li> <li>First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC)</li> </ol>

Table 3: The number of distribution toolkits and places of distribution, by community

Conne Rivers NL	5	1 Tru Value
	5	2 Haakh Clinia
		3. Wellness Centre
		4. School
		5. Band Office
	5	1. Health Contac
Saddle Lake, AB	5	1. Health Centre
		2. Wah-Koh-To-Win Child Care Society
		3. Onchaminahos School
		4. Boys and Girls Club
		5. St. Paul Alberta
Enoch, AB	5	1. Enoch Kitaskinaw School
		2. Enoch Health Centre
		3. Enoch Child Care Centre
		4. Enoch Elders Centre
		5. Enoch Housing
Postville, NL	5	<ol> <li>Department of Health and Social Development (DHSD), Nunatsiavut Building</li> </ol>
		2. Dental Office, Nunatsiavut Building
		3. Town Office, Postville Inuit Community Government
		4. Postville Clinic/Nursing Station
		5. B.L. Morrison School

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Prince George, BC	6	<ol> <li>Kikino Métis Children and Family Services Society</li> </ol>
		2. Prince George Métis Housing society
		3. Prince George Nechako Métis Elders
		4. Blade Runners
		5. Prince George Métis Elders Society
		6. All Nations Elders
Grand Total		36

### Individual Packages

Individual packages of selected materials were developed for wider distribution to individuals at the community level. All newly developed materials and resources, as well as selected existing materials, were included in individual packages (Appendix 30). For individual packages, two-pocket blue folders were chosen and educational materials were organized under four categories: Outdoor Air Quality; Indoor Air Quality; Traditional and Commercial Tobacco Use (Smoking); and Knowledge on Chronic Respiratory Disease. The individual packages were customized and included materials specific for First Nations, Inuit and Métis community members (Attachments 16, 17 and 18, respectively). A package with materials in French was prepared for the French-speaking First Nations community in Wendake (Attachment 19).

A total of **910** individual packages were sent to participating communities, and each community received **135** individual packages, with the exception of the Inuit community in Postville which was provided with **100** packages based on its population size. The COCLs were asked to distribute individual packages to all community members, including adults with asthma and associated allergies, parents and grandparents with children living with asthma and associated allergies, people who are at risk of developing chronic respiratory disease, including smokers, ex-smokers, and people with a family history of lung disease, pregnant women and young parents, extended family members, cultural and community leaders (i.e. Elders, community Chiefs/Band Councils, knowledge keepers), housing officials and/or landlords, and the general public.

The COCLs applied various strategies while disseminating the Individual Packages to community members. For example, in the Listuguj First Nations community, a lunch and learn session was conducted by the COCLs where community members were provided with Respiratory Health Awareness Individual Packages. During this session, community members

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also shared their stories on how environmental factors could impact individuals living with asthma and other chronic respiratory diseases. One of the community members shared his story about his personal asthma triggers, such as road dust and grass fires. A similar strategy was applied by the Prince George Métis community where the COCL found that distributing packages during community events and programs was a great way to connect with community members, and answer any questions that they had on the Toolkit materials. Another strategy applied in the Postville Inuit community was to contact community members by phone or inperson, and provide packages directly to families in the community by going door-to-door. A similar approach was also applied in the Saddle Lake First Nations community where the COCL distributed Individual Packages, while delivering meals to community members. Overall, Individual Packages were well-received by community members, and some communities (Enoch, Prince George, and Postville) were interested in receiving additional packages.

#### Participating in community events and programs

Respiratory health education was delivered during community events and programs by COCLs and/or trained community Respiratory Health Champions. Participating communities were asked to conduct the following project activities during community events and programs: (1) deliver the Master Group Presentation specifically develop for this project (Attachment 12); (2) organize interactive activities (i.e., trivia games, etc.) at community events and/or programs, and (3) distribute individual packages/Toolkits during these events/programs.

In the beginning of the project, pilot communities were asked to identify three community events (i.e., information nights, celebrations, health and wellness fairs, school information sessions, social gatherings for parents, seniors, youth or children, community dinners, etc.) where presentations on respiratory health and the risk factors for chronic respiratory disease would be delivered to community members. They were also asked to identify five existing community programs (e.g., after-school programs, seniors' monthly sessions, youth education programs, family fun programs, etc.) where presentations on respiratory health would be organized and be potentially well-received by community members. To help with this task, several documents were prepared by the ASC Project Team and disseminated to the COCLs as a folder (hard and electronic copies of the documents prepared) (Attachment 20: red folder). These documents were reviewed by NAC members, translated into French, and presented below:

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#### a) A Guide on how to identify community events and programs

The guide on how to identify community events and programs was provided to assist the COCLs when selecting community events and programs for delivery of the Master Group Presentation. The ASC Project Team prepared an outline on what community events and programs could be suitable for the presentation delivery, and how to identify them. They were also given two templates that could be used to record community programs and events identified. An additional template/list was provided to keep track of the number of individuals who attended community events and programs and the COCLs were asked to record this number. All templates were to be completed by the COCLs and submitted back to the ASC.

#### b) A Budget for community events and programs

The COCLs were also provided with a budget outline explaining what funds were available for conducting community events and programs. A total fund of \$150 was given to each community for refreshments to be provided during presentations. Communities were also provided with funds for prizes to be given out during interactive activities (i.e., trivia or bingo games, etc.) organized during these events and/or programs. A total fund of \$300 was provided to each community to purchase prizes and/or supplies needed to organize trivia games on respiratory health and/or other interactive activities. Two expense forms were developed to keep a record of how the funds were spent for refreshments and the interactive activities.

The Master Group Presentation (Attachment 12) was easily integrated by participating communities into their existing group activities and programs. For instance, it was used during community information nights, celebrations, health and wellness fairs, school information sessions and other community events (i.e. social monthly sessions for seniors, community dinners, etc.). A total of **44** presentations were delivered during the model implementation at various community gatherings and programs (Table 4). The most common events chosen for the presentation delivery were Wellness Fairs, community-based conferences, and community celebrations (e.g., Christmas dinner and social, Baby celebration, etc.). The most common community programs used to deliver respiratory health messages were schools events (e.g., parent-teacher interviews) and after-school programs, youth and seniors groups, and information sessions/nights.

Community	Number of community events conducted	Number of community workshops/programs attended
Listuguj, QC	2	5
Wendake, QC (French- speaking)	3	2
Conne River, NL	2	1
Saddle Lake, AB	4	2
Enoch, AB	4	2
Postville, NL	3	5
Prince George, BC	3	6
Total	21	23
Grand Total	44	

Table 4: The number of community events and programs conducted, by community

During the project, participating communities felt that the Master Group Presentation was a great way to interact with community members and provide information on chronic respiratory disease and risk factors for its development. Some communities modified the presentation to target different audiences (i.e., teenagers, seniors). A total of **3157** individuals attended these presentations during model implementation and a community breakdown is presented in Table 5 below. In Wendake, the community also conducted a radio podcast reaching out to approximately **8,000** community members. In total, approximately **11,157** individuals were provided with information on respiratory health and risk factors for chronic respiratory disease during the Model implementation.

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Community	Community Attendance at the events	Community Attendance at the programs	Total
Listuguj, QC	400	45	445
Wendake, QC (French- speaking)	270	15	285
Conne Rivers, NL	8	7	15
Saddle Lake, AB	800	19	819
Enoch, AB	1,150	54	1204
Postville, NL	242	41	283
Prince George, BC	39	67	106
Grand Total	2909	248	3157

**Table 5**: The number of community members attended community events and programs, by community

Participating communities showed some creativity and adapted, or further developed, the Master Group Presentation based on their needs and preferences. For example, the Inuit Community in Postville created a BINGO game, with a total of 30 cards with terminology related to the respiratory system, respiratory conditions, smoking, etc. This game was played at the Christmas social for seniors, with a total of **11** players in attendance. The BINGO game was extremely well-received by community members and participants felt it was a good learning experience. The Postville community was also able to incorporate the delivery of respiratory health presentation in already existing community programs at the Department of Health and Social Development (DHSD).

In Wendake, a special presentation was developed and pilot tested at the Centre for Training and Workforce Development (CDFM). First, the draft presentation was delivered to 43 CDFM students from CDFM and comments were received on how to improve it. The revised presentation was shown next day to 27 students and was accompanied by interactive activities such as breathing by using a plastic bag and/or a straw to demonstrate how difficulty breathing feels. This activity also provided an opportunity for an exchange between the presenter and the students. In total, the community engaged **70** students at the CDFM in discussions on respiratory health.

Some communities implemented various methods to inform community members about upcoming events. For example, the COCL working in the Enoch First Nations community, Alberta developed a newsletter that presented information about the project and described activities on respiratory health that were undertaken by the community (Appendix 31 ). In Alberta, the COCLs participated in various community events, including the Treaty 6 Education Conference, the Enoch Band Meeting, and Family Day Celebration on February 20, 2012. They also set up respiratory health awareness booths during community celebrations or gatherings such as the Community Hall for a Baby Celebration in Saddle Lake and the school conference in Blue Quills.

A few communities, which did not have immediate community programs and events in place, faced challenges as they had to organize their own programs and events. For example, the Métis community in Prince George organized a "Meet and Great Tea" event where the Master Group Presentation was delivered by the community COCL.

Other community-based activities related to the Model implementation included the Artwork Contest organized to engage youth and young adults in project activities. Due to the amount of work required to conduct the main project activities, the communities were not able to allocate time and adequate resources to organize and promote the contest. As a result, a total of only four artwork designs was submitted to the ASC.

### **Completing the training of Respiratory Health Champions**

The online information Module (session) that was developed by the ASC project team, in partnership with the Division of e-Learning Innovation, McMaster University, was used to train community leaders, Elders, and Knowledge Keepers to become Respiratory Health Champions in their communities (refer to the link of the Module provided in the USB key submitted along with the final report). The COCLs were responsible for organizing the training process in their communities and the ASC project team provided COCLs with necessary information on how to complete the online information session. They were also briefed on when and how to obtain informed consent prior to the session and to administer evaluation documents upon Module completion. In addition, a special guide was prepared describing the main steps involved in conducting the session, including the consent process (Appendix 32). Subsequent conference calls were conducted to answer any outstanding questions and the COCLs were encouraged to contact the ASC project team in case they experienced any technical difficulties while completing the module.

The online training Module (session) was completed by Respiratory Health Champions either individually or in a group setting and this process was facilitated by COCLs. Some communities decided to organize group sessions to compete the Module. For example, as the Module is available in English only, the French-speaking First Nations community in Wendake conducted a group session to train community Respiratory Health Champions and invited a French interpreter to facilitate its completion. In both scenarios, the COCLs were given community specific passwords, as well as sign in sheets with a list of numeric login identifications (IDs) for Respiratory Health Champions. The COCLs were instructed to record the login ID assigned to each Respiratory Health Champion and the date of their session.

This set of unique numeric login IDs was also used to track the Module completion by each Respiratory Health Champion, as well as to ensure confidentiality and privacy of Module participants. This type of ID and password designation helped to track the data and Module completion by community.

In the beginning of the session and prior to logging in, Respiratory Health Champions were asked to sign a paper-based consent form (Appendix 33) that was administered by COCLs. Then Respiratory Health Champions were given their ID and password to login in to start the session. Once they logged in, the online information session prompted them to fill out a pre-knowledge questionnaire (Appendix 34) to assess their understanding of chronic respiratory disease and its risk factors before completing the Module. This questionnaire was also available in a paper-based copy for Respiratory Health Champions who were not comfortable completing it online. After completing the questionnaire, participants were prompted to begin the information session which took approximately 30 to 60 minutes to complete. After finishing the session, they were asked again to complete a post-knowledge questionnaire, which was similar to the pre-test, to assess how effective the information session was in educating on the main topics related to chronic respiratory disease and its risk factors. At the end of the session, participants were asked to provide their feedback on session, including its content, design, voiceover, and cultural content. A total of **52** Respiratory Health Champions completed the Module and a breakdown by community is presented in Table 6 below.

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Community	Number of individuals who completed the Respiratory Health Information Module (Session)
Listuguj, QC	7
Wendake, QC (French-speaking)	4
Conne Rivers, NL	9
Saddle Lake, AB	15
Enoch, AB	7
Postville, NL	5
Prince George, BC	5
Grand Total	52

**Table 6:** The number of Respiratory Health Champions who completed the online training

 Module, by community

After the training was completed, the ASC provided **21** prizes to participating communities to be given to winners of the nomination process draw. In the French-speaking First Nations community (Wendake), Community Advisory Group members decided to provide the prizes to the Respiratory Health Champions.

After completing the training, Respiratory Health Champions were actively involved in the project activities at the community level and participated in various community events such as Lunch and Learns or a Christmas Eve dinner and social. In some communities (e.g., Conne River, Prince George), community Respiratory Health Champions delivered the Master Group Presentation and were helpful in informing community members about the project activities. They were instrumental in distributing Individual packages and providing respiratory health information to community members and bringing awareness about issues related to respiratory health. They also took part in the development of digital stories and were involved in the work on Community Advisory Groups, including Toolkit evaluation.

### Completing the development of digital stories

As a part of this stage, the development of digital stories was completed. In total, **15** community members participated in their development and provide their personal stories to educate community members on the risk factors for chronic respiratory disease. A total of **ten** stories (3 audio and 7 video) were recorded (see Table 7 below for the number of personal stories developed per community).

Community	Number of Digital Stories (audio and video)
Listuguj, QC	1
Wendake, QC (French-speaking)	2
Conne Rivers, NL	1
Saddle Lake, AB	1
Enoch, AB	1
Postville, NL	1
Prince George, BC	3
Grand Total	10

Table 7: The number of personal stories developed during the project, by community

The French-speaking First Nations community in Wendake developed two audio scripts, one on indoor air quality (i.e., tobacco smoke, dust mites, and mould), and the second one on outdoor air quality (i.e., AQHI rating, woodstoves and road dust) (refer to the USB key submitted along with the final report). The community plans to broadcast these topics through their local community radio station and will provide the ASC with recordings of the radio broadcasts. Other communities developed stories on a variety of topics, including life with asthma or COPD, and commercial and traditional tobacco use. Participating communities are planning to play the developed digital stories on radio stations (i.e., radio podcasts), at community health centres, physicians'' offices, community recreational centres, etc. After editing, all digital stories will be also available through the Clearing House website (see Section 4.6. for more detail).

#### Working with community-based healthcare professionals

Under the Community healthcare delivery component of the Model (Appendix 2), a liaison was established with healthcare professionals working in the community to ensure that they were properly informed about the project and the Toolkit. It was also aimed to make a connection between community-based initiatives and healthcare delivery.

Community-based healthcare professionals (Table 8) were both directly and indirectly involved during the Model implementation and participated in the following activities: working directly with the COCLs on conducting model-related activities; providing guidance and support when planning community events and programs; assisting in the development and organization of display boards or community interactive activities (e.g., games), and informing community members about the project and its activities.

Some specific examples included the placement of a nursing student in the Métis community (Prince George). The COCL in this community was approached by the Coordinator in charge of community placements for nursing students at the University of Northern British Columbia (UNBC), who showed great interest in having a student do a practicum with the COCL and be involved in the project. The nursing student was of Métis background and she was involved in all stages of the project implementation, and assisted the COCL in organizing community events and programs and connecting with community members. At the end of her practicum, she did a PowerPoint presentation about the project (refer to Attachment 21 for a hard copy of the presentation) to her class at UNBC. She also provided them with examples of the materials and resources that were developed during the project. This allowed reaching out to nursing students who would be entering the health care field and providing them with information on chronic respiratory diseases and the risk factors for their development that exist in the Prince George Métis
Community	Number of healthcare professional that were involved directly in the project	Number of healthcare professionals that were involved indirectly in the project	
Listuguj, QC	3	1	
Wendake, QC (French-speaking)	5	13	
Conne Rivers, NL	2	10	
Saddle Lake, AB	1	2	
Enoch, AB	2	2	
Postville, NL	2	1	
Prince George, BC	-	3	
Total	15	32	
Grand Total	47		

**Table 8**: The number of healthcare professionals involved in the model implementation, by community

Another example was observed in the French-speaking community (Wendake), where Community Advisory Group members were nurses themselves or worked directly with nurses during the project implementation. The community also developed a brochure on asthma and COPD in collaboration with two hospitals located nearby (the Institute of Cardiology and Pulmonology, Laval Hospital and Chauveau Hospital). The brochure (Attachment 22) includes a questionnaire to be used for initial screening of asthma or COPD in community members. After an individual has completed the questionnaire, an appointment is automatically made with a nurse who will perform further assessment and refer the individual for either a spirometry test, or a teaching clinic. The community found that this new brochure was the good first step in providing screening to community members who could be potentially affected by asthma or COPD.

In addition, Distribution Toolkits were made available in various healthcare settings within participating communities, specifically: Community Health Centres (i.e., provided to a community physician or nurse), community health programs (i.e., Ciga-Stop smoking cessation program), community Health Clinics/nursing stations, the Wellness Centre, dental offices, and the Department of Health and Social Development in the Postville community. This gave

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communities an opportunity to inform community health representatives and other healthcare professionals about the materials available for patient education. A total of **18** community-based healthcare organizations received a copy of the Distribution Toolkit (Table 9).

Community	Number of healthcare settings that received the Distribution Toolkit
Listuguj, QC	-
Wendake, QC (French-speaking)	4
Conne Rivers, NL	2
Saddle Lake, AB	4
Enoch, AB	5
Postville, NL	3
Prince George, BC	-
Grand Total	18

Table 9: The number of health care settings that received the Distribution Toolkit, by community

Further, a special tool (Access map/checklist) was designed to inform community members about respiratory health resources available at the community level and how to access them (Appendix 35a). This tool provides community members with information on where to go within their community to access resources on respiratory health. The checklist is a template that could be modified by each community to be specific to the community's resources and services. Participating communities will be able to insert their community name, logo, and other community-related images or cultural symbols. They will also include the name, location and phone number of services and programs where respiratory health awareness resources and materials are available at the community level. Additional information was also provided on how community members could access the **BREATHE** Clearing House (see Section 4.6. for details) and receive educational materials on respiratory health and the risk factors for chronic respiratory disease. Having a template also will give participating communities the opportunity to update it and add or remove services as required. A copy of the Access map/checklist was also translated and provided to the French-speaking First Nations community (Appendix 35b).

### **Establishing the National Coordination Centre/Clearing House**

The National Coordination Centre/Clearing House (**BREATHE**) was created to provide resource support to participating communities, as well as to establish one point of contact for information on respiratory health and the risk factors for chronic respiratory disease targeting Aboriginal community members. The Toolkit materials and resources are housed at the website of the Clearing House and, if resources can be secured, will be available to be downloaded for use by Aboriginal communities across Canada.

### Development of the Clearing House name and the logo

The name of the Clearing House was developed jointly by the ASC, main project partners, and NAC members. Initial suggestions for the name were provided and discussed during the project launch meeting/workshop in May 2011. The ASC Project Team then compiled a list of the names suggested and developed a web-based survey for NAC members and community representatives to vote on the potential names for the Clearing House. Strong feedback was received in regard to using First Nations, Inuit and Métis in the overall name instead of "Aboriginal". The name **BREATHE** was finalized and agreed upon by follow-up e-mail correspondence. It stands for **Building Respiratory Education** and **A**wareness for First Nations, Inuit and Métis: **T**ools for **H**ealth **E**mpowerment.

The project and Clearing House logo (Appendix 36) was developed by a First Nations designer and represents First Nations, Inuit and Métis communities, as well as showing the partnership and collaboration among them.

#### Development of the Clearing House website

One of the main project objectives was to create a website for the National Coordination Centre/ Clearing House. The ASC Project Team worked closely with the Division of e-Learning Innovation, McMaster University, to develop it over an eight month period. The website content was developed by the ASC project team in consultation with partners, and NAC members. The team at the Division of e-Learning Innovation lead by Dr. Anthony Levinson used the content to create a clearinghouse on the machealth public domain (see Appendix 37 for a screenshot of the website). The website can also be accessed from the ASC main page or at www.asthma.ca/breathe (refer to the website link on the USB key submitted along with the final report).

Numerous discussions with communities and partners reaffirmed the need to make the Clearing House website culturally appropriate and visually appealing to First Nation, Inuit and Métis community members. During the website development, special attention was paid to inclusion of

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cultural symbols (e.g., the feather, Inukshuk, and infinity), and images (e.g., the drum, beading, and photos of community members).

The website includes BREATHE's mission, information about the project/model (the Respiratory Health Awareness Model Description), and the list of project partners and participating communities, as well as providing access to the Respiratory Health Awareness Toolkit materials and the Respiratory Health Information Session (training module).

The Respiratory Health Awareness Toolkit on the website includes all the newly developed materials that are available for download in PDF format. They are organized on the website under the six Toolkit categories and can also be accessed by specific Aboriginal community (First Nations, Inuit and Métis). All resources are available in English and the First Nations resources are available in both official languages. After editing is complete, digital stories will be posted on the website as well.

# Inquiries from Aboriginal communities

From the project's onset, there have been several inquiries from other Aboriginal communities regarding resources on respiratory health and the risk factors for chronic respiratory disease. The ASC Project Team maintained a log of all the inquiries. Inquiries were received via phone calls to a national toll-free number (1-866-787-4050) or by e-mail to <u>breath@asthma.ca</u>

Approximately, a total of **23** requests for educational materials and support were received during the project. In particular, 19 First Nation, 2 Inuit and 2 Métis organizations spanning the entire country (from British Columbia and Yukon to Nova Scotia) contacted the ASC requesting materials and resources. Given that many of the newly developed Toolkit resources were not available at the time of the initial inquiries, existing ASC materials were distributed, including the Asthma Patient Bill of Rights poster, and the ASC Asthma Booklet Series: Diagnosis, Triggers, Medications and Kids booklets. Later in the project, other existing and newly developed resources from the Toolkit were sent to organizations and individuals. These resources included, but were not limited to, Environmental Activity booklets developed by Health Canada; the Air Quality Health Index (AQHI) Wheel developed by Environment Canada, as well as the Outdoor Air Quality Fact Sheet, the Mould Information Card, and the Seven Sacred Teachings Poster developed during this project.

# Stage 4: Model Evaluation and Results Dissemination

Overall project success was evaluated by applying a mixed-method approach (quantitative and qualitative analysis), as well as assessing community participation and project outputs that are

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presented earlier in this report (refer to Section 4. *Stage 3: Model Implementation*). The effectiveness of the Model implementation and the Toolkit was assessed according to the evaluation plan (Appendix 9) that was developed in the beginning of the project by Dr. Wayne Warry and Dr. Oxana Latycheva, and approved by NAC members. According to the plan, several data collection tools were developed by the Principal Investigator (Dr. Wayne Warry, McMaster University) and the ASC Project Team. Some tools were designed based on the existing validated tools and others were developed specifically for the project's evaluation needs based on existing conceptual frameworks (e.g., Kirkpatrick's conceptual framework). All of the evaluation tools are available, or were translated, in French to facilitate data collection in Wendake, the French-speaking First Nations community.

Community Outreach Coordinators/Liaisons (COCLs) facilitated administration of the evaluation tools and data collection, and were trained to undertake this task. They were equipped for this by way of training sessions conducted over the phone by the ASC Project Team and later through Evaluation Process Guides (Part 1 and 2). The guides were prepared by the ASC Project Team for the first (September 2011 – December 2011) and second stages (January 2012 – March 2012) of the evaluation process and are available in English and French. They described the evaluation tools, the target audience, how the tools should be administered, whether consent was required and the timeline for data collection. Part 1 of the Guide was distributed to the communities electronically, as well as by mail as a hard copy (refer to Attachment 23: black folder). A drop box was also included in the mail to be placed in a central location and be used to collect completed forms at the community level. Part 2 of the evaluation guide was sent via e-mail communication (Appendix 38) and subsequent conference calls were conducted with the COCLs to provide them with a detailed explanation on how to use it. COCLs were encouraged to refer to the Evaluation Process Guide and contact the ASC Project Team if they had any questions as they progressed through the evaluation component of the project.

Following the evaluation plan (Appendix 9), special tools were used to evaluate the implementation of the Model, as well as to receive comprehensive feedback on the Toolkit. A brief description of the tools used is presented below under two main evaluation categories: Toolkit evaluation and Model evaluation.

#### **Toolkit Evaluation**

*The Respiratory Health Awareness Toolkit* (the Master Toolbox, Distribution Toolkit, and Individual Packages) was piloted in the participating communities and community members, as well as community organizations, were asked to assess and rate the materials in the Toolkit, and

provide their comments (qualitative feedback). A report card to evaluate the Toolkit was designed and included in Individual Packages, as well as in the Distribution Toolkits that were disseminated to community organizations and healthcare facilities.

### Assessing Distribution Toolkits and Individual Packages

The report card for the Distribution Toolkit (Appendix 39) is an evaluation tool to assess organizations' satisfaction with the respiratory health awareness materials included in the Toolkit and gain a better understanding on how community and healthcare organizations intend to use the Toolkit. The card is structured to have a 5-point scale and open-ended questions. As the Toolkit differs slightly regarding target materials for First Nations, Inuit, and Métis communities, three versions of the report card for Distribution Toolkits were developed (refer to Appendix 39, A, B, and C, respectively). The target audience for this evaluation tool is representatives from health care and community organizations/businesses. Not all community members feel comfortable accessing information from healthcare organizations or institutions which makes it important to offer educational packages in other places that community members may frequently visit (e.g., schools, local stores, community and recreation centres, etc.). This approach extended outreach and awareness efforts to a wider array of community members.

The report card for Individual Packages (Appendix 40) is an evaluation tool used to assess community members' satisfaction with the respiratory health awareness and educational materials in the Package by applying a 5-point scale, as well as by asking questions about the design, cultural imagery, and the language level of the materials provided. One open-ended question was also asked on which resource community members liked the most and which the least to understand their preferences for the design and content of educational materials. The last section of the report card assessed willingness to use the information using the first three levels of the Kirkpatrick's conceptual framework (Watkins et al., 1998). The report card questions were organized around the three main levels of the framework as follows: (a) Were the participants pleased with the program? (Reaction level); (b) What did the participants learn in the program? (Learning level); and (c) Did the participants change their behavior based on what was learned? (Behaviour level). The fourth level (The Results level): (d) Did the change in behaviour positively affect the community? was not included in the current evaluation due to the short duration of the initial Model implementation pilot and will be considered for subsequent pilots. Similar to the report card for Distribution Toolkits, the report card for Individual Packages was available in three versions for First Nations, Inuit, and Métis communities (refer to Appendix 40, A, B, and C, respectively).

Evaluating the Master Toolbox by Community Advisory Group members

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To enhance the evaluation of the Toolkit at the community level), members of the community advisory groups were asked to review the Master Toolbox and organize a focus group discussion to summarize their feedback and comments. This methodology was strengthening by collecting quantitative feedback as well by asking them to rate the materials included in the Master Toolbox by using a specially designed ballot (Appendix 41).

To evaluate the Toolbox, a two-pronged approach was followed. First, the COCLs facilitated a focus group discussion with the members of their Community Advisory Group. Second, they distributed ballots to all Community Advisory Group members asking them to rate the materials in the Toolbox and provide their comments. For the focus group discussions, the COCLs were provided with a discussion guide prepared by the ASC Project Team to help facilitate their dialogue with the Community Advisory Group members (Appendix 42).

The discussion guide provided questions on the following topics:

- Overall satisfaction with Toolkit materials;
- The Toolkit as an effective tool to educate community members and increase their awareness on the risk factors for chronic respiratory disease;
- Toolkit design and its ability to meet community's needs and educational preferences.

Before the discussion commenced, the newly-developed materials in the Master Toolbox, specific to the group reviewing them, were distributed by the COCL one at a time by category (e.g., indoor and outdoor air quality, traditional and commercial tobacco use (smoking), exposure to second and third hand smoke, and knowledge on chronic respiratory disease). That allowed the Advisory Group members to review the materials before the focus group discussion.

The second part of the Master Toolbox evaluation by Community Advisory Groups involved an individual assessment of the materials via a ballot (Appendix 41). Following the discussion of the Toolbox, the COCL administered ballots to each member of the Community Advisory Group. After the distribution of ballots, the COCL presented each newly-developed material listed on the ballot, one at a time, making sure there was enough time to allow the group to score each material. The ballot lists each material alongside a 5-point scale with ratings from poor to excellent. Three community-specific ballots (refer to Appendix 41, A, B, C) were developed and given to the appropriate community (i.e., First Nation, Inuit and Métis) due to the fact that the materials included in the Master Toolbox varied by community (for example, the Inuit community's ballot did not include the Seven Sacred Teachings Poster given that they do not use traditional tobacco).

Evaluating the Master Toolbox by the main project partners and NAC members

To collect partner feedback on the Toolkit materials, a form was constructed by the ASC Project Team (Appendix 43). Three versions of the form were prepared to evaluate the Toolkit materials included for First Nations, Inuit, and Métis communities. The form is organized into two tables for 1) Newly-developed materials and 2) Existing resources, each broken down into six major sections:

- Outdoor air quality
- Indoor air quality
- Traditional and commercial tobacco use (smoking)
- Exposure to second and third hand smoke
- Smoking Cessation
- Knowledge on chronic respiratory disease

The resources under each of these sections varied based on the specific materials that the partners were asked to review (for example, the AFN was tasked to review First Nations specific materials). In additional, some partners were asked to review specific resources according to their expertise (for instance, HIP reviewed materials related to indoor air quality; CAN-ADAPTT provided feedback on all smoking-related materials, etc.). The NAC members mostly reviewed materials and resources pertaining to their expertise.

When it came to the newly-developed materials, the main Project Partners were asked to rate each resource listed on their form, and included in their package, on a 5-point scale. They were encouraged to elaborate on their quantitative rating with some qualitative feedback in the space provided on the form or via an attachment. Since existing materials could not be modified by the ASC, we asked partners to indicate whether or not a resource should be kept in the Toolkit or not (i.e., a dichotomous variable, yes/no). Again, they were encouraged to elaborate on their quantitative feedback in the free space provided on the form.

# Reviewing the newly-developed materials in the Toolkit by expert reviewers

In addition to partners, expert reviewers from government agencies and other lung health stakeholders (see Appendix 8 for the list of Expert Reviewers) were asked to provide feedback on the educational materials that were created for the Toolkit. Expert reviewers were given specific materials pertaining to their expertise. For instance, Environment Canada was consulted on the outdoor air quality and the Air Quality Health Index (AQHI)-related materials.

Evaluating specific resources in the Toolkit

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Some newly developed resources such as the Master Group Presentation and the online information session were evaluated using specially designed satisfaction or feedback surveys.

# a) A Satisfaction Survey to evaluate the Master Group Presentation

The satisfaction survey (Appendix 44) is an evaluation tool used to assess community member satisfaction with the Master Group Presentation (i.e., satisfaction with the content, usefulness of information, and cultural appropriateness) on a 5-point Likert scale. It also aimed to assess community members' willingness to use the information provide during the presentation by applying the three first levels of Kirkpatrick's conceptual framework (i.e., reaction level, learning level, and behavior level) (Watkins et al., 1998). For instance, community members were asked if they liked the presentation, if it provided new information, and if they would make changes based on what they learned. These questions provided a dichotomous "yes/no" response option and an open-ended section for more detailed responses was also included for each question. The COCL were instructed on how to administer the survey to community members after conducting the Master Group Presentation to ensure a timely response. Late submissions from community members were also welcomed and accepted.

# b) A Feedback Survey to evaluate the online information session (Training Module)

The feedback survey (Appendix 45) is a tool used to assess the level of satisfaction with the online information session or Training Module using a 5-point scale. Questions were asked about the format of the session, the usefulness of information, cultural content, interactive features, length, voiceover delivery, and the language level. COCLs distributed these surveys after *Respiratory Health Champions* completed their information sessions. Since some communities held the sessions in a group format and some individually, the survey was either distributed right after the session or shortly thereafter.

The main Project Partners were also asked to provide feedback on the Module by completing the same feedback survey (Appendix 45). This information was gathered and analyzed separately from the community members feedback and is presented in Chapter IV of this report.

#### **Model Evaluation**

To evaluate the effectiveness of the Model implementation in the selected communities, a pre/post evaluation design was chosen and data collection tools were administered before and after the Model implementation. Several tools were adapted and/or developed to assess the level of community engagement in Model implementation. They were also aimed to measure

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community capacity-building in health promotion (i.e., collective efficacy, community commitment, community networks, etc.)

The Community Capacity Building Tool (CCBT) developed by the Public Health Agency of Canada and Respiratory Health Awareness and Support Scales developed by the ASC were completed by the communities before and after model implementation. It is described below. The pre- and post- implementation design is commonly used to evaluate the effectiveness of various programs and population-based interventions. The goal of this approach is to understand, on an aggregate level, how the community was faring before the project started and the changes that may have resulted from the project implementation. Specifically, the ASC's goal was to understand if and how community capacity on respiratory health had changed due to the Model activities.

# The Community Capacity Building Tool (CCBT)

The CCBT is an instrument that was developed and validated by the Public Health Agency of Canada, Alberta and NWT region (Appendix 46). It aims to assess community capacity through questions that fall under the following nine features:

- Participation
- Leadership
- Community Structures
- Role of external support (for example, a funding agency)
- Asking why
- Obtaining resources
- Skills, knowledge, and learning
- Linking with others
- Sense of community

The ASC Project Team worked closely with the PHAC, Alberta and NWT to modify the original version of the CCBT to meet the project's purposes and evaluation objectives. A series of phone conversations and e-mail correspondence with Genevieve Montemurro, an evaluation consultant with the Public Health and Management Knowledge Management Division (the PHAC), helped the ASC adapt the instrument to make it appropriate for application in Aboriginal communities involved in the project. The modified tool (Appendix 47) was used for all communities except Wendake, Quebec where the original French-language version of the tool was applied (Appendix 48). The First Nations community in Enoch, Alberta also used the original CCBT version as this

community was additionally funded through the funding provided by AllerGen NCE Inc. In accordance to that funding allocation, the use of validated tools was required.

The CCBT was developed for group discussion use. For the purpose of this project, the Community Advisory Groups were assigned the task of completing the tool and met to answer the CCBT's questions pre-(before December 2011) and post-(before March 30, 2012) Model implementation. The COCLs facilitated discussions of the Community Advisory Groups after being trained by a member of the ASC project team on how to conduct them.

# Community Respiratory Awareness and Support Scales

The Community Respiratory Health Awareness (Appendix 49) and Support (Appendix 50) Scales were developed by Dr. Wayne Warry, Principal Investigator and the ASC project team specifically for the purpose of this project. They were designed on the base of the existing tools such as the Multidimensional Sense of Community Scale for local communities (Prezza et al., 2009), and other instruments to assess collective self-efficacy (Hawe at al., 2000). These scales are also based on the key elements of the Community Capacity Health Building framework (McGinty, 2002), as well as the Community Capacity Health Development index (Bush, 2001). The scales are primarily designed to evaluate the level of community engagement in model implementation.

Overall, the scales helped assess the level of community confidence (empowerment) and capacity in dealing with issues related to respiratory health. Community members were asked to rate the following indicators using a five point scale:

- Network partnerships
- Knowledge building and transfer
- Problem solving
- Community leadership
- Community-based resources and capacity.

The Respiratory Health Awareness Scale (Appendix 49) is a short version of the questionnaire that COCLs administered, on the spot, to any or all community members. This scale was also given to community members on multiple occasions and each community established a drop box in a central location in order to collect them.

The Respiratory Health Support Scale (Appendix 50) is a longer questionnaire with the same goal as the awareness scale, however, the target audience for this scale is a community member actively involved in or closely related to the project (e.g., community *Respiratory Health Champions*, Community Advisory Group members, community healthcare professionals, or

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school personnel). Community members interested in providing more detailed feedback were also given an opportunity to complete this scale. The Support Scale differs from the Awareness Scale in that it was administered to the same person pre- and post-model implementation. The COCLs were instructed to keep track of individuals who completed the Support Scale before the Model implementation by using a sign-in sheet (Appendix 51) that helped them contact the same participant to administer the scale again after the project. The COCLs asked participants to complete this scale only if they were comfortable leaving their contact information and being interested in completing the form post-model implementation.

Both scales were administered by COCLs and on each form a community code was noted to track the community from which these forms were submitted in order to compare combined community scores before and after model implementation.

# Gathering feedback from Elders/Knowledge Keepers and/or community leaders

In order to evaluate community perspectives on Model implementation, interviews with community leaders, Elders and/or knowledge keepers were conducted in each of the participating communities. An interview guide was developed to guide these interviews and disseminated to the COCLs (Appendix 52). Using the interview guide, the COCLs collected information on the Model implementation process to help the ASC understand the following:

- Successful methods of community engagement;
- Lessons learned during the model implementation;
- Lessons learned during the toolkit development and distribution.

In addition, the interviews collected feedback on the Toolkit and other model-related activities (e.g., community-based presentations and events) by asking the following questions:

- What communities liked
- What worked well
- What they would like to change
- How well the tool kit was adapted to meet the community needs.

A special consent form was developed, submitted to the Research Ethics Board (REB), and administered by the COCLs to community leaders, Elders or Knowledge Keepers prior to their participation in the interviews (Appendix 53). The COCLs were trained during a telephone conference call with a member of the ASC Project Team on how to conduct interviews including the process of obtaining informed consent before these interviews took place.

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#### **Project Evaluation Workshop**

On March 19<sup>th</sup>, 2012, a one day project evaluation workshop was held in Toronto, organized by the ASC Project Team. This meeting was a first step in presenting and disseminating project preliminary results to the main Project Partners and NAC members. The purpose of the Phase II Evaluation workshop was to present preliminary evaluation results of the Toolkit based on the data collected to-date, review and discuss what changes to make to the Toolkit materials and resources, and provide recommendations for next steps in the Model implementation (Phase III).

Twenty-one individuals representing key Project Partners, stakeholders, and experts attended the workshop (refer to Appendix 54 for the participant list). An individual meeting folder was prepared for each participant and distributed to participants attending the meeting in-person. It included the following documents: workshop agenda (Appendix 55); participant list; project fact sheets for Stage 1, and Stages 2 and 3 (Appendices 56 and 57, respectively); Phase II project Executive Summary (Appendix 12), and the list of materials and resources included in the individual packages for First Nations, Inuit and Métis community members (Appendix 30). Participants were also provided with a sample of the newly-developed materials and resources included in the Toolkit. All Toolkit formats such as the Master Toolkit (Toolbox), the Distribution Toolkit, and Individual Packages were displayed during the meeting (refer to Appendix 26 for the Toolkit images). NAC members who joined via conference call received a copy of all documents through email and were previously provided with hard or electronic copies of the newly-developed Toolkit materials.

The main meeting agenda items (Appendix 55) included presentations about origins and context of the project, project overview, and the materials in the Toolkit. The second half of the meeting was dedicated to a discussion about project sustainability and potential next steps in Model implementation (Phase III of The Respiratory Health Awareness Community Outreach and Engagement Model in First Nations, Inuit and Métis Communities).

During the workshop, the ASC presented feedback on the Model implementation received from participating communities and lessons learned from the ASC Project Team, as well as gave Project Partners the opportunity to provide their feedback and reflect on the overall implementation of the project. The ASC Project Team also provided preliminary feedback and comments on the Toolkit and the online information session (Training Module) obtained from Project Partners and participating communities. Workshop participants were asked for their recommendations for changes to be made to the Toolkit materials and resources, as well as discussed strategies and processes for making suggested revisions to the Toolkit. At the end of the workshop, two breakout sessions were conducted where participants were asked to generate

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and prioritize ideas for Phase III of the Model implementation. They were also asked to identify potential funding sources and in-kind resources that can be allocated to support priorities in Phase III of the project. Participants who joined the meeting via the conference call were also given the opportunity to provide their feedback on the project implementation, Toolkit, and priorities for Phase III during the workshop or through email thereafter (refer to Attachment 24 for the workshop notes).

In addition to the project evaluation workshop, two separate meeting were held in two pilot communities: Prince George (on February 8-10, 2012) and Wendake (on February 22-23, 2012). The Project Manager travelled to both communities during Stage 4 of the project. She was joined by the Project Coordinator for her visit to the French-speaking First Nations community in Wendake.

During the visit to Prince George, a luncheon meeting was held on February 09, 2012 with approximately 8 community members in attendance who were either involved in the project as a member of the Community Advisory Group, a trained Respiratory Health Champion or a member of the Prince George Métis Community Association (PGMCA). During the meeting, community members provided their overall positive feedback on the project, and commented on the work of the COCL. They also provided positive feedback on the materials and resources developed for the Master Toolbox and Individual Packages. Participants agreed that the project was a great way to reach out to and communicate with Métis community members in Prince George. In addition, representatives from the Housing Unit in Prince George provided their comments about the overall design of the materials included in the Distribution Toolkit. They noted that the Distribution Toolkits could be used to create awareness of housing issues and their potential impact on one's respiratory health. Housing officials were also impressed with the Master Group Presentation and felt that it could be modified and used for presentations on mould at the Housing Unit. Community members supported the idea of having the Master Group Presentation as a template that could be revised to be specific to the community's needs and priorities. They also liked the idea of having an Access map/checklist to provide information about all community locations where respiratory health awareness and educational resources are available.

Further, the Metis community in Prince George look forward to provide the Toolkit materials and resources to neighbouring communities to create awareness on respiratory health and risk factors for chronic respiratory disease among other Métis and First Nations community members in the same region.

During a two-day visit to Wendake First Nations community (French-speaking), the COCL provided the Project Manager and Project Coordinator with a small tour of the community where

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they were able to visit the Community Health Centre, the Centre for Training and Workforce Development (CDFM), Ts8taïe School and Marcel-Sioui Residence. The next day, they participated in the training session of the Respiratory Health Champions, as well as attended meeting of the Community Advisory Group as guests. A French interpreter was present during both the training session and the meeting to facilitate communication with community members. Overall, the Respiratory Health Champions were excited about their new role within the community that allowed them to participate in several initiatives and motivate others by sharing newly learned information. They also found that the Module provided them with adequate tools and information which could be further used to educate fellow community members.

During the meeting of Community Advisory Groups, a variety of project-related topics were discussed, including radio broadcasts, motivational approach training (offered by the Lung Association of Quebec), training of the Respiratory Health Champions, development of a community calendar, and the Artwork Contest. The Project Manager and Project Coordinator were shown digital stories that were under development and were able to provide guidance on how to complete them. They also answered questions that the Community Advisory Group members had on the materials and resources included in the Master Toolbox, Distribution Toolkits and Individual Packages. The Community Advisory Group members also talked about developing radio announcements on indoor and outdoor air quality that would be used later to raise awareness of these topics.

Other activities related to results dissemination are described in Chapter II, Section 7: Partnerships and Intersectional Collaboration.

# **Project Governance and Implementation**

#### **Project Team**

The project was implemented by the ASC in collaboration with the main partners and participating communities. The Project Team was led by Dr. Oxana Latycheva, Vice-President, Programming at the ASC and included Rupinder Chera, the Project Manager, and Tara Hahmann, the Project Coordinator. In addition, the project team included COCLs who were hired by community Health Directors and/or leaders to work within their respective First Nations, Inuit, and Métis Communities. The Project Team further solicited advice and support through a core group of partners (included representatives from the AFN, ITK, MNBC, AllerGen, and SSRP, University of Alberta), project supporters (NCCAH, CAN-ADAPTT, HIP, and the Division of e-Learning Innovation, McMaster University) and a wider National Advisory Committee (NAC) of experts.

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### The National Advisory Committee (NAC)

The list of the NAC members is presented in Appendix 7. The National Advisory Committee (NAC) was established to fulfill the following responsibilities:

- Oversee and guide the project implementation;
- Provide input during all stages of the project development and make recommendations for changes as necessary;
- Ensure cultural appropriateness and relevance of the Toolkit newly developed ;materials and resources;
- Finalize outcome measures and data collection tools to evaluate the effectiveness of the pilot model implementation.

Representatives from key partner organizations (AFN, ITK, MNBC and AllerGen NCE Inc.) and project supporters (NCCAH, Division of e-Learning Innovation, SSRP, CAN-ADAPTT and HIP) were invited to participate in the NAC work. Each community provided one representative to participate in the NAC. Additionally, key opinion leaders in the area of Aboriginal health and culture were invited to be involved in the Committee in a consultative role.

Throughout the duration of the project, NAC members met **six** times. There were **four** meetings held via conference calls. **Two** in-person NAC meetings coincided with two project workshops, the launch meeting/workshop in May 2011 and the evaluation workshop in March 2012. Documents required for the meetings were provided ahead of time and translated into French as needed. In addition, separate conference calls were conducted with community representatives from the French-speaking First Nations community, where a French interpreter was present during the calls. A detailed summary of the project launch meeting/workshop (May 17-18, 2011) and the project evaluation workshop (March 19, 2012) is presented in Sections 2 and 5 of the report, respectively. A brief summary of the NAC conference calls is presented below.

# NAC conference calls

During the first meeting via conference call on April 27, 2011, an overview of the project main goals, objectives, communities involved, and project milestones (Stage 1) were presented and discussed. Participants also discussed additional partners were to be invited to be involved in the project and talked about organizing the project launch meeting. A draft evaluation plan was reviewed and suggestions were made on how to strength it.

During Stage 2 of the project, NAC members held a conference call on July 12, 2011 to review the main project activities for this stage, as well as to discuss the key outcomes of the project

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launch meeting and the list of existing materials and resources to be included in the Toolkit. A list of communication partners (Appendix 10) was presented and agreed upon.

During the conference call on October 11, 2011, the project milestones for Stage 3 were discussed. Participants also talked about strategies were to be used for the Toolkit distribution, as well as reviewed questions related to the development of the Train-the-Trainer Module, the Master Group Presentation, and Digital Stories. Drafts of the Clearing House name and logo were also presented and discussed.

The final conference call took place on January 26, 2012. Project updates were provided and a discussion took place about the evaluation component of the project. Ideas were solicited on how to conduct the project evaluation workshop in March 2012.

# **Community Advisory Groups**

Community Advisory Groups were established in each participating community to oversee the model implementation at the community level and were responsible for the following:

- Ensure that the model was appropriately modified according to the community's needs and practices;
- Ensure proper engagement of community members, organizations, and the general public in the project;
- Provide feedback on the Toolkit materials and resources;
- Ensure sustainability of the model-related activities at the community level beyond the project timelines.

Community Advisory Group membership was identified by each community and comprised of main community stakeholders, community leaders, Elders, Knowledge Keepers, Band Council members, healthcare professionals, and other members of the community (i.e., students, administrative staff, etc.). The Community Advisory Group membership is presented in Table 10 below. In total, **52** community members participated in the work of Community Advisory Groups in all communities combined.

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Community	Community leaders/ Band Council members	Community organizations	Elders/ Knowledge Keepers	Healthcare professionals	Community members	Total
Listuguj, QC	1	1	2	3	-	7
Wendake, QC	1	3	-	6	2	12
Conne River, NL	2	-	1	1	3	7
Saddle lake, AB	-	-	2	1	3	6
Enoch, AB	-	-	3	1	6	10
Postville, NL	1	-	1	1	1	4
Prince George, BC	-	4	1	-	1	6
Total	5	8	10	13	16	52

**Table 10:** Community Advisory Group membership, by community

The COCLs were provided with information on how to conduct Community Advisory Group meetings and were advised to organize approximately three to five Community Advisory Group meetings during the project implementation. A total of **30** meetings were conducted in participating communities (see Table 11 below).

The Community Advisory Groups were instrumental in conducting the Model pilot at the community level and guiding implementation of all model-related activities. Many communities are planning to keep the Community Advisory Groups in place beyond the project completion.

Table 11: The number of Com	munity Advisory Group	Meetings conducted,	by community
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Community	Number of Meetings
Listuguj, QC	5
Wendake, QC (French-speaking)	7
Conne Rivers, NL	3

Saddle Lake, AB	2
Enoch, AB	4
Postville, NL	6
Prince George, BC	3
Total	30

# Partnerships and Intersectoral Collaboration

The main partnerships that were maintained and/or established for this project can be divided into six main categories based on the partner's involvement, their role and their contribution to the project as follows: 1) Key Project Partners; 2) Community Partners; 3) Support Partners; 4) Project Advisors (the National Advisory Committee); 5) Expert Reviewers; and 6) Communication Partners. Detailed information about each of the partners and their respective involvement in the project implementation and activities is summarized below.

### **Key Project Partners**

Since 2007, the ASC has been working in close partnership with the AFN and ITK to empower Aboriginal communities to increase their awareness about respiratory health and the risk factors for chronic respiratory disease (i.e., outdoor air quality, housing and smoking). In 2008/09, the ASC, AFN and ITK conducted a baseline needs assessment of asthma and allergy resources and programs available for First Nations and Inuit communities and produced the "A Shared Vision" report (Asthma Society of Canada, 2009). The project was also supported by AllerGen NCE Inc., National Centre of Excellence for Asthma and Allergy Research.

The "Shared Vision" project was followed by the "A Shared Voice" project which focused on engaging First Nations and Inuit community members, particularly youth and their families, in developing respiratory health educational initiatives and materials by gathering their input on the kinds of programs and materials they felt would be beneficial for their communities. In 2010, the ASC secured a partnership with the MNBC to expand its work to Métis communities in Canada during the implementation of the Phase 1 project "An Exploration of First Nations and Inuit Perspectives on Community Respiratory Health Awareness Initiatives" (Asthma Society of

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Canada, 2010), which was a baseline needs assessment of awareness, materials and resources on respiratory health among First Nations, Inuit, and Métis community members. At the same time, the ASC secured support from the National Collaborating Centre for Aboriginal Health (NCCAH).

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 the specific communities they represent. 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 involved in continuing the connections and relationships established with the key community organizations, leaders and contacts of the communities identified during the Phase I project, who went on to participate in the Phase II project. Furthermore, the key partners participated in the development and review of all data collection tools and other documents related to the project to ensure that all documents were culturally sensitive and appropriate. In addition, a representative from each organization was a member of the National Advisory Committee.

Additional partnerships were developed with other organizations such as AllerGen NCE Inc.; the Social Support Research Program (SSRP), University of Alberta; the Canadian Action Network for the Advancement, Dissemination and Adoption of Practice-informed Tobacco Treatment (CAN-ADAPTT), and the Division of e-Learning Innovation, McMaster University. These organizations added research expertise, knowledge regarding the social determinants of health particularly in Aboriginal communities, design expertise regarding social support interventions, on-line educational expertise and specialized experience and expertise regarding tobacco cessation.

*Overall*, the project helped strengthen the relationships with the AFN, ITK and MNBC. Longterm relationships have been continued and fostered among the other key project partners as well. A brief organizational overview of the key partners and their specific role in delivering the project activities is presented below.

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**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.

**Role:** Dr. Diego Garcia, Public Health Coordinator, at the AFN's Health and Social Secretariat represented the AFN and contributed to the project implementation by reviewing materials and resources developed for First Nations communities by the project team, in particular, the Seven Sacred Teachings Poster, the Mould Card, and the BREATHE magazine. Tobacco-related materials were reviewed by an AFN representative with expertise on the culture and traditions of traditional tobacco use. The AFN provided important recommendations for changes in the content and design of the newly developed materials. The AFN was instrumental during the pilot implementation of the *Respiratory Health Awareness community outreach and engagement model* (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 through its respective network.

Inuit Tapiriit Kanatami (ITK)



**Background:** Inuit Tapiriit Kanatami (ITK), formerly Inuit Tapirisat of Canada, is the national voice of the Inuit of Canada. 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 continued the partnership established with the Inuit community involved in Phase I during the Phase II project. As well, it helped the project team for the development of materials and resources specifically for Inuit communities, keeping in mind the unique Inuit culture and traditions practiced by Inuit community members. They also helped prepare all necessary documents to be compliant with established research-related practices.

Anna Fowler, Assistant Director, Department of Health and Social Development, ITK worked closely with Tina Buckle, a Community Health Nursing Coordinator, at the Nunatsiavut Government when reviewing and approving all documents related to the project.

Métis Nation British Columbia (MNBC)



The partnership and collaborative relationship established in Phase I of the project with Métis Nation British Columbia (MNBC) were further developed throughout the project and a valuable new partnership was solidified. This collaboration helped identify an appropriate Métis community to participate in the project and ensure that both the model and materials produced were sensitive to Métis people and communities.

**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 further explore this issue in Métis communities and learn about their needs and priorities when developing materials and resources on chronic respiratory disease and its risk factors during the project implementation. The MNBC helped the project team by continuing the established partnership with 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.

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Tanya Davoren, Health and Sport Director at MNBC, has continued to serve as a representative of the MNBC on the project. Tanya Davoren was instrumental in developing all project documents, specifically bringing information about the availability of materials and resources for the Métis community members and what needed to be developed and piloted during this project.

*In summary*, the ASC continues to strengthen its partnerships with the core existing partners (the AFN, ITK and 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 further implement and disseminate the Model into First Nations, Inuit and Métis communities across Canada.

#### AllerGen NCE Inc.



**Background:** AllerGen, National Centre of Excellence (NCE) for Asthma and Allergy Research represents a network of researchers from 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), the "A Shared Voice" report (Asthma Society of Canada, 2010) and the Phase I project "*An Exploration of First Nations and Inuit Perspectives on Community Respiratory Health Awareness Initiatives*" (Asthma Society of Canada, 2010). For this particular project, AllerGen provided its research and academic expertise and additional funds to supplement the funding for pilot communities in the province of Alberta. It also guided the ASC in the overall project implementation, as well as providing its expertise on community engagement approaches and the Model implementation. Dr. Diana Royce, Managing Director, AllerGen NCE Inc., was involved in reviewing materials developed during this project and facilitated the Project Implementation workshop and the Evaluation workshop. Dr. Malcolm King, Scientific Director, Canadian Institutes of Health Research and Institute of Aboriginal's Peoples' Health was involved in the project and participated in the work of the National Advisory Committee (NAC). Dr. Heather Castleden Assistant Professor, School for

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Resource and Environmental Studies, Dalhousie University, represents AllerGen on the project and sits on the NAC.

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

National Collaborating Centre for Aboriginal Health (NCCAH)



NATIONAL COLLABORATING CENTRE FOR ABORIGINAL HEALTH CENTRE DE COLLABORATION NATIONALE DE LA SANTÉ AUTOCHTONE

**Background:** The NCCAH, located at the University of Northern British Columbia in Prince George, BC supports First Nations, Inuit and Métis peoples in realizing their public health goals and reducing health inequities that currently exist for Aboriginal populations in Canada, Established in 2005, the centre uses coordinated, holistic, community-centered and strengthsbased 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, respecting cultural, geographic and historical diversity.

**Role:** The NCCAH provided its knowledge and expertise on social determinants of health as they could be applied in this case to respiratory health. It also provided its specific 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 National Advisory Committee and reviewing materials developed by the project team (e.g. the materials for the Toolkit). Donna Atkinson, Manager represented the NCCAH on the project and was involved in the work of the NAC.

As will other partners, the NCCAH will be involved in the dissemination of the final report through its communication channels and by posting the main project results on its website.

Social Support Research Program (SSRP), University of Alberta



**Background:** The SSRP is a multidisciplinary, multi-site program of research focused on social support as a health determinant and protective factor. It is engaged in assessing the mechanisms by which social support exerts an impact on health status, health behaviour, and health services use. It investigates the links between social support and other key determinants of health, specifically socioeconomic status, culture, and gender and examines the role of social support as a protective factor for vulnerable families, groups, and communities. It helps design and implement support interventions targeted at vulnerable families, groups, and communities using innovative mechanisms and modalities and tests the impact of support interventions on health, functioning, and resilience outcomes. It identifies implications of the research for programs and policies in health and health-related sectors.

**Role:** The Principal Investigator, Dr. Miriam Stewart, Professor in the Faculty of Nursing and School of Public Health, University of Alberta and an AllerGen investigator has been involved on several projects funded by AllerGen in the area of respiratory health and Aboriginal communities. The current project initiative was piloted in two of Dr. Stewart's research sites in Alberta.

<u>Canadian Action Network for the Advancement, Dissemination and Adoption of Practice-</u> informed Tobacco Treatment (CAN-ADAPTT)



**Background:** CAN-ADAPTT is a Practice-based Research Network facilitating research and knowledge exchange among practitioners, researchers and policy makers in the area of smoking cessation. Its vision is a Canada where health care providers have access to the tools needed to deliver up-to-date evidence-based smoking cessation interventions to reduce the prevalence of tobacco use and dependence. It aims to bridge the gap between research and practice following knowledge creation, synthesis and translation activities. It is a pan-Canadian initiative with funding provided by the Drugs and Tobacco Initiatives Program, Health Canada.

**Role:** Dr. Peter Selby is the Clinical Director, Addictions Program, and Head of the Nicotine Dependence Clinic at the Centre for Addiction and Mental Health (CAMH). He is an Associate Professor in the Departments of Family and Community Medicine, Psychiatry and Public Health Sciences at the University of Toronto and a Principal Investigator (PI) with the Ontario Tobacco Research Unit (OTRU). He was represented by Karina Czyzewski, Aboriginal Project Coordinator, Nicotine Clinic and Tobacco Control projects, Centre for Addiction and Mental Health (CAMH) on the National Advisory Committee. The team at CAN-ADAPTT and CAMH was instrumental in reviewing and providing feedback on the tobacco related materials developed for this project. They provided a toolkit called "IT'S TIME -Indigenous Tools and Strategies on Tobacco: Interventions, Medicines & Education" to provide community workers, community members and others with culturally relevant commercial tobacco cessation materials and resources in Aboriginal communities. This toolkit was provided to First Nations and Métis communities in this project.

#### **Community Partners**

**Background:** This project was principally community-based and collaborative in nature, both requiring and providing opportunities for in-depth partnerships with identified and selected Aboriginal communities and community leaders/representatives. These communities were chosen from among several identified First Nations, Inuit or Métis communities in various parts of Canada and were built on relationships established in Phase I. The ASC worked closely with the AFN, ITK and the MNBC to secure community participation in the project. Initially, it was planned to recruit six communities (four First Nations, one Inuit and one Métis). However, because of the high interest to participate in the project, seven communities were secured (five First Nations, one Inuit and one Métis). The communities involved in the project and their leaders/representatives are presented in Table 12 below. Detailed profiles of each community may be found in the community profiles section under Project Activities and Accomplishments. All participating communities have shown great interest in continuing to collaborate in future projects conducted by the ASC beyond this piloting of Model and development of the Toolkit. It is hoped that they will be engaged particularly in further dissemination of the project and its materials.

**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 further implementation of the model to neighbouring communities, as well as any future projects conducted by the ASC.

Community	Community	Community Outreach Coordinator
	Leaders/Representatives	and Liaison (COCL)
Wendake, QC First Nations (French-speaking)	Micheline Roy Health Director	Marie-Pier D. Coulliard (March – July 2011) Jeanette Daigle (July – March 2012)
Listuguj, QC	Donna Metallic	Monica Barnaby
First Nations	Director of Health	Patricia Gray
Conne River, NL	Theresa O'Keefe	Elaine Jeddore
First Nations	Director, Health & Social Services Ada Roberts Nurse Practitioner	
Prince George, BC	Tom Spence	Kimberly McLeod
Métis	President, Prince George Metis Community Association (PGMCA) (March – May 2011) Patrick Pocha Acting President of PGMCA (May – March 2012)	

Table 12: Participating communities and community leadership

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Postville, Labrador	Shirley Goudie	Margaret Edmunds
Inuit	Town Clerk	
	Joan Goudie	
	Community Health Nurse	
	Department of Health and	
	Social Development	
Saddle Lake, AB	Theresa Cardinal	Rosina Stamp (March – December 2011)
First Nations	Health Director, Saddle	Maureen Cardinal (December 2011-
	Lake	March 2012)
	Sharon Anderson	
	Research Associate,	
	Social Support Research	
	Program	
	Roxanne Blood	
	Alberta Coordinator,	
	Saddle Lake	
Enoch, AB	Ron Morin	Amber Ward
First Nations	Chief, Enoch	
	Elaine Papin	
	Director, Enoch Health	
	Centre	

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 Phase I project and their participation continued in the current 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 a request for permission to continue the Phase II project in the Postville Inuit community. A copy of the signed REB approval letter from Health Canada/Public Health Agency of Canada (Appendix 3) and additional supporting documents were provided to John Lampe, the IRA for the Nunatsiavut government. The comprehensive review of the proposal involved all appropriate Nunatsiavut Government departments, Inuit Community Government(s) and staff. The ASC were successful in its request and received a letter of support by the Nunatsiavut government on June 6, 2011 (refer to Appendix 5 for the letter of support issued by the Nunatsiavut government).

Upon completion of the project, the ASC will work with participating communities to disseminate project results to community members. Potential methods of dissemination include, but are not limited to the following: presentation of results at community-based workshops or information nights; presentation of results to community health representatives/workers and other healthcare professionals; information about the project available through local media (e.g., radio podcasts), and presentation of results to community leaders, and the Band/Town Councils as applicable. All-mentioned above presentations will be organized at the community level and delivered by the COCLs, Health Directors, and/or community healthcare professionals involved in the project. Community Respiratory Health Champions will also assist with disseminating the main project findings in their communities.

#### **Support Partners**

Two organizations provided technical support to the project and the project team. They were involved in consultative ways and also participated on the National Advisory Committee.

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**Background:** The Division of e-Learning Innovation is an educational research and development group within the Michael G. DeGroote School of Medicine at McMaster University. Its development team brings together expertise in instructional design, problem-based learning, evidence-based medicine, multimedia development, computer-based learning technologies, technology-enabled knowledge translation, knowledge management, information architectures and instructional design, as well as research and evaluation general expertise.

Programs are funded through educational grants and developed in partnership with other organizations, in this case, the Asthma Society of Canada. Dr. Anthony Levinson is Director of the Division and Associate Professor at McMaster University. He holds the John R. Evans Chair in Health Sciences Educational Research and Instructional Development. He is also involved in AllerGen NCE Inc. as one of the network investigators.

**Role:** The ASC worked closely with Dr. Levinson and his team at the Division of e-Learning Innovation, McMaster University to create the BREATHE Clearing House and to develop the train-the-trainer online information session to be used during the project implementation.

The Healthy Indoors Partnerships (HIP)

**Background:** The Healthy Indoors Partnership (HIP) is an industry association which attempts to catalyze action on Canadian indoor environmental issues through multi-stakeholder collaboration. It connects people, ideas and resources from government, industry, educational and research institutions and public interest groups to provide the tools and expertise to prmote health indoor environments. Its mandate is to bring industry, government and non-governmental organizations together to identify, develop and implement activities designed to create healthier indoor environments in Canada. Among its several goals is the desire to promote health conscious individual behaviour and consumer awareness.

Role: Craig Jobber, President, Healthy Indoors Partnership, was involved in reviewing and providing feedback on the Healthy Homes Poster and other materials on indoor air quality



developed for First Nations, Inuit and Métis communities by the project team. He also represented HIP on our National Advisory Committee and was present during the evaluation workshop at the end of the project.

### **Project Advisors (National Advisory Committee)**

The National Advisory Committee (NAC) was established to oversee and guide the project implementation. In addition to the ASC staff, project team and a Board member, representatives from all key partner organizations (the AFN, ITK, MNBC, AllerGen, the NCCAH, SSRP and CAN-ADAPTT) were invited to participate in the work of the Committee. Invitations were also sent to representatives from the communities involved in the project, with each community having individual representation. Additionally, representatives from the Support Partners (HIP and the Division of e-Learning Innovation, McMaster University), a Communications Partner, and Members at Large added for specific expertise also served on the Committee.

Expertise in respiratory health and Aboriginal communities was provided by Dr. Dilini Vethanayagam, MD, FRCPC; Associate Professor, University of Alberta, Dr. Louise Brenda Giles, Pediatric Respirology Program Director, University of Manitoba, and Dr. Kim Barker, University of Toronto. Dr. Susan Waserman, Professor of Medicine, Division of Clinical Immunology and Allergy, McMaster University provided expertise in asthma and respiratory allergies.

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.

In total, **26** people served on the National Advisory Committee (Appendix 7). Further information regarding their meetings and input are detailed in Section 6. Project Governance and Implementation of this report. Each member of the Committee participated in the work and provided their expert knowledge on data collection tools, on the existing and already developed materials and resources for the Toolkit, as well as the pilot implementation of the Model. The NAC also provided overall guidance and advice on project implementation and its activities.

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#### **Expert Reviewers**

Throughout the entirety of the project, both the processes employed and the resources generated were reviewed by Expert Reviewers with knowledge, experience and expertise in Aboriginal health issues, respiratory health, resource development and related matters of interest in this project (refer to Appendix 8 for the list of expert reviewers).

Personnel from the following government departments and agencies, associations and organizations were consulted and provided valuable information for the successful completion of this pilot project: Health Canada, Environment Canada, the Public Health Agency of Canada, Canada Mortgage and Housing Corporation, Canadian Lung Association, Manitoba Lung Association, and Ontario Physical and Health Education Association.

#### **Communication Partners**

During the project, relationships were formed, maintained or renewed with **17** groups, programs organizations and projects with interests in respiratory health and Aboriginal communities (refer to Appendix 10 for the list of communication partners). Communication activities were conducted according to a results dissemination and communication plan, which is presented in Appendix 58. The plan was developed by applying the AllerGen Knowledge Translation (KT) tool (AllerGen, 2009), and finalized with input from the NAC members, and upon review by all key Project Partners. In brief, four main strategies have been employed to communicate project results and preliminary findings, including: (1) Dissemination of project findings to participating communities and other Aboriginal communities that expressed an interest to know about the Model; (2) Results dissemination through partners' respective networks and channels; (3) Results dissemination to main stakeholders working in the area of Aboriginal health; and (4) Results dissemination to a broader group of healthcare professionals, including presentation at conferences and manuscript preparation.

First two activities are described earlier in this section of the report. Following the third strategy, through the course of the project, status updates were circulated to communication partners (Appendix 10). In addition to informal communications, requests for information and potential resources and expertise, the ASC communicated formally with these partners following Stage 1 and after the completion of Stages 2 and 3 with updates on the progress of the project, as well as a summary of its partners, communities, goals and objectives. For this purpose, project fact sheets were developed and disseminated to the main project and communication partners at the

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end of Stages 1 and 3 (see Appendix 56 and 57 for project fact sheets: Stage 2, and Stages 2 and 3, respectively). The fact sheets were translated into French to provide project updates to Wendake, the French-speaking First Nations community, as well as the Assembly of First Nations of Quebec, and Labrador.

In regard to the fourth strategy listed above, the ASC submitted an abstract and was accepted to present project results at the Canadian Public Health Association (CPHA) Conference that will take place in Edmonton, Alberta on June 11-14, 2012. Other opportunities to present key project findings to a broader audience of public health and healthcare professionals will be sought out in the future as appropriate.

According to the results dissemination and communication plan (Appendix 58), linkages were established with projects funded through the Phase II funding of the National Lung Health Framework. In particular, the ASC project team made connections with three project leads who were conducting projects in Aboriginal communities funded through the Phase II funding. For example, the ASC Project Manager met with Dr. Richard Long during the Canadian Respiratory Conference in April 2011 and discussed potential links with the project "*Tuberculosis Education in Canadian Aboriginal and Non-Aboriginal Youth: An Historical, Socio-Cultural and Public Health Promotional Curriculum*". A follow-up conference call was conducted with Dr. Long and his team at the University of Alberta to share information about the projects and discuss potential exchange of materials and resources.

Another connection was made with the project "Addressing Barriers to Accessing Smoking Cessation Services and Promoting Early Detection of COPD" conducted by Yukon Government. The ASC project team established on-going communication via phone or e-mail with Ian Parker, Manager Health Promotion Unit and Brianne Meister, Health Promotion Coordinator to provide project updates and inform each other about development of new materials and resources. Some Toolkit materials (e.g., the online information Module, COPD Postcard) were shared with the project team in Yukon. The ASC project team also made connection between Yukon government and the CAN-ADAPPT team to exchange information about existing smoking cessation resources. The team in Yukon provided the ASC with information on materials and resources developed by the Northwest Territories Health and Social Services (i.e., "Smoke Free Because We Care" program).

The ASC project team also contacted Ainiak Korgak, Manager of External Public Health Relations, the Department of Health and Social Services, Government of Nunavut who was responsible for the project: *"Tobacco Has No Place Here: Nunavut Tobacco Education and Communications Campaign"* to inform her team about the Model implementation and the project

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conducted by the ASC. Subsequent updates and ongoing communication was provided through emails as needed.

# **Challenges and Lessons Learned**

In addition to raising awareness of respiratory health issues in the pilot communities, the Model implementation gave the opportunity to gain valuable insights on how to conduct populationbased initiatives in First Nations, Inuit, and Metis communities. It also allowed the ASC to better understand what outreach strategies worked well in these communities and what health awareness and educational approaches are less appreciated by community members.

During Stage 4 of the project (project evaluation), the ASC Project Team gathered feedback on the project implementation from participating communities, key Project Partners, as well as analyzed its own experience working with Aboriginal communities during this project. Findings obtained through collecting this feedback are presented below in detail.

# Lessons learned from participating communities

To assess the communities' perception of the entire project, keeping in mind the entire Model implementation process, the ASC Project Team generated a feedback report template (Appendix 59). The Community Outreach Coordinators/Liaisons (COCLs) were a key point of contact for both community members and the ASC from project commencement to completion and played a central role in its implementation at the community level. Therefore, they were asked to complete this template providing their opinion and perspectives about the project. They were also requested to consult with other people involved in the project as required. The Community feedback report template (Appendix 59) contained a series of questions as follows:

- What worked well during the project?
- What didn't work well during the project?
- What was the community most impressed about during the project?
- What was the best outcome from the project?
- What were some of the biggest challenges and barriers felt during the project?
- What would the community like to see in Phase III of the project?

Receiving community feedback on all of the above questions helped the ASC Project Team better understand what aspects of the project worked well and which posed challenges at the

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community level, as well as to learn about the most valuable community-based project outcomes.

### What worked well

The COCLs and other community members suggested that many aspects of the project worked well. The ASC Project Team's direct assistance during different phases of the project was perceived as supportive and very helpful. Further, the creation of the Community Advisory Groups and their involvement and guidance throughout the entire project implementation helped achieve project goals and objectives. The recruitment and training of the Respiratory Health Champions worked well and allowed them to become respiratory health advocates in their community.

The *Respiratory Health Awareness Toolkit* was well received by community members. Some communities noted certain materials in the Toolkit that were more effective in providing information on respiratory health. For example, the Master Group Presentation was found to be very useful given its interactive format. In fact, according to many of the communities, the best way to provide respiratory health education during the project was through established interactive community programs. The times of greatest participation in project activities was also observed during community celebrations related to various holidays (i.e., Christmas, Family Day) or when the Band Councils were not in session. Participation was heightened by way of interactive games that were created to make learning about respiratory health fun and engaging (e.g., one COCL created a BINGO game to help educate seniors in her community). Other effective methods to encourage participation were gift incentives, free draws, and refreshments provided as a part of the community events and programs.

The engagement of community members in the project helped facilitate dialogue about respiratory health, risk factors for chronic respiratory disease, and health in general. The collaborations with community organizations (e.g., schools) and health centres or other healthcare settings also helped spread information about respiratory health and ensure involvement of community members in the project.

With respect to project evaluation, the COCLs supported the use of digital tape recorders to collect focus group and interview data, and suggested to use them to gather quantitative data from the elderly population as well.

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### Aspects of the project that did not work as well

There were several aspects of the project that did not work as well as planned. Some communities found that the time frame to complete the tasks and all project activities was too short. It was also challenging to recruit members in some community to attend events, as well as fill out evaluation forms. This was partially due to the fact that some formats of advertisement did not work as expected (e.g., posting information on community bulletin boards). Although incorporating project activities into existing events and programs helped educate larger segments of the population, some of the respiratory health topics (e.g., exposure to second-and third-hand smoke) and their content conflicted with the cultural nature of activities (e.g., traditional ceremonies).

Some modifications were suggested for the Toolkit materials and resources before its wider dissemination. Some of the newly-developed materials were difficult for Elders to read due to the font size, and should be modified keeping in mind the literacy level and sight limitations of certain segments of the population. The content of some resources could be pared down and additional materials need to be developed as required.

With respect to project evaluation, many community members, especially seniors, were reluctant to fill out lengthy evaluation surveys, and recommendations were made on how to make this process more suitable for individuals with low literacy level (e.g., using a tape recorder to collect quantitative survey results).

# The most valuable perceived community-based project outcomes

Despite there being aspects of the project that did not work well, communities were impressed with most parts of the project. The Toolkit was well received by most and the cultural appropriateness of newly-developed materials was appreciated. Community members were particularly engaged by educational materials that had images and pictures from their communities as this helped them to better relate to the materials. The Master Group Presentation was deemed useful to participating communities as demonstrated by their posting of specific slides (e.g., the respiratory system, indoor and outdoor air quality) on bulletin boards. That approach was applied to create better awareness on respiratory health and to educate others not present at the group events. Most community members were particularly interested in the new information provided on third-hand smoke exposure, COPD, radon, asthma and its triggers, and respiratory allergies.
Generally, communities were impressed that an outside body was working towards increasing awareness and advocating for the improvement of Aboriginal peoples' lung health. They saw the efforts of the ASC as a catalyst that could lead to practice reform and policy changes within Aboriginal communities.

The communities described the best outcome of the project as increased awareness of, and education on, respiratory health and the risk factors for chronic respiratory disease. For example, increased interest in respiratory health in one of the participating communities was demonstrated by the creation of a database with the contact information of community members suffering from chronic respiratory disease. The project implementation also managed to reach out to community members that rarely frequented at community events before.

Another main project output was the creation of a set of materials and resources that are accessible at the community level (e.g., the Toolkit). The project also revealed community member additional interest and educational needs on additional information about third-hand smoke exposure, COPD and radon.

# Challenges and barriers at the community level

Communities faced some challenges and barriers during the project. For one, the Community Advisory Group members had prior commitments that affected their participation in the beginning of the project. Similarly, finding appropriate COCLs and Respiratory Health Champions was difficult for some communities, as people were involved in other initiatives. In general, organizing events, arranging meetings, and recruiting individuals to participate in the project in a short timeframe proved somewhat challenging. Further, in pilot communities without a community calendar, COCLs found it hard to plan project activities and integrate them into existing community events and programs.

### Next Steps in Model Implementation

With respect to the next phase of the Model implementation, participating communities are eager to have this project moving towards a next phase (Phase III). In this next phase, communities involved in the Model pilot would like to see the school system and housing organizations/officials become target groups for the Toolkit dissemination and implementation of Model-related activities. One community also would like to have COPD and asthma screening activities incorporated into the next phase. This would allow environmental health officers or

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other housing officials to become involved in the house inspection of people who have been recently diagnosed with chronic respiratory disease (e.g., asthma or COPD).

Furthermore, the communities want to preserve the Community Advisory Groups with some already scheduling meetings past project completion, highlighting their commitment to the continuation of the project. The training of Respiratory Health Champions worked very well for both the trainees and the community, and many communities have requested additional training and educational information to be provided during the next phase.

As mentioned previously, the Toolkit materials require some revision, and communities would like to be actively involved in finalizing them. Once they are finalized, they would like wider dissemination of the Toolkit to surrounding communities, to expand awareness and education.

Communities would also like this project's findings to be presented to agencies and regional authorities for potential collaborations and partnerships with the goal of extending the aims of the project to other communities in the same region.

# Lessons learned from Project Partners

Feedback from Project Partners and the lessons they learned during the project implementation was gathered during the project evaluation workshop on March 19, 2012. In addition, comments were collected throughout the project implementation on some issues as they arose (e.g., using "First Nations, Inuit and Métis" instead of "Aboriginal"; receiving formal approval to use the Seven Sacred Teachings; including Inuit-specific images, etc.) They also provided comments on the Toolkit by completing a partner feedback form specifically designed for that purpose (Appendix 43).

The findings from the submitted feedback forms in combination with evaluation workshop discussions highlighted aspects of the project that worked well and others that needed some improvement. In general, all Project Partners were very impressed with the amount of work and activities accomplished in a short time frame. Many attributed the success of the project to the ASC Project Team and the COCLs in each community who worked diligently to carry out the implementation of the Model activities.

In general, the Toolkit materials were well received by the Project Partners, with most rating them **4 or 5** on a 5- point scale, with 5 being the highest rating (i.e., excellent). Project Partners liked both the structure and organization of the Master Toolbox. Partners found the photos, images and colours used on the materials visually appealing. The use of outdoor scenery and pictures of community members, as well as cultural symbols were deemed culturally appropriate.

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The content was described as well organized and clearly presented. Some partners suggested that some materials had too much information, but they also found the information appropriate. Suggestions for improvement were made on the literacy level and the small font size of some materials (e.g., the Asthma, Allergies and Anaphylaxis chart and Healthy Homes poster), which could create learning difficulties for the elderly segment of the population. They also recommended changing certain images to make the materials even more culturally relevant.

In regard to the online information module, partners found it to be comprehensive and provided information at a level that can be easily understood by Respiratory Health Champions. The online format and structure was well received as were the images displaying the diversity of the communities involved in the project. The images and overall design were perceived as the best feature of the information Module. Project Partners suggested some cultural and content/technical improvements to be made to improve the learning experience related to the use of the Module.

In addition, Project Partners provided some ideas on how the Model implementation could be taken further. They all agreed that the Model needed to be offered to additional communities. It was suggested that this could start with a transition into "sister communities", where local networks and connections already exist. It would also be important to identify new communities in other regions and involve national organizations to establish necessary connections. According to their recommendations, scaling up should be done in a stepwise fashion to allow for interim evaluation and adjustments. The effectiveness of the Toolkit needs to be assessed further by disseminating it to communities from neighbouring regions. It would be also important to create materials for children and adolescents/youth by working with schools and Aboriginal sports organizations. Ensuring more active participation of healthcare providers in a future phase was named as a strategy that could help with further Model implementation and Toolkit dissemination.

# Lessons learned from the Project Team

The ASC Project Team worked closely with partners, expert reviewers, COCLs and other community leaders to facilitate this project. The full engagement of all those involved in the project was the key to the successful implementation of the Model-related activities and the Model evaluation. Multi-stakeholder and community involvement could be challenging given somewhat conflicting interest and priorities. Adding to this challenge was the extensive scope of this project over the very short 13-month time period.

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The most challenging elements of the project were the development of new materials included in the Toolkit (**18** items), the online information Module, and the **BREATHE** Clearing House. The development process proved more time consuming than anticipated originally. Project Partners helped review the content of Toolkit materials and information Module at many stages of the development process. With many partners and expert reviewers involved, gathering feedback in a timely manner was a demanding task. Some delays ensued when waiting for feedback due to busy schedules of partners and National Advisory Committee (NAC) members. An additional set of challenges was the developing of resources and materials at an acceptable literacy level while communicating clinical information and trying to make it appropriate for all three Aboriginal communities, as well as fitting all necessary content into a limited space (e.g., a postcard size material to provide information on mould or COPD).

The cultural appropriateness of materials was a key priority of the ASC Project Team and this led to the team's partnership with an Aboriginal designer. The ASC Project Team worked closely with Hiro Chavez, and this collaboration required much time and creative input on an ongoing basis from the Project Team. Waiting on input from Project Partners during the development process added to the slightly delayed production and distribution of the Toolkit.

The delayed release of the Toolkit to participating communities was part of the reason for a delay in completing evaluation surveys. The extensiveness of the project evaluation component further contributed to the complexity of the tasks performed. For instance, several evaluation documents needed to be distributed and collected back in a short time period, which was challenging, especially when unforeseen quandaries arose during the process of data entry and analysis.

The ASC's effective collaboration with the Division of e-Learning Innovation, McMaster University, on both the development of the information Module and the **BREATHE** Clearing House website allowed for the successful completion of both. As noted previously, the time frame was short for the development of both resources. Another challenge related to the creation of the Module was the necessity to develop the content for slides, as well as a voiceover. Images and pictures also had to be carefully selected to make the overall session engaging and relatable to the audience. The development of the Clearing House possessed similar challenges and the website has yet to be launched to the public. It will provide a central location to access most of the Toolkit materials online. In future, adding blogs and forums pages will help link First Nations, Inuit and Métis individuals from across Canada.

In summary, the project helped strengthen the relationship with the AFN, ITK and MNBC. New partnerships and collaborations were built throughout the project with communities that were not a part of the Phase I project, "An Exploration of First Nations and Inuit Perspectives on

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*Community Respiratory Health Awareness Initiatives*" (Asthma Society of Canada, 2010). For instance, two Alberta First Nations communities (Saddle Lake and Enoch) were new to this project.

This project helped further established an inter-sectorial collaboration where ITK, AFN and MNBC work together in representing their respective communities of First Nations, Inuit and Métis individuals across Canada. This partnership was further enhanced by involvement of AllerGen researchers and experts in the area of Aboriginal health and culture. With a next Phase of this project, this collaboration will continue to grow and knowledge gained in this project will be used to disseminate the *Respiratory Health Awareness community outreach and engagement model* to other Aboriginal communities in the future.

# **Project Evaluation and Results**

Project Evaluation was conducted by the ASC in accordance to the evaluation plan (Appendix 9) that was developed and approved in the beginning by the ASC Project Team. At the community level, data collection was undertaken by the COCLs who were specifically trained to conduct this process. The project evaluation could be divided into two components: Toolkit evaluation and Toolkit evaluation. Evaluation results and key findings are presented below under each of these components. Community leaders, Elders, and/or knowledge keepers provided feedback on both the Model implementation and Toolkit materials.

# **Model Evaluation**

To evaluate the effectiveness of the model implementation in the participating communities, a pre/post evaluation design was applied and data collection tools described earlier in the report (Section 5. Model Evaluation and Results Dissemination) were administered before and after the Model implementation (the Community Capacity Building Tool, the Respiratory Health Awareness and Support Scales). In addition, overall feedback on the Model implementation and the developed Toolkit was gathered from community leaders, Elders, and/or knowledge keepers by means of individual interviews. These interviews were conducted at the end of the project, recorded by using audio recording and/or paper-based notes, and transcribed by the COCLs. Formal consent was acquired (Appendix 53) before conducting interviews and participants were given a small honorarium as a token of appreciation for their participation.

Electronic written transcripts of the interviews were manually analyzed by question. Every comment was summarized and included in the analysis. When completing summaries, such as the list of things learned from the materials, similar comments were grouped manually and presented in order of frequency mentioned. A second data analyst reviewed the transcripts, analysis, and summaries of the interviews to ensure that points were interpreted correctly and that nothing was missed.

### Interviews with Elders and/or community leaders

As a key part of evaluating the implementation of the Respiratory Health Awareness Model, interviews were conducted with Elders and community leaders. By the end of the project, only three communities (Postville, Prince George, and Conne River) were able to find Elders or community leaders to do interviews. Two pilot communities in the province of Alberta continue implementing the Model beyond the timelines established for the project funded by the PHAC as they received additional funding form AllerGen NCE Inc. and are planning to conduct these interviews in August 2012. The Listuguj First Nations community conducted an interview with an Elder; however, this conversation was informal and was not recorded based on the Elder's request. Comments from this interview were submitted with the community feedback on the Toolkit and are not included in the below analysis.

In total, six interviews took place at the end of the project in three communities (two per community) and five of these were with Elders and one was with a community leader. The ages of the interviewees ranged from 36 to 74 years, with most falling over age 60. All interviewees were First Nations, Inuit or Metis and all of them reported that they do not speak or read an Aboriginal language (two could understand a little of their language). Three interviewees had chronic respiratory conditions themselves (two had asthma and one had chronic bronchitis). Only one participant was a current smoker and three were ex-smokers. Interviewees played important roles in their communities as Elders, Council members, community health workers, community association executives, and teachers.

### Impressions of the Model implementation

All of the Elders and community leaders who were interviewed thought that the Model implementation worked well in their communities. They felt that the communities were properly engaged during the process and community members were interested in participating. It was noted that there are always some people who are not ready or interested in participating but that it is important to reach out and offer information. Those who are ready to learn will learn.

They felt the community members liked the activities and the materials and found them helpful and appealing. Some mentioned the hands-on nature of the activities as a positive aspect of the

Model. Bingo games, draw prizes, and involving the Elders were important aspects of the activities and Model implementation.

Different communities had different experiences implementing the Model based on their own issues related to respiratory health. For example, in one community that is part of a larger centre, the air pollution is a major concern: "You see all this brown sludge hanging over our city and you know there has to be some harmful things done to our air". One Elder from that community felt that involving the city administration in the Model implementation would have been helpful and could be done as a next step in Model implementation. Other suggestions for improvement included:

- Providing more workshops for the community and for other surrounding communities
- Organizing more potluck suppers and prizes to draw people in
- Including ideas for ice-breakers
- Developing school presentations

Overall, the project was well received at the community level and there was an interest to implement the Model activities in other surrounding communities.

# Impressions of the Toolbox and Individual Packages

The Elders and community leaders interviewed had strongly positive impressions of the information presented in the Master Toolbox and Individual Packages. They found the information helpful and interesting. They all felt that the materials were good tools for educating community members about respiratory health. In one community, the mould information was deem to be the most useful while in another, the information about COPD and oxygen use was helpful.

In addition to liking the content and usefulness, Elders and community leaders also generally liked the design and appeal of the educational materials. One questioned the inclusion of posters in the Individual Packages and suggested that postcards, bookmarks or fridge magnets would be more appropriate formats. Specifically, the interviewees liked the following features of Toolkit materials:

- The inclusion of locally and culturally relevant images
- The colour and design of the posters
- The overall order and layout
- The inclusion of activity books for kids

They noted that some improvements could be made in regards to the print size of certain materials (""too small"); the size of the posters ("make them bigger"), and the density of the information provided ("information should be separated out in different materials").

Half of the interviewees said that there was nothing they would like to see changed or added to the Toolkit packages. However, they made some suggestions for future Toolkit developments as such:

- Develop culturally appropriate materials for young children
- Make the Toolkits available in a broader locations within communities, including "health agencies, doctors' offices, schools, senior centres and Aboriginal offices"
- Improve some of the pamphlets based on recommendations provided (e.g., print size, etc.)
- Include more information on COPD
- Produce smaller versions of the conversational cards to put on tables at community events

Some of the information that interviewees thought was particularly helpful was around cleaning products, third-hand smoke, wood stoves, and potential causes of respiratory disease. All said that their general knowledge of respiratory health increased and that they learned things from using the Master Toolbox and Individual Packages. Specific things they learned from the materials included information about:

- Using natural cleaning products (e.g., cleaning mould without bleach, using baking soda, vinegar)
- Third-hand smoke
- Difference between COPD and emphysema
- Radon
- Importance of a cleaner, smoke-free environment

# Use of the Toolbox and Individual Packages in the communities

All Elders and community leaders interviewed thought that the Toolbox and Individual Packages were adapted to their community's needs. Specific positive comments were made on improved access to information, the appropriate reading level, the cultural adaptation and local images, and the intergenerational application of the materials.

All interviewees also felt that, by making the Toolkit available to community members, the barriers to accessing materials and resources on respiratory health would be overcome. They

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suggested making it available in the right places, such as places where there are public gatherings. In this case, people in the community could read about respiratory health when they were interested and at their own pace.

The interviewees generally felt that the materials were sufficient to educate community members. They felt that the Master Toolbox and Individual Packages covered the right amount of information and the right content, for the most part. Elders and community leaders reinforced their suggestions to increase the poster size, to add more information on COPD and third-hand smoke, and to create materials for preschoolers.

### **Community Respiratory Health Awareness Scales**

Prior to the implementation of the Model, community members in each of the seven participating communities were asked to complete a brief survey to assess their community's awareness of respiratory health: the Community Respiratory Health Awareness Scale (Appendix 49). The scale consisted of seven statements and respondents were asked to rate their agreement with each statement on a 5-point scale (Strongly agree, Disagree, Neither agree nor disagree, Agree, and Strongly agree). The scale was also administered after the Model implementation to assess the effectiveness of the Model in increasing the information available on respiratory health in each community.

Completed baseline respiratory health awareness scales were manually entered into Microsoft Access using a data entry form constructed for the purpose of this project. Then, data were extracted and imported into Stata statistical analysis software, Version  $7^3$ . Frequencies and percentages were calculated for each question by community. Results were imported into Microsoft Excel and weighted average percentages were calculated to ensure that the different number of responses in each community did not skew the overall results. Tables and graphs for the overall and community-specific percentages were also created using Microsoft Excel.

### Baseline community awareness results

A total of **411** baseline surveys were completed in the seven communities. Because there were uneven numbers completed in each community (see Appendix 60, Table 13 for details), we presented the aggregate results both as overall percentages and also as weighted average

<sup>&</sup>lt;sup>3</sup> Stata statistical analysis software, Version 7 can be accessed at <u>www.stata.com</u>

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percentages to avoid skewing the results to the communities with the largest number of respondents. While the results tables below are shown in the highest level of detail available, the results are discussed and interpreted by combing the categories of "strongly disagree" with "disagree" and "strongly agree" with "agree".

#### Access to resources and materials

Before the Model was implemented, 39% of the respondents disagreed that their communities had sufficient resources and materials to deal with issues related to respiratory health. Notably, over one quarter stated that they neither agreed nor disagreed, indicating a potential lack of awareness of respiratory health related resources within the community (Table 1.2.-1 below).

**TABLE 1.2-1**: Summary of responses to "There are enough resources and materials in my community to deal with issues related to respiratory health" by community (Percent of respondents)

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville (Inuit)	17	6	22	44	11
Prince George (Métis)	6	58	26	10	0
Wendake (First Nation, French)	0	0	47	47	7
Listuguj (First Nation)	21	24	21	25	9
Conne River (First Nation)	0	35	16	45	3
Saddle Lake (First Nation)	9	27	27	18	18
Enoch (First Nation)	15	51	16	16	2
Overall percent	16	30	22	25	7
Weighted average percent	10	29	25	29	7

While the overall results indicate that the seven communities were collectively balanced in their stated need for resources and materials, there were important differences between communities, as shown in the community-specific results. The majority of respondents from Prince George (64%) and Enoch (66%) felt that their communities were starting with insufficient resources (Table 1.2.-1). Conversely, approximately half of respondents in Postville (55%), Wendake (54%), and Conne River (48%) agreed that their community was better equipped with some resources prior to Model implementation. Of note, nearly half of the respondents from Wendake neither agreed nor disagreed, indicating a potential lack of awareness that was higher than that seen in other communities.

One third of participants also disagreed that relevant materials and resources were available at a variety of places around the community. Table 1.2-2 above shows the community variation on the location of resource materials prior to the Model implementation. Over half of the respondents in Enoch (54%) disagreed that resources were available in a variety of locations throughout the community and nearly half disagreed in Saddle Lake (45%). In only one community, Postville, the majority of respondents (67%) felt that respiratory resources were available at various places throughout the community.

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville (Inuit)	6	6	22	67	0
Prince George (Métis)	6	39	16	39	0
Wendake (First Nation, French)	0	7	67	27	0
Listuguj (First Nation)	15	22	26	29	7
Conne River (First Nation)	0	32	29	32	6
Saddle Lake (First Nation)	18	27	36	14	5
Enoch (First Nation)	23	31	28	18	0

**TABLE 1.2-2**: Summary of responses to "Resources and materials on respiratory health are available at a variety of places around my community" by community (Percent of respondents)

Overall percent	14	24	28	29	5
Weighted average percent	10	23	32	32	3

When asked about resources outside of their community, the majority (53%) said that there were excellent materials available (7% disagreed). This indicates that, in the absence of resources within their communities, respondents were accessing materials from other places, many of which would not have been adapted to their specific community and cultural needs. When considering respiratory health resources available outside of the communities, several communities showed a potential lack of awareness of available resources with high level of "neither agree nor disagree" responses (Table 1.2-3). These included Wendake (53%), Saddle Lake (50%), and Prince George (48%).

TABLE 1.2-3: SUMMARY OF RESPONSES TO "THERE ARE EXCELLENT RESOURCES AND MATERIALS OUTSIDE
MY COMMUNITY I CAN TURN TO FOR ADDITIONAL INFORMATION ON RESPIRATORY HEALTH" BY
COMMUNITY (PERCENT OF RESPONDENTS)

	Strongly	Disagree	Neither Agree	Agree	Strongly
	Disagree (%)	(%)	nor Disagree (%)	(%)	Agree (%)
Postville	6	0	22	61	11
(Inuit)					
Prince George	6	19	48	19	6
(Métis)					
Wendake	0	0	53	40	7
(First Nation, French)					
Listuguj	8	12	29	33	17
(First Nation)					
Conne River	0	13	19	52	16
(First Nation)					
Saddle Lake	5	0	50	32	14
(First Nation)					
Enoch	2	21	10	52	16
(First Nation)					

Overall percent	6	12	29	38	15
Weighted average percent	4	9	33	41	12

Further, 61% of respondents said that there were excellent online resources and materials available (11% disagreed). These responses indicate that the majority of community members were also comfortable accessing online respiratory health resources. Similarly, a high proportion of respondents from every community said that there were excellent online respiratory health resources (Table 1.2-4). Notably, Conne River had a substantially higher proportion of respondents who did not agree (29%) with this than other communities. In Saddle Lake, half of the respondents did not have an opinion about online resources, indicating a possible lack of awareness about them. These results also indicate that most communities demonstrate potential for use of online resources.

**TABLE 1.2-4**: Summary of responses to "There are excellent online resources and materials I can turn to for additional information on respiratory health" by community (Percent of Respondents)

	Strongly	Disagree	Neither Agree	Agree	Strongly
	Disagree (%)	(%)	nor Disagree (%)	(%)	Agree (%)
Postville	6	0	22	50	22
(Inuit)					
Prince George	6	0	29	52	13
(Métis)					
Wendake	7	0	33	53	7
(First Nation, French)					
Listuguj	10	8	26	38	18
(First Nation)					
Conne River	3	26	16	29	26
(First Nation)					
Saddle Lake	0	0	50	36	14
(First Nation)					
Enoch	2	11	20	48	20
(First Nation)					

Overall percent	7	8	26	41	18
Weighted average percent	5	6	28	44	17

#### **Community leadership**

At baseline, 26% of the respondents disagreed that they had community leaders in place to provide information and resources on respiratory health (Table 1.2.-5) and **40%** felt that their leaders were not paying enough attention to respiratory health issues (Table 1.2.-6). As shown in Tables 1.2-5 and 1.2-6 below, communities varied in their perception of the leadership capacity prior to Model implementation.

TABLE 1.2-5: SUMMARY OF RESPONSES TO "THERE ARE COMMUNITY LEADERS IN PLACE TO PROVIDE MI
WITH INFORMATION AND RESOURCES ON RESPIRATORY HEALTH" BY COMMUNITY (PERCENT OF
RESPONDENTS)

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville (Inuit)	6	0	6	78	11
Prince George (Métis)	10	19	39	29	3
Wendake (First Nation, French)	0	0	27	53	20
Listuguj (First Nation)	19	18	29	26	7
Conne River (First Nation)	0	6	13	77	3
Saddle Lake (First Nation)	27	18	18	36	0
Enoch (First Nation)	11	48	16	23	2
Overall percent	15	21	25	33	6
Weighted average percent	10	16	21	46	7

While several communities had some strongly positive perceptions of their leadership, such as Postville, Wendake and Conne River, others were lacking it. Notably, in Enoch, the majority of respondents (59%) felt that there was no strong respiratory health leadership in place nor was there enough attention paid by leaders to respiratory health issues. Several other communities showed substantial negative responses on the presence of community leadership, including Saddle Lake (45%), Listuguj (37%) and Prince George (29%). Respondents from these communities indicated a corresponding lack of attention by community leadership to respiratory health issues at 55%, 54% and 51% respectively.

Further, a relatively high proportion of respondents (from 18% in Saddle Lake to 47% in Wendake) neither agreed nor disagreed when asked whether community leaders were paying enough attention to respiratory health issues. This indicates that many respondents were not aware of the perspective of their leaders on issues related to respiratory health.

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville (Inuit)	0	28	28	33	11
Prince George (Métis)	16	35	39	10	0
Wendake (First Nation, French)	0	0	47	40	13
Listuguj (First Nation)	25	29	28	15	2
Conne River (First Nation)	0	32	19	39	10
Saddle Lake (First Nation)	23	32	18	14	14
Enoch (First Nation)	15	44	29	13	0
Overall percent	19	31	29	18	4
Weighted average percent	11	29	30	23	7

**TABLE 1.2-6:** SUMMARY OF RESPONSES TO "LEADERS ARE PAYING ENOUGH ATTENTION TO ISSUES RELATED TO RESPIRATORY HEALTH" BY COMMUNITY (PERCENT OF RESPONDENTS)

#### **Community effort**

Before the Model was implemented, a total of **58%** of the respondents from the participating communities felt that their community was not working together to increase awareness of respiratory health and the risk factors for chronic respiratory disease (24% of respondents) or they were unaware of any community efforts (34%) (Table 1.2-7). This opinion was particularly strong in Alberta communities (Enoch and Saddle Lake). Responses from Wendake (40%) and Prince George (52%) showed particularly high levels of respondents who had no opinion about community efforts on increasing awareness of respiratory heath and dealing with issues related to chronic respiratory disease.

**TABLE 1.2-7**: SUMMARY OF RESPONSES TO "MY COMMUNITY IS WORKING TOGETHER TO ENSURE COMMUNITY MEMBERS KNOW THAT WE CAN ACHIEVE BETTER RESPIRATORY HEALTH" BY COMMUNITY (PERCENT OF RESPONDENTS)

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
	(%)	(%)	(%)	(%)	(%)
Postville (Inuit)	0	22	28	33	17
Prince George (Métis)	6	13	52	29	0
Wendake (First Nation, French)	7	7	40	40	7
Listuguj (First Nation)	12	15	32	30	12
Conne River (First Nation)	0	6	23	45	26
Saddle Lake (First Nation)	18	23	32	23	5
Enoch (First Nation)	5	35	33	26	2
Overall percent	9	17	33	30	10
Weighted average percent	7	17	34	32	10

### **Follow-up Results**

To-date, the Respiratory Health Awareness Scale (Appendix 49) was re-administered in five communities following the Model implementation with two Alberta communities (Enoch and Saddle lake) scheduled to complete it in August 2012. The baseline results for these two communities were excluded from the follow-up analysis. There were **150** follow-up surveys (refer to Appendix 60, Table 13 for a breakdown of the number of surveys completed by community). These surveys were completed by the general community members and were not linked to the baseline survey so they may have been a different set of respondents completing the forms pre- and post-Model implementation. Therefore, the follow-up data were analyzed as independent samples (rather than paired samples).

As with the baseline forms, follow-up scales were manually entered into the same Microsoft Access database with a flag for "follow-up" using a data entry form constructed for this purpose. Data were extracted and imported into Stata statistical analysis software, Version 7. Frequencies and percentages were calculated for each question by community. Results were imported into Microsoft Excel and weighted average percentages were calculated to ensure that the different number of responses in each community did not skew the overall results. Graphs for the pre-and post-implementation overall and community-specific percentages were created in Excel. Logistic regression models were constructed that compared the pre and post implementation combined likelihood of rating "agree" or "strongly agree", adjusting for the effect of community. Alpha was set at 0.05 for statistical significance. Adjusted odds ratios and accompanying 95% confidence intervals and p-values were reported for significant results. As with the baseline results, the weighted average percentages are presented to account for community differences. Final results were checked against the output from Stata 7 and Excel, as appropriate.

### Impact on access to resources and materials

In general, following the Model implementation, a greater proportion of respondents felt that there were enough resources and materials in their communities to deal with issues related to respiratory health (Figure 1.2-1). For the five communities that participated in the follow-up analysis, the weighted percentage rose from 40 to 51%. This change was substantial but not statistically significant. The latter could be explained by the fairly short duration of the Model implementation (3 months) that was not enough to show statistically significant results.

The number of people who agreed that there were materials available at a variety of place within the community increased after the mode implementation. Thus, the weighted percentage of participants, which agreed or strongly agreed with this statement, increased by **19** percentage points to **61%** of respondents after the Model implementation. Figure 1.2-2 below shows the

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substantial, yet not statistically significant, increase in agreement among community members that materials were available in a variety of community locations at the time of the follow-up. Notably, the number of respondents who neither agreed nor disagreed at baseline (32%) was decreased to 19% following Model implementation.



**FIGURE 1.2-1**: DISTRIBUTION OF PRE-POST MODEL IMPLEMENTATION RESPONSES TO "THERE ARE ENOUGH RESOURCES AND MATERIALS IN MY COMMUNITY TO DEAL WITH ISSUES RELATED TO RESPIRATORY HEALTH" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)



**FIGURE 1.2-2**: DISTRIBUTION OF PRE-POST MODEL IMPLEMENTATION RESPONSES TO "RESOURCES AND MATERIALS ON RESPIRATORY HEALTH ARE AVAILABLE AT A VARIETY OF PLACES AROUND MY COMMUNITY" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

At baseline, there was a high level of agreement that excellent resources and materials were available outside of the communities (Figure 1.2-3). This number `further increased from 52 to 62% following Model implementation. The odds ratio for the change approached significance at 1.45 (95% confidence interval (CI): 0.98 to 2.17, p=0.066).



**FIGURE 1.2-3**: DISTRIBUTION OF PRE-POST MODEL IMPLEMENTATION RESPONSES TO "THERE ARE EXCELLENT RESOURCES AND MATERIALS OUTSIDE MY COMMUNITY I CAN TURN TO FOR ADDITIONAL INFORMATION ON RESPIRATORY HEALTH" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

In regard to the availability of online resources on respiratory heath, Figure 1.2-4 shows the there is a statistically significant increase in the weighted percentage of respondents who agreed or strongly agreed that excellent online resources and materials on respiratory health exist. Respondents were 1.82 times more likely to agree or strongly agree with this statement following the Model implementation (95%CI: 1.19 to 2.79, p=0.006). At follow-up, **75%** of respondents indicated that availability of excellent online resources which could be partially accounted by the implementation of various Model-related activities which brought awareness about respiratory health and information about available materials, including web-based resources.



**FIGURE 1.2-4**: DISTRIBUTION OF PRE-POST MODEL IMPLEMENTATION RESPONSES TO "THERE ARE EXCELLENT ONLINE RESOURCES AND MATERIALS I CAN TURN TO FOR ADDITIONAL INFORMATION ON RESPIRATORY HEALTH" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

### Impact on perception of community leadership

The number of community members who had a high perception of the availability of community leaders to provide information on respiratory health increased further at follow-up (from 62% to 74%) (Figure 1.2-5). At the time of the follow-up, **74%** of respondents agreed or strongly agreed that there were community leaders who could inform them about respiratory health and issues related to it. While the proportion in disagreement did not substantially change, the percentage of people who neither agreed nor disagreed reduced from 23 to 11%, indicating that the Model implementation may have influenced both the availability and awareness of resources and support available from community leader resources. As community leaders were actively involved in the Model implementation and some of them became Respiratory Health Champions in their own communities, this result indicates that community leaders could represent an excellent source of health-related information and awareness of their availability in that role has increased after the Model implementation.



**FIGURE 1.2-5**: DISTRIBUTION OF PRE-POST MODEL IMPLEMENTATION RESPONSES TO "THERE ARE COMMUNITY LEADERS IN PLACE TO PROVIDE ME WITH INFORMATION AND RESOURCES ON RESPIRATORY HEALTH" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES).

The overall impressions of whether or not community leaders were paying enough attention to respiratory health issues did not change substantially after the Model implementation (Figure 1.2-6) in the follow-up communities. The largest change was a modest increase of eight percentage points in the proportion of respondents who agreed or strongly agreed that community leaders were paying attention to respiratory health issues faced by communities.

# Impact on community effort

When asked if the community is working together to improve respiratory health awareness, respondents from the five follow-up communities showed a modest shift to agreement (from 47% to 56%) and away from ambivalent responses (from 35% to 29%) (Figure 1.2-7). However, the number of community participants who were in disagreement with this statement has not been changed much.

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**FIGURE 1.2-6**: DISTRIBUTION OF PRE-POST MODEL IMPLEMENTATION RESPONSES TO "LEADERS ARE PAYING ENOUGH ATTENTION TO ISSUES RELATED TO RESPIRATORY HEALTH" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)



**FIGURE 1.2-7**: DISTRIBUTION OF PRE-POST MODEL IMPLEMENTATION RESPONSES TO "MY COMMUNITY IS WORKING TOGETHER TO ENSURE COMMUNITY MEMBERS KNOW THAT WE CAN ACHIEVE BETTER RESPIRATORY HEALTH" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

# Key Respiratory Health Awareness Findings

Based on the main results of the analysis of Respiratory Health Awareness scales, the following key observations were made *prior* to the implementation of the Model and its activities:

- About a quarter of respondents (**25%**) felt that community leaders were not in place to provide information on respiratory health issues and an additional **20%** did not have an opinion on the presence of leadership demonstrating a general lack of presence of leadership on respiratory health issues within their communities
- About **40%** of community members were disappointed with the amount of attention that leaders were paying to respiratory health issues and an additional one third were not aware of their leaders' priorities and perspectives regarding respiratory health
- About a third stated that their communities did not have enough respiratory health materials and that these materials were not available at various locations throughout the community
- Respondents showed a lack of awareness regarding materials available outside of their community and online. Among those who were aware, most agreed that there were excellent resources available.
- The majority of respondents from the participating communities (**58%**) felt that their community was not working together to increase awareness of respiratory health. In some communities, there were particularly high levels of respondents who had no opinion about community efforts regarding respiratory health.
- There was a difference among participating communities in regards to existing resources on respiratory health. In general, the community that had the most respiratory health information and support available prior to Model implementation was Postville (Inuit community). The communities with the least information and support available were Enoch (First Nations community) and Prince George (Metis community). The French speaking First Nations community (Wendake) showed high levels of ambivalent responses, indicating potentially lower levels of awareness of respiratory health issues.

Positive changes in community awareness of respiratory health and related issues were determined *after* the Model implementation as follows:

• There was an overall shift to more positive responses on every measure of respiratory health awareness

- There was a statistically significant increase in awareness and appreciation for online respiratory health resources and materials. This result indicates that most communities demonstrate potential for use of online resources for health awareness and education.
- A greater proportion of community members felt that there were enough resources and materials in their communities to deal with issues related to respiratory health (this increase was substantial but not statistically significant)
- The number of people who agreed that there were materials available at a variety of places within the community also increased after the Model implementation
- The Model implementation may have influenced both the availability and awareness of resources and support available from community leaders. There was an increase (from 62% to 74%) in the number of community members who agreed that community leaders could provide information and resources on respiratory health
- The overall impressions of whether or not community leaders were paying enough attention to respiratory health issues did not change substantially after the Model implementation, possible due to the short duration of the pilot intervention (3 months)
- There was a modest shift to agreement (from 47% to 56%) and away from ambivalent responses (from 35% to 29%) in regards to communities working together to achieve better respiratory health

# **Community Respiratory Health Support Scales**

Prior to the Model implementation, community members who were actively involved in the project or would like to provide more detailed feedback in each of the seven participating communities were also asked to complete a detailed survey to assess the support available in their community for improvements on respiratory health: the Community Respiratory Health Support scale (Appendix 50). As with the Respiratory Health Awareness scale discussed in section 1.2 of this report, the Respiratory Health Support scale was also administered after the Model implementation. Unlike the Respiratory Health Awareness scale, in this case, the same individuals were asked to complete the scale at both time points. As the response rate for the follow-up survey was 37%, the baseline results are presented separately in their entirety followed by a discussion of the pre/post paired results.

### **Baseline community support results**

A total of **106** baseline surveys were completed in the seven communities. As with the Respiratory Health Awareness scale, there were uneven numbers completed in each community (see details in Appendix 61, Table 14). Baseline Respiratory Heath support scales were analyzed by using similar data entry and analysis methods as discussed previously. The aggregate results are presented both as overall percentages and also as weighted average percentages to ensure that the communities with the higher number of survey completed did not skew the overall results. Where there is substantial community variation, community-specific distributions are presented and discussed. While the results tables are shown in the highest level of detail available, the discussion combines the categories of "strongly disagree" with "disagree" and "strongly agree" with "agree" for the purpose of interpretation.

#### Membership

Overall, respondents agreed (46%) or strongly agreed (13%) that community members were committed to improving respiratory health in their communities before the Model was implemented. However, the individual communities differed substantially in their answers (Table 1.3-1). Thus, Prince George, Saddle Lake, and Enoch communities had a notable number of respondents (27%, 25%, and 33%, respectively) that disagreed or strongly disagreed that community members were committed to improving respiratory health. Conversely, in Postville, Wendake, Conne River and Listuguj, none of the respondents felt a lack of communities, there were about a third of respondents who did not agree or disagree with this statement (Table 1.3.-1). This may indicate a lack of conversation around respiratory health and risk factors for chronic respiratory disease in most of the communities and a corresponding lack of awareness.

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville	0	0	33	50	17
(Inuit)					
Prince George	9	18	45	27	0
(Métis)					
Wendake	0	0	27	55	18

**TABLE 1.3-1**: SUMMARY OF RESPONSES TO "I FEEL MEMBERS OF MY COMMUNITY ARE COMMITTED TOIMPROVING RESPIRATORY HEALTH" BY COMMUNITY (PERCENT OF RESPONDENTS)

(First Nation, French)					
Listuguj	0	0	0	86	14
(First Nation)					
Conne River	0	0	21	43	36
(First Nation)					
Saddle Lake	8	17	33	38	4
(First Nation)					
Enoch	12	21	36	27	3
(First Nation)					
Overall percent	7	12	31	40	10
Weighted average percent	4	8	28	46	13

Further, respondents were asked if members of their communities would support their individual decisions to lead a healthier life and adopt a healthy lifestyle, including stop smoking and discontinue open burning. In general, most community members felt that they would have the support of fellow community members for all three categories (healthy lifestyle, stop smoking, and discontinue open burning), as shown in Figure 1.3-1. This motion was particularly stronger for leading a healthier life. Thus, the majority of respondents (**83%**) believed that fellow community members would offer them their support in this regard.

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**FIGURE 1.3-1**: DISTRIBUTION OF RESPONSES TO "I FEEL COMMUNITY MEMBERS WOULD SUPPORT MY DECISION TO LEAD A HEALTHIER LIFE" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

However, fewer respondents were sure of similar support when asked specifically about community support to stop smoking or open burning (23% and 42% neither agreed nor disagreed, respectively) (Figures 1.3-2 and 1.3.-3). The results indicate that leading a healthier lifestyle is a concept that is largely supported, but likely includes many particular factors. Respondents were less sure how their community members would react if they decided to quit smoking or stop open burning.

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**FIGURE 1.3-2**: DISTRIBUTION OF RESPONSES TO "I FEEL THAT IF I STOPPED SMOKING, COMMUNITY MEMBERS WOULD BE SUPPORTIVE" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

In regard to discontinuing open burning, community members were less sure if they would have receive the same level of support from other members of their community, indicating potential sensitivity of this issue (Figure 1.3.-3).



**FIGURE 1.3-3**: DISTRIBUTION OF RESPONSES TO "I FEEL THAT IF I STOPPED OPEN BURNING, COMMUNITY MEMBERS WOULD BE SUPPORTIVE" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

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#### Shared influence

Respondents were posed with a set of questions to assess the perception of shared influence within the community. For example, they were asked about their ability to help create or influence policies to improve the respiratory health of their communities (Table 1.3-2). Overall, **35%** of respondents did not agree that they would be able to help create such policies, including 28% who were unsure.

These results vary by community with respondents from three communities: Prince George, Saddle Lake, and Enoch who mostly disagreed or unsure about this statement. Conversely, in Postville, Wendake, and Conne River communities, respondents, agreed or strongly agreed that they could help create policies to improve community respiratory health (84%, 82%, and 93%, respectively). While the majority (58%) of Listuguj respondents agreed or strongly agreed about their ability to help create policies, at the same time, 43% neither agreed nor disagreed about their ability to help create policies (Table 1.3.-2).

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville	0	0	17	67	17
(Inuit)					
Prince George (Métis)	0	27	36	36	0
Wendake	0	0	18	73	9
(First Nation, French)					
Listuguj	0	0	43	29	29
(First Nation)					
Conne River	0	0	7	93	0
(First Nation)					
Saddle Lake	8	0	46	46	0
(First Nation)					
Enoch	0	15	27	45	12

**TABLE 1.3-2**: Summary of responses to "I feel I can help create policies to improve theRespiratory health of my community" (Weighted percent of respondents, all communities)

(First Nation)					
Overall percent	2	8	29	54	8
Weighted average percent	1	6	28	55	9

Overall, the majority of respondents in all communities (83%) agreed that when people of their community get together, they can achieve their respiratory health goals (Figure 1.3-4). Respondents reported similar positive perceptions when asked specifically about working together to improve outdoor air quality (indicated by 69% of participants) and indoor air quality (indicated by 79% of participants) (see Appendix 62, Figures 1 and 2, respectively). These results suggest and optimism and a pre-existing high level of social cohesion within the communities on which to build during the Model implementation.



**FIGURE 1.3-4**: DISTRIBUTION OF RESPONSES TO "WHEN PEOPLE IN MY COMMUNITY GET TOGETHER, THEY CAN ACHIEVE THEIR RESPIRATORY HEALTH GOALS" (WEIGHTED PERCENT OF RESPONDENTS FROM ALL COMMUNITIES)

When participants were asked if help exists in the community for an individual with a serious respiratory health problem, overall, the majority of respondents (60%) believed that this kind of help would be available.

Despite the above overall optimism about the availability of help for people with serious respiratory health problems, this differed substantially by community (Table 1.3-3). While respondents from some communities (Postville, Prince George, Wendake, and Conne River) mostly agreed or strongly agreed that help for people with chronic respiratory disease was available within the community, the majority of participants from Listuguj, Enoch, and Saddle Lake and did not (72%, 66%, and 66%, respectively). This further confirms that the participating communities had different perceptions about support available for community members with chronic respiratory disease at the community level before Model implementation (Table 1.3 -3).

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville (Inuit)	0	17	17	67	0
Prince George (Métis)	0	9	0	82	9
Wendake (First Nation, French)	0	0	18	55	27
Listuguj (First Nation)	14	29	29	14	14
Conne River (First Nation)	0	0	7	57	36
Saddle Lake (First Nation)	8	25	33	25	8
Enoch (First Nation)	3	21	48	21	6
Overall	4	16	28	39	13
Weighted average	4	14	22	46	14

**TABLE 1.3-3**: Summary of responses to "If someone has a serious respiratory health problem,THEY CAN GET HELP FOR IT IN MY COMMUNITY" BY COMMUNITY (PERCENT OF RESPONDENTS)

#### percent

#### Help in case of need

The Respiratory Health Support Scale (Appendix 50) asked respondents several additional questions about the availability of help within the community in case of need. In general, **43%** of respondents agreed that it would be hard to mobilize the community and get their communities to do things to help improve the respiratory health of community members and almost one quarter of respondents were not sure about it (Figure 1.3-5).



**FIGURE 1.3-5**: DISTRIBUTION OF RESPONSES TO "IT WOULD BE HARD TO GET MY COMMUNITY TO DO THINGS TO HELP IMPROVE THE RESPIRATORY HEALTH OF COMMUNITY MEMBERS" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

In general, the majority of respondents (68%) agreed or strongly agreed that they could personally contact a community member if they needed information about respiratory health (Figure 1.3-6).

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**FIGURE 1.3-6**: DISTRIBUTION OF RESPONSES TO "I FEEL I COULD CONTACT A COMMUNITY MEMBER (CHAMPION) IF I NEEDED INFORMATION ABOUT RESPIRATORY HEALTH" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

In some communities, the majority of respondents agreed or strongly agreed that people with respiratory health problems could turn to other people in the community for help (Table 1.3-4). However, in Listuguj and Saddle Lake communities, a substantial proportion of respondents disagreed (29% and 21%, respectively).

Of note, overall, over one quarter of the respondents did not agree or disagree, with over a third of respondents in Conne River and Enoch communities (36% both) being unsure about whether people with respiratory health problems could turn to other community members for help.

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville	0	17	17	67	0
(Inuit)					
Prince George	0	0	18	82	0
(Métis)					
Wendake	0	9	18	55	18
(First Nation, French)					
Listuguj	0	29	29	29	14
(First Nation)					

**TABLE 1.3-4**: Summary of responses to "Community members who have problems with theirRespiratory health can turn to people in the community for help" by community: Percent ofRespondents

Conne River	0	0	36	43	21
Saddle Lake	8	21	25	38	8
(First Nation) Enoch	0	12	36	48	3
(First Nation)					
Overall	2	12	28	49	8
Weighted average percent	1	12	26	51	9

When specifically asked if communities would be willing to help improve air quality in someone's home, overall, the majority of participants (**58%**) stated that either their community would not be willing to help community members to improve the air quality in their home (23%) or were not sure whether or not their community would be willing to help (34%) (Table 1.3-5).

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville	0	33	17	50	0
(Inuit)					
Prince George	0	45	36	18	0
(Métis)					
Wendake	0	0	55	36	9
(First Nation, French)					
Listuguj	0	14	29	43	14
(First Nation)					
Conne River	0	0	29	50	21
(First Nation)					
Saddle Lake	13	25	38	25	0
(First Nation)					
Enoch	6	21	33	36	3
(First Nation)					
Overall	5	20	35	35	6

**TABLE 1.3-5**: Summary of responses to "IF a community member needed to improve air quality in their home, my community would be willing to help them" by community (Percent of Respondents)

Weighted average percent	3	20	34	37	7

Similar results were seen for the communities' willingness to help with the negative impacts of open burning (Table 1.3-6). Notably, a higher proportion of respondents stated "neither agree nor disagree" for community members' willingness to help with open burning. On both questions, communities differed in the patterns of their responses (Tables 1.3-5 and 1.3-6). These results may indicate a lack of awareness and open discussion about issues, particularly open burning. Alternatively, it may also indicate that these issues are not perceived as substantial concerns at the community level.

		Chuckally	$\mathbf{D}$ : $\mathbf{D}$	Na:thau	A	Chuchall
COMMUNITY (H	PERCENT OF RES	PONDENTS)				
IMPACTED BY O	OPEN BURNING, I	PEOPLE IN MY	COMMUNITY WC	ULD BE WILLING	G TO HELP TH	ЕМ" ВҮ
TABLE 1.3-6: 3	SUMMARY OF RE	ESPONSES TO '	IF A COMMUNIT	Y MEMBER'S HE	ALTH WAS NE	GATIVELY

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville	0	17	33	50	0
(Inuit)					
Prince George	0	36	45	18	0
(Métis)					
Wendake	0	10	60	30	0
(First Nation, French)					
Listuguj	0	29	14	43	14
(First Nation)					
Conne River	0	0	38	46	15
(First Nation)					
Saddle Lake	13	13	42	33	0
(First Nation)					
Enoch	6	15	42	33	3
(First Nation)					
Overall	5	15	41	35	4
Weighted average percent	3	17	39	36	5

#### Social climate

Respondents were asked questions related to social climate to assess the perception of community support and comfort level in regards to respiratory health issues. Overall, **41%** of the respondents were unsure if community members were comfortable sharing information about their respiratory health and about one quarter thought that community members were not comfortable with sharing this information (Figure 1.3-7).

When further asked about their own individual comfort level of talking about personal respiratory health concerns, respondents showed a higher tendency to agree, with 59% saying that they were comfortable (Figure 1.3-8).



**FIGURE 1.3-7**: DISTRIBUTION OF RESPONSES TO "COMMUNITY MEMBERS ARE COMFORTABLE SHARING INFORMATION ABOUT THEIR RESPIRATORY HEALTH" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)


**FIGURE 1.3-8**: DISTRIBUTION OF RESPONSES TO "I FEEL COMFORTABLE TALKING TO COMMUNITY MEMBERS ABOUT MY RESPIRATORY HEALTH CONCERNS" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

Correspondingly, 55% disagreed or strongly disagreed that it was difficult to discuss personal or familial breathing problems with community members (Figure 1.3-9).

For both of the above questions about individual comfort level in discussing respiratory health concerns, almost one-third (30% and 28%, respectively) said that they "neither agree nor disagree", indicating a potential lack of community conversation, lack of individual awareness, or lack of individual concern about respiratory health issues.

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**FIGURE 1.3-9**: DISTRIBUTION OR RESPONSES TO "IT IS DIFFICULT FOR ME TO TALK TO COMMUNITY MEMBERS ABOUT MY BREATHING OR MY FAMILY'S BREATHING PROBLEMS" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

Respondents were also asked whether community members would support their decisions to create a smoke-free home and to get tested for a respiratory disease. While over one quarter of respondents (28% for both questions) were unsure of community member support for both of these decisions, most agreed (41% and 54%, respectively) or strongly agreed (25% and 13%, respectively) that they would have the support of community members for smoke-free homes and respiratory disease testing (see Figures 3 and 4, Appendix 63).

### **Community capacity**

Respondents were asked about the capacity of their communities to support a healthier lifestyle. Overall, 36% of respondents agreed or strongly agreed that it is difficult to try to live a healthier lifestyle in their communities (Table 1.3-7). Notably, in some communities, this number of respondents was higher with 56% of respondents from Saddle Lake, 43% from Listuguj, and 36% from each of Prince George and Enoch reported that it is difficult to try to live a healthier lifestyle in their communities.

**TABLE 1.3-7**: SUMMARY OF RESPONSES TO "IN THIS COMMUNITY, IT IS DIFFICULT TO TRY TO LEAD AHEALTHIER LIFE" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville (Inuit)	0	67	33	0	0
Prince George (Métis)	9	18	36	36	0
Wendake (First Nation, French)	27	36	9	9	18
Listuguj (First Nation)	14	14	29	29	14
Conne River (First Nation)	0	64	36	0	0
Saddle Lake (First Nation)	13	0	30	39	17
Enoch (First Nation)	3	21	39	27	9
Overall	9	26	32	24	10
Weighted average percent	10	26	32	24	10

In addition, community members were asked if their community makes it easy to work towards better respiratory health. While 38% of the respondents agreed that their specific community makes it easy to work towards better respiratory health, nearly half (47%) neither agreed nor disagreed and additional 15 % disagreed or strongly disagreed. (Figure 1.3-10).

These findings indicate that the general climate for health awareness, promotion and education in the several of the pilot communities may have been unsupportive or underdeveloped prior to the Model implementation.

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**FIGURE 1.3-10**: DISTRIBUTION OR RESPONSES TO "THIS COMMUNITY MAKES IT EASY TO WORK TOWARDS BETTER RESPIRATORY HEALTH" (WEIGHTED PERCENT OF RESPONDENTS , ALL COMMUNITIES)

Respondents were asked about the availability of materials and programs on respiratory health at the community level in case a community member needs help in regards to respiratory health. In general, approximately one third (32%) disagreed that excellent materials and programs were available in their communities to help with respiratory health-related needs with almost the same number of respondents (33%) agreeing with this statement. An additional 35% neither agreed nor disagreed showing a possible lack of awareness about respiratory health programs available in the community.

These results varied by community, as shown in Table 1.3-8. Specifically, a lack of excellent community resources was reported by approximately half of the respondents in Listuguj (57%), Enoch (51%) and Saddle Lake (50%) communities. In Postville, 67% of respondents neither agreed nor disagreed about the availability of excellent materials and programs for help with respiratory health, indicating either a lack of awareness or ambivalence about the effectiveness of existing resources.

**TABLE 1.3-8**: Summary of responses to "If I need help with my respiratory health, there areEXCELLENT MATERIALS AND PROGRAMS THAT EXIST IN MY COMMUNITY TO MEET MY NEEDS" BYCOMMUNITY (PERCENT OF RESPONDENTS)

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville (Inuit)	0	17	67	17	0
Prince George (Métis)	0	27	36	36	0
Wendake (First Nation, French)	0	9	27	45	18
Listuguj (First Nation)	14	43	29	14	0
Conne River (First Nation)	0	7	36	50	7
Saddle Lake (First Nation)	21	29	21	25	4
Enoch (First Nation)	18	33	30	18	0
Overall	11	25	31	28	4
Weighted average percent	8	24	35	29	4

When asked about materials and programs to help with information on how to maintain good indoor air quality specifically, overall, 30% of participants disagreed that there were existing materials and programs available to meet their needs. A further **45%** of respondents neither agreed nor disagreed (Figure 1.3-11). This could indicate an overall lack of information regarding indoor air quality, a lack of awareness about existing information or the inability of existing resources to meet the community members' needs on indoor air quality information and education.



**FIGURE 1.3-11**: DISTRIBUTION OR RESPONSES TO "IF I NEEDED HELP WITH MY INDOOR AIR QUALITY, THERE ARE MANY EXISTING MATERIALS AND PROGRAMS TO MEET MY NEEDS" (WEIGHTED PERCENT OF RESPONDENTS, ALL COMMUNITIES)

Regarding information and resources on outdoor air quality, **45%** of respondents reported that it would be difficult to convince community members to stop open burning or idling (Table 1.3-9). Another 39% did not have a definite opinion about the issue and, showing a lack of dialogue on issues related to outdoor air quality at the community level.

When looking at community-specific answers to this question, the majority or at least half of respondents from Prince George (73%), Enoch (67%), Wendake (55%), and Saddle Lake (50%) communities felt this way. In some communities, there were a higher number of participants who were unsure if it would be difficult to convince community members to stop open burning or idling. This sentiment was particularly strong in Conne River and Postville communities, where 64% and 50% were uncertain, respectively. This could indicate a general lack of conversation in the community about open burning and idling or it could indicate that open burning and idling are not perceived as possible concerns in these communities.

	Strongly Disagree (%)	Disagree (%)	Neither Agree nor Disagree (%)	Agree (%)	Strongly Agree (%)
Postville (Inuit)	0	17	50	33	0
Prince George (Métis)	0	9	18	55	18
Wendake (First Nation, French)	0	0	44	33	22
Listuguj (First Nation)	14	29	43	14	0
Conne River (First Nation)	0	14	64	21	0
Saddle Lake (First Nation)	8	13	29	25	25
Enoch (First Nation)	3	6	24	58	9
Overall	4	11	35	38	13
Weighted average percent	4	12	39	34	11

**TABLE 1.3-9:** Summary of responses to "It would be difficult to get community members tostop open burning or idling" by community (Percent of respondents)

## **Follow-up results**

In pilot communities, the Respiratory Health Support Scale was repeated following the Model implementation with the same individuals who completed the baseline survey. The two communities where the survey will be still re-administered in August 2012 are Saddle Lake and Enoch as they have been supported by the complementary funding received form AllerGen NCE Inc. Overall, **42** post-implementation forms were completed (the response rate -37%), 39 of which could be matched to a pre-implementation survey and, therefore, were included as a follow-up survey in the analysis of post-implementation results.

For follow-up analysis, the 39 paired surveys were analyzed and a community breakdown is presented in Appendix 61, Table 14. Ratings were assigned numbers where 1=strongly disagree, 2=disagree, 3=neither agree nor disagree, 4=agree and 5=strongly agree. The pre and post implementation results were presented as the percentage of individual respondents, who increased their agreement rating on the scale, decreased their rating or stayed the same for each question. Wilcoxon matched pairs tests (with alpha set at 0.05) were used to determine if the median response to each question was the same pre- and post-Model implementation. Results were imported into Microsoft Excel where graphs for the pre-and post-implementation overall and community-specific results were created. Final results were checked against the output from Stata 7 and Excel, as appropriate.

### Impact on membership

At baseline, the agreement ratings were fairly high for all membership measures such as: collective community commitment to improve respiratory heath; community support towards a personal decision to lead a healthier lifestyle; support to someone's decision to stop smoking and open burning. Following implementation of the Model, there was a slight further positive change with participants shifting to a higher level of agreement. None of the changes in average ratings were statistically significantly different.

Figure 1.3-12 shows the percentage of respondents who decreased, retained and increased their rating for each question. Almost half of respondents did not change their ratings and approximately one third reported a higher level of agreement with the statements following the implementation of the Model. While interpreting, these results should take into consideration the initial fairly high level of agreement determined before the Model implementation.

Notably, the percentage of people who reported "neither agree nor disagree" reduced by between 9 and 14 percentage points for each question except for the question regarding community support for a healthier life, which increased by 5 percentage points.



**FIGURE 1.3-12**: PAIRED CHANGE IN RATINGS FOR MEASURES OF MEMBERSHIP, PRE AND POST MODEL IMPLEMENTATION IN FOLLOW-UP COMMUNITIES

#### Impact on shared influence

In general, the baseline results showed high ratings on measures of the communities' shared influence. The results were largely unchanged in the follow-up survey except for one item: the perceived availability of help within the community for someone with a serious respiratory health problem (Figure 1.3-13). For this category, **41%** of the respondents increased their rating at follow-up. The increased positive response was statistically significant (p=0.0157)<sup>4</sup>.

The percentage of people who reported "neither agree nor disagree" was also reduced by between 9 and 14 percentage points for each question except for the question regarding community support for a healthier life, which increased by 5 percentage points.

<sup>&</sup>lt;sup>4</sup> Statistically significant: median response differ between pre and post implementation (Wilcoxon matched pairs test)

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**FIGURE 1.3-13**: PAIRED CHANGE IN RATINGS FOR MEASURES OF SHARED INFLUENCE, PRE AND POST MODEL IMPLEMENTATION IN FOLLOW-UP COMMUNITIES

#### Impact on help in case of need

Following the Model implementation, over half (53%) of the respondents increased their rating related to community willingness to help reduce the negative effects of open burning. Additionally, 46% of participants increased their agreement rating related to the willingness of the community to provide help in improving indoor air quality in their homes (Figure 1.3-14). These both increases in agreement ratings were both statistically significant (p=0.0019 and p=0.0226)<sup>1</sup>. In addition, the already high baseline rating for being able to contact a community member for information further increased significantly despite 51% of the respondents having unchanged responses (p=0.0306).

### Impact on social climate

The ratings related to social climate generally increased or stayed the same. For most of the measures, over one third of respondents increased their agreement rating at follow-up (Figure 1.3.-15). For one measure, community members being comfortable sharing information about their respiratory health, there were a substantially lower percentage of respondents who decreased their agreement level. This resulted in a statistically higher median rating at follow-up (p=0.0087).

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**FIGURE 1.3-14**: PAIRED CHANGE IN RATINGS FOR MEASURES OF HELP IN CASE OF NEED, PRE AND POST MODEL IMPLEMENTATION IN FOLLOW-UP COMMUNITIES



FIGURE 1.3-15: PAIRED CHANGE IN RATINGS FOR MEASURES OF SOCIAL CLIMATE, PRE AND POST MODEL IMPLEMENTATION IN FOLLOW-UP COMMUNITIES

#### Impact on community capacity

As Figure 1.3-16 shows, there were clear increases in perceptions of the materials and programs available, with nearly half of respondents increasing their agreement ratings following Model implementation. This also corresponded to a statistically significant increase in average ratings for the availability of materials and programs: for help with indoor air quality (p=0.0025) and for help with respiratory health (p=0.0151)<sup>5</sup>.



**FIGURE 1.3-16**: PAIRED CHANGE IN RATINGS FOR MEASURES OF COMMUNITY CAPACITY, PRE AND POST MODEL IMPLEMENTATION IN FOLLOW-UP COMMUNITIES

Additionally, a substantial shift from the high proportions of "neither agree nor disagree" responses observed at baseline is seen here. Respondents, on average, reduced this rating by 20 percentage points for the questions on community capacity, indicating a heightened awareness and increased conversation about respiratory health.

<sup>&</sup>lt;sup>5</sup> Statistically significant: median response differ between pre and post implementation (Wilcoxon matched pairs test)

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## Key respiratory heath support findings

Some of the measures of community support based on the Respiratory Health Support scale (Appendix 50) demonstrated quite high levels before the Model implementation. The following categories/statements were rated fairly highly before the intervention:

- The sense of community help was strong in regards to getting support towards leading a healthier lifestyle. The majority of community members (83%) believed that this kind of support would be available from their fellow members. Community members also believed that they would have necessary support to stop smoking, create a smoke-free home, and get respiratory disease testing.
- All communities felt strength in collective action and optimism that people of their community could work together to improve respiratory health in general and specifically outdoor air quality and indoor air quality in their communities.
- Overall, almost **60%** believed that necessary help would be available for people with serious respiratory health problems at the community level; however, this response differed across communities and some communities were less certain about access to and availability of this kind of resources.
- Personal support available from the fellow community members was also rated at a high level, with **68%** of participants agreeing or strongly agreeing that they could personally contact a community member if they needed information about respiratory health.

Although community members stated that general support related to respiratory health would be available in their communities, some of the specific categories were rated on a lower level or the respondents did not have a definite opinion about them ("neither agree nor disagree"). These findings may indicate a lack of community conversation about and support for respiratory health and associated risk factors in most of the communities and a corresponding lack of activity, awareness and/or individual concern about respiratory health issues. Here are some categories of community support that were assessed less favorably by the project participants before the Model implementation:

• Despite the high level of agreement towards the general community support to have a healthier life, respondents were less sure how their fellow community members would react to specific activities (e.g., if they decided to stop open burning or idling) or efforts to curb these practices. These results may indicate a lack of awareness and open discussion about certain issues, particularly open burning. Alternatively, it may also indicate that this issue is not perceived as a substantial concern at the community level.

- At the same time, **36%** of respondents noted (agreed or strongly agreed) that it was difficult to lead a healthy lifestyle in their communities
- The majority of participants (57%) also said that either their community would not be willing to help community members to improve the air quality in their home (23%) or were not sure whether or not their community would be willing to help (34%)
- Results also indicate that there is an overall lack of information regarding indoor air quality, a lack of awareness about existing information on the topic or the availability of existing resources to meet the community members' needs on indoor air quality information and education. Thus, 30% of participants disagreed that there were existing materials and programs on indoor air quality that could meet their needs and a further 45% of respondents provided ambivalent responses
- In most communities, there were about a third of respondents who were unsure if their community was committed to improving respiratory health and half were unsure whether or not their community makes it easy to work towards this improvement
- Overall, **35%** of respondents did not agree or were not sure that they would be involved and able to help create community policies related to respiratory health showing a lack of confidence in individual influence in helping address respiratory health issues
- Overall, **43%** of respondents agreed that it would be hard to mobilize their community to implement activities aimed to improve respiratory health of community members and almost one quarter of respondents did not have a clear opinion about it
- Overall, over one quarter of the respondents was unsure whether people with respiratory health problems could turn to other community members for help and support. This number was higher in some communities (e.g., 36% of respondents in Conne River and Enoch)
- Overall, **41%** of the respondents were also unsure about the support and comfort level within their community for conversation and information sharing about respiratory health and about one quarter (**24%**) thought that community members were not comfortable sharing this kind of information. They were more confident in their individual ability to share personal respiratory health information comfortably.
- In general, there is a split between community members who think that excellent materials and programs were available in their communities to help with respiratory health-related needs (33%) and the number of them who disagreed with this statement (32%). An additional 35% neither agreed nor disagreed, indicating either a lack of awareness or ambivalence about the effectiveness of existing resources on respiratory health.

These findings indicate that there were potential gaps in services and support on respiratory health available for community members. Participating communities varied in their level of commitment to respiratory health and some communities were more prepared than others to support community respiratory health. The results also showed that there was a lack of dialogue at the community level on particular issues, namely outdoor air quality, open burning and idling. Another possibility is that these issues were not perceived as the main concerns affecting respiratory health in these communities. The pre-Model implementation results showed that there was general community support towards leading a healthier lifestyle and a supportive climate for health awareness, promotion and education; however, this support appeared to be underdeveloped or not in existence in the several communities prior to the pilot Model implementation.

After the intervention, there were positive changes in community members' perception about community support and services related to respiratory health. Thus, there was a slight further positive change with a higher level of agreement on categories related to community membership and commitment to improving respiratory heath such as community support towards a personal decision to lead a healthier lifestyle; support to someone's decision to stop smoking, and discontinue open burning. The ratings related to social climate also generally increased or stayed the same, with over one third of respondents increasing their agreement rating at follow-up for most of the measures within this category. Other significant changes after the Model implementation included the following:

- Increase in perceived availability of help within the community for someone with a serious respiratory health problem: **41%** of the respondents increased their rating at follow-up. This positive increase was statistically significant (p=0.0157).
- Over half (**53%**) of the respondents increased their rating related to community willingness to help reduce the negative effects of open burning. This increase was statistically significant.
- Additionally, **46%** of participants increased their agreement rating related to the willingness of the community to provide help in improving indoor air quality in their homes. This increase was statistically significant.
- There are clear increases in perceptions of the materials and programs on respiratory health available at the community level, with nearly half of respondents increasing their agreement ratings following Model implementation.
- There is a statistically significant increase in average ratings for the availability of materials and programs: for help with indoor air quality issues (p=0.0025) and for help with respiratory health (p=0.0151).

- Project participants reduced their uncertain rating in regards to community capacity on average, by 20 percentage points, indicating a heightened awareness and increased conversation about respiratory health at the community level.
- A significant increase in the ability to contact a community members for information on respiratory health and the community members' comfort level in sharing information about their respiratory health

# **Community Capacity Building Tool**

Each of the seven communities that participated in the pilot project was asked to complete the Community Capacity Building Tool (CCBT) before and after Model implementation (Appendix 47). Using this tool, the communities assess nine features of their community capacity: Participation, Leadership, Community structures, Role of external support, Asking why, Obtaining resources, Skills/knowledge/learning, Linking with others, and Sense of community. The tool asks communities to rate their progress on a 4-point scale that includes "just started", "on the road", "nearly there", and "we are there".

## **Baseline results**

All seven of the pilot communities completed baseline assessments of their community capacity using the Community Capacity Building Tool. Results were analyzed using the same statistical methods and programs as described previously in this chapter. Tables were created in Microsoft Word depicting the frequency and community names by rating level for each question. Qualitative comments provided were also extracted into Microsoft Word and manually summarized for each question. Where responses were similar, they were combined appropriately.

### Participation

In general, prior to Model implementation, most of the communities were in the early stages of engaging their community members in the project (Table 1.4-1). Prince George and Enoch communities were just getting started on all aspects of building community participation in the project.

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	Just started	On the road	Nearly there	We're there
Have you actively involved community organizations in your project?	<b>2</b> Prince George Enoch	3 Postville Listuguj Saddle Lake	0	<b>2</b> Wendake Conne River
Have you actively involved a representative range of community members in your project?	<b>2</b> Prince George Enoch	<b>2</b> Postville Saddle Lake	1 Listuguj	<b>2</b> Wendake Conne River
Have you overcome barriers for community members in the project?	4 Postville Listuguj Prince George Enoch	1 Saddle Lake	2 Wendake Conne River	0
Are you using different methods to inform everyone about the project?	<b>2</b> Prince George Enoch	1 Saddle Lake	<b>1</b> Listuguj	<b>3</b> Postville Wendake Conne River

# **TABLE 1.4-1**: Community responses to measures of participation pre-implementation of the model (Number and List of Communities)

Most communities (five out of seven) reported 'just starting' or being 'on the road' in regards to using different methods to inform community members about this initiative. This also applied to involving a representative range of community members, and involving community organizations in the project. In their comments, communities mentioned reaching out to specific organizations (Health and Justice Departments, seniors homes, youth centres/organizations, schools, etc.), and inviting youth, Elders, and parents to participate in project activities. Outreach methods for informing community members listed in the tool included the following:

- Newsletter ads
- Meetings and attending community events
- Posted notices
- Radio station announcements
- Email communication and online resources
- Mail-outs
- Word of mouth

• Organizing displays in public places

Some communities were also just starting or on the road to work on overcoming barriers for community members to be involved in the project. Barriers included need for transportation, convenient meeting places and times, prepaid phone cards, after school care, community database, and ways to increase motivation. Delays, caused by waiting for project approvals at the community level, were also noted as a barrier.

## Leadership

Overall, communities were also in early stages of developing and nurturing community leaders prior to implementation of the Model. Four of seven communities had not yet defined key roles and responsibilities of leaders in the project and had not yet identified the informal leaders in the community (Table 1.4-2). Key leaders that communities were involving include those from partner organizations and Council members.

**TABLE 1.4-2**: Community responses to measures of leadership pre-implementation of theMODEL (NUMBER AND LIST OF COMMUNITIES)

	Just started	On the road	Nearly there	We're there
Have you defined the key roles and responsibilities of project and community leaders involved in the project?	4 Prince George Listuguj Saddle Lake Enoch	1 Postville	1 Wendake	1 Conne River
Have you encouraged and supported the involvement of informal leaders in the community in the project?		0	2 Wendake Conne River	1 Postville

### **Community structures**

Most communities were in very early stages of connecting with existing community structures and developing new ones (Table 1.4-3). Four communities were not yet aware of other existing groups and committees that needed to be involved in the project. Further, five out of seven communities had not yet considered how the project would support the formation of new structures. Existing community structures and organizations that were working on the project included friendship centres, smoking cessation programs, public health, health centres, schools, youth organizations, and other community-based programs.

	Just started	On the road	Nearly there	We're there
Have you developed links with pre-existing community structures?	4 Prince George Listuguj Saddle Lake Enoch	0	1 Postville	2 Wendake Conne River
Have you created new community structures that help community members?	5 Postville Prince George Listuguj Saddle Lake Enoch	0	1 Wendake	1 Conne River

# **TABLE 1.4-3**: COMMUNITY RESPONSES TO MEASURES OF COMMUNITY STRUCTURES PRE-IMPLEMENTATIONOF THE MODEL (NUMBER AND LIST OF COMMUNITIES)

### **External Supports**

All communities were asked if they receive project-related information from external supports. Five communities reported not knowing yet that external supports could provide such information (Table 1.4.-5). Those who were receiving external information were seeking it from provincial or federal government departments, the Asthma Society of Canada, the Lung Association, and local healthcare providers and hospitals.

**TABLE 1.4-4**: COMMUNITY RESPONSES TO MEASURES OF EXTERNAL SUPPORT PRE-IMPLEMENTATION OFTHE MODEL (NUMBER AND LIST OF COMMUNITIES)

	Just started	On the road	Nearly there	We're there
Do external supports provide you with project- related information?	5 Postville Prince George Listuguj Enoch Saddle Lake	0	0	<b>2</b> Wendake Conne River

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#### Asking why?

The communities were generally just starting to think about the root causes of respiratory health issues in their communities (Table 1.4-5). In particular, three of the communities (Prince George, Saddle Lake and Enoch) had not given thought to finding root causes and/or solutions or involving the community in those processes. Two additional communities (Postville and Listuguj) had made some initial efforts to begin this work. Conne River and Wendake reported being well on their way to asking why.

	Just started	On the road	Nearly there	We're there
Have you explored the root causes of issues targeted by your project?	4 Postville Prince George Saddle Lake Enoch	1 Listuguj	1 Wendake	1 Conne River
Have you involved the community in the process of asking why?	3 Prince George Saddle Lake Enoch	<b>2</b> Postville Listuguj	1 Conne River	1 Wendake
Have you involved the community in finding solutions to root causes of issues?	5 Postville Prince George Listuguj Saddle Lake Enoch	1 Conne River	1 Wendake	0

**TABLE 1.4-5**: COMMUNITY RESPONSES TO MEASURES OF ASKING WHY PRE-IMPLEMENTATION OF THEMODEL (NUMBER AND LIST OF COMMUNITIES)

#### **Obtaining resources**

With the exception of Wendake and Conne River, the communities had not yet identified (or had just begun to identify) resources outside of the community that could contribute to the project's success (Table 1.4.-6). Besides the ASC, communities noted key external resources such as Friendship Centres, provincial Lunch Associations, hospitals, government health departments, and partner agencies as relevant resources.

 TABLE 1.4-6: COMMUNITY RESPONSES TO MEASURES OF OBTAINING RESOURCES PRE-IMPLEMENTATION OF

 THE MODEL (NUMBER AND LIST OF COMMUNITIES)

	Just started	On the road	Nearly there	We're there
Do you have access to external resources needed for the project's success?	<b>4</b> Postville Prince George Saddle Lake Enoch	1 Listuguj	0	2 Wendake Conne River

#### Skills, Knowledge, and Learning

In general, participating communities were in early stages of building skills, knowledge, and learning related to respiratory health (Table 1.4-7). Four communities (Prince George, Listuguj, Saddle Lake and Enoch) had not yet provided learning opportunities for their community and community members. Examples of learning opportunities communities were planning to conduct included presentations, distributing information about the project, working with other community agencies and offering a training course to community leaders.

**TABLE 1.4-7**: COMMUNITY RESPONSES TO MEASURES OF SKILLS, KNOWLEDGE AND LEARNING PRE-IMPLEMENTATION OF THE MODEL (NUMBER AND LIST OF COMMUNITIES)

	Just	On the	Nearly	We're
	started	road	there	there
Have you provided the community and	4	1	2	0
community members with opportunities for learning?	Prince George Listuguj Saddle Lake Enoch	Conne River	Postville Wendake	

### Linking with Others

In general, more communities were further along the capacity continuum with respect to linking with others compared with other categories of community capacity building tool (Table 1.4-8). The notable exceptions were Prince George, Saddle Lake and Enoch communities, where they had not yet considered who they could be networking with and what information could be shared to support the project. In Listuguj, they had determined who to network with and what information to share but they had not yet acted on that.

The pilot communities who were actively linking with others reported working with community governments, provincial health departments, seniors' homes, Friendship Centres, smoking cessation programs, public health clinics and schools, health centres, and youth organizations.

	Just started	On the road	Nearly there	We're there
Are you networking with diverse sectors to gain support for the project?	3 Prince George Saddle Lake Enoch	1 Listuguj	3 Postville Wendake Conne River	0
Have you provided information to the project links?	3 Prince George Saddle Lake Enoch	1 Listuguj	2 Postville Conne River	1 Wendake
Have you received information from your project links?	4 Prince George Listuguj Saddle Lake Enoch	0	2 Postville Conne River	1 Wendake

**TABLE 1.4-8**: COMMUNITY RESPONSES TO MEASURES OF LINKING WITH OTHERS PRE-IMPLEMENTATION OFTHE MODEL (NUMBER AND LIST OF COMMUNITIES)

#### **Sense of Community**

Several of the communities had not yet considered how the project could contribute to a sense of community among community members (Prince George, Saddle Lake and Enoch) (Table 1.4.-9). In Listuguj, the team saw the benefit of building community capacity, but did not know yet how to proceed. The other three communities (Postville, Wendake and Conne River) were actively in the process of building a sense of community among community members. They were doing this through their community-based advisory groups, their community Respiratory Health Champions, as well as by holding community events, and attending community gatherings.

**TABLE 1.4-9**: Community responses to measures of sense of community pre-implementation ofTHE MODEL (NUMBER AND LIST OF COMMUNITIES)

	Just started	On the road	Nearly there	We're there
Does your project contribute to a sense of	3	1	3	0
community among community members?	Prince George Saddle Lake	Listuguj	Postville Wendake	



# Follow-up results

Five of the seven communities (Postville, Prince George, Listuguj, Enoch, and Conne River) completed the Community Capacity Building Tool after the Model implementation. The Saddle Lake community in Alberta is planning to re-administer the tool in August 2012 according to the plan approved by AllerGen NCE Inc.

Follow-up CCBT forms were entered into the same database as the baseline forms, with a tag for "follow-up". The pre and post ratings for each community and question were extracted and imported into Microsoft Excel. Results for each community were summarized separately in a graph.

Overall, the post-implementation results demonstrate a shift towards enhanced community capacity for addressing issues related to respiratory health. Key success factors appeared to be integrating or linking the work of the project with existing community structures and organizations. Communities found interesting ways to engage community members, including art contests, flyers, development of personal digital stories, information sessions, and bingo games. Communities reported on efforts to attract diverse group members, including the challenge of engaging some specific groups such as men and youth. Motivating people to participate and to volunteer was also discussed as a challenge. Challenges associated with linking to other sectors and groups, within and outside the communities, were also noted. One community noted significant technological issues that made working and communicating on this project challenging.

The specific post-implementation results for each community are best understood in the context of the pre-implementation responses. Figures 1.4-1 to 1.4-5 show the pre and post implementation results for each CCBT category by community. The questions for each figure are ordered according to the community's pre-implementation response from lowest ("just started") to highest ("we're there").

Postville's pre-implementation profile was mixed with just over half of responses at the "just started" or "one the road" levels (Figure 1.4-1). The community had room for improvement overall, with only two responses at the "we're there" level prior to Model implementation. Post-implementation, Postville showed marked improvement on community capacity with increases

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on all but four of the measures. The community experienced no change in accessing external resources and creating new community structures. The community saw a decrease in sharing information with project links over the course of the Model implementation which could be explained less intense communication for project coordination towards the end of the project.

Prior to Model implementation, Listuguj community was in the early stages of building community capacity on most of the measures. The community was at the "just started" or "on the road" levels for all categories except the use of multiple methods to share information and involving a representative range of community members, where they had begun the process and were "on the road" (Figure 1.4-3). Listuguj community showed the most dramatic and significant improvement of the communities who provided post-implementation data. During the course of implementing the Model, the community moved to active or proficient levels for every measure of community capacity. For 10 of the 18 measures, Listuguj community achieved the highest "we're there" level.



**FIGURE 1.4-1**: POSTVILLE COMMUNITY CAPACITY RESULTS PRE AND POST IMPLEMENTATION BY QUESTION (ORDERED BY PRE-IMPLEMENTATION RESPONSES FROM LOWEST TO HIGHEST)

Prior to Model implementation, the Metis community in Prince George reported that they were at the "just started" level for all measures of community capacity (Figure 1.4-2). The community showed substantial improvement over the course of implementing the Model. They reached active levels on 10 of the 18 measures, with particular improvements in community engagement and accessing and/or sharing information related to the project.

Prior to Model implementation, Enoch community reported that they were "just started" on all measures of community capacity (Figure 1.4-4). Enoch community provided follow-up information on 11 of the 18 measures. This community showed little change in community capacity except on overcoming barriers to participation, where they moved to "on the road".

Of the five communities for which follow-up information is available, Conne River reported the highest pre-implementation position on the capacity spectrum overall (Figure 1.4-5). The community made progress on involving the community in finding solutions to root causes of respiratory illness, contributing to a sense of community, and sharing information with project links. For all but one item (providing opportunities for learning), Conne River community finished the project at the 'nearly there' or 'we're there' levels for all measures of community capacity.



**FIGURE 1.4-2**: PRINCE GEORGE COMMUNITY CAPACITY RESULTS PRE AND POST IMPLEMENTATION BY QUESTION (ORDERED BY PRE-IMPLEMENTATION AND POST-IMPLEMENTATION RESPONSES FROM LOWEST TO HIGHEST)



**FIGURE 1.4-3**: LISTUGUJ COMMUNITY CAPACITY RESULTS PRE AND POST IMPLEMENTATION BY QUESTION (ORDERED BY PRE-IMPLEMENTATION RESPONSES FROM LOWEST TO HIGHEST)

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**FIGURE 1.4-4**: ENOCH COMMUNITY CAPACITY RESULTS PRE AND POST IMPLEMENTATION BY QUESTION (ORDERED BY PRE-IMPLEMENTATION RESPONSES FROM LOWEST TO HIGHEST)

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FIGURE 1.4-5: CONNE RIVER COMMUNITY CAPACITY RESULTS PRE AND POST IMPLEMENTATION BY QUESTION (ORDERED BY PRE-IMPLEMENTATION RESPONSES FROM LOWEST TO HIGHEST)

## Summary of key findings

In the beginning of the project (pre-Model implementation), most communities were "just started" or on "the road" in building community capacity on respiratory health, more specifically, they were:

- In the early stages of engaging their community members and/or leaders in the project, linking with others and building a sense of community
- In very early stages of connecting with/developing community structures and external supports and resources
- In very early stages of exploring the root causes of respiratory disease in their communities
- In very early stages of providing community members with opportunities for learning

Wendake and Conne River communities were exceptions and reported being further along the capacity continuum for almost all measures. All participating communities were using a variety of outreach methods for informing community members about the project, as well as for reaching out to various organizations and/or programs within the community. The post-implementation results demonstrate a shift towards enhanced community capacity for addressing issues related to respiratory health. Key success factors appeared to be the following:

- Integrating or linking the work of the project with existing community structures and organizations
- Finding interesting ways to engage community members, including art contests, flyers, development of personal digital stories, information sessions, and bingo games.
- Implementing various efforts to attract diverse group members to be involved in the project, including the challenge of engaging some specific groups such as men and youth.

Among challenges, motivating people to participate and to volunteer was noted as a challenge, linking to other sectors and groups, within and outside the communities.

According to the CCBT results, one of the greatest improvements was observed in the Listuguj First Nations community which showed significant improvements in all categories. Substantial improvements were also seen in Postville and Prince George communities. Notably, these findings indicated that implementation of the Model and related activities could be beneficial for both communities with existing resources (Postville), as well limited resources (Listuguj) as identified in the beginning of the intervention, and could be adopted based on the community's specific needs. The community with highest scores before the intervention (Conne Rover) stayed the same or increased its scores after the Model implementation which might mean that the project could bring additional improvements to communities with satisfactory community capacity. The Enoch First Nations community in Alberta showed little change post implementation, with scores that remain low on all measures. This result could be explained by the fact that the community continues Model implementation as part of the AllerGen-funded project and/or requires more time to show any changes.

## Model evaluation

In general, the *Respiratory Health Awareness Model* was well received by the participating communities. The process of implementing the Model incorporated substantial community engagement and capacity building activities. Overall, participating communities experienced increased levels of respiratory health awareness over the course of the Model implementation. In addition, community support for respiratory health increased in most communities on most

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measures. Some communities showed marked progress in the development of community capacity to address respiratory health in their communities.

The Model implementation worked well and the participating communities were properly engaged in the process, showed high interest levels towards the project, and indicated that Model-related activities were positively received by and were appealing to the community members. Interactive activities (e.g., bingo games, draw prizes) were seen as positive Model components. Involving Elders or knowledge keepers in Model implementation and community activities was considered to be one of the key success factors in Model implementation.

The Toolkit materials were deemed to be good for educating community members and were appreciated for the helpful, useful and interesting information; appropriate content and reading level; appealing design; locally and culturally relevant images, and the intergenerational applicability of the materials. The Master Toolbox, Distribution Toolkits and Individual Packages were adapted to the community's needs and were used to improve access to information on respiratory health, potentially overcoming barriers to accessing this type of resources.

Based on the overall findings of Model evaluation, there were improvements demonstrated by the following indicators of community engagement, support, and capacity building after the Model implementation:

- Increased awareness of respiratory health and factors that can affect it (outdoor and indoor air quality, exposure to smoking, etc.)
- Increased awareness about online respiratory health resources and demonstrated potential for use of online resources for respiratory health education
- Greater awareness and increased perceived availability of adequate community-based respiratory health resources and materials at a variety of places within the community. This improvement was more pronounced for the availability of general respiratory health information and materials to help with indoor air quality issues
- Improved perceptions of the materials and programs on respiratory health available at the community level, as well as help for someone with a serious respiratory health problem
- Enhanced community leadership on respiratory health demonstrated by increased availability and awareness of support and information offered by community leaders
- Improved perceptions about community support, commitment, and social climate in regards to dealing with issues related to community respiratory health
- Increased community willingness to help reduce negative effects of open burning

- Increased community willingness to provide help in improving indoor air quality in homes of community members
- Increased conversation about respiratory health at the community level
- Increased community members' comfort level in sharing information about their respiratory health and the ability to contact a community member for information on respiratory health
- A shift towards enhanced community capacity in addressing issues related to respiratory health
- Improved integration or linkages of respiratory health programs with existing community structures and organizations

# **Toolkit Evaluation**

The materials and resources in the Toolkit were evaluated using a variety of methods. The Master Toolbox was assessed by members of the Community Advisory Groups and the main Project Partners. In additional, report cards were completed to assess the Distribution Toolkit, as well as Individual Packages. Toolkit evaluation results are presented below in detail.

## **Results of Feedback Session and Ballot (Community Advisory Groups)**

As part of *the Respiratory Health Awareness Toolkit*, communities were provided with the Master Toolbox with materials and resources related to respiratory health and the risk factors for chronic respiratory disease. Each community's Advisory Group participated in a Toolbox Feedback Session (focus group discussion) to assess the materials in the Toolbox. Members were then asked to complete a Ballot (Appendix 41) where they rated the individual Toolbox materials on a scale including poor, fair, satisfactory, good and excellent.

Feedback session transcripts/notes were received from five communities: Postville, Prince George, Wendake, Conne River, and Enoch. The Saddle Lake community will submit their notes in August 2012. Community Advisory Group members in the Listuguj community had a discussion about the Toolbox materials and provided their feedback directly to the ASC Project Team. The notes were compiled and thematically analyzed. Each separate point made during the session was tagged with the following information: community, question number, Toolkit item (if appropriate), positive/negative sentiment, and theme. Initial themes emerged as the comments were analyzed and included: content, culture, design, youth/children, use, images, overall learning, and next steps. These themes were further simplified into: information content, design,

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cultural content, and improving access. Results were written up as general impressions (not pertaining to a specific Toolkit item) and by specific Toolkit items. A second analyst reviewed the feedback session transcripts against the written-up results to ensure that the themes and summarizations adequately reflected the feedback.

Accompanying Ballots were received from each of those communities, for a total of **21** (see Table 15 in Appendix 64). Ballot forms were manually entered into Microsoft Access using a data entry form constructed for this purpose. Data were extracted and imported into Stata statistical analysis software, Version  $7^6$ . Frequencies and percentages were calculated for each rating question by community. Results were imported into Microsoft Excel and weighted average percentages were calculated to ensure that the different number of responses in each community did not skew the overall results. Tables and graphs for the overall and community-specific percentages were created in Excel. Final results were checked against the output from Stata 7 and Excel, as appropriate.

## **General impressions of the Master Toolbox**

# **Overall impressions: what participants liked and did not like**

In terms of overall content, Community Advisory Group members liked the information provided in the Toolbox and the way the information was presented and organized, with sheets of different colours. Participants noted that the information was provided in a clear and concise way and they appreciated the positive tone of the respiratory health messages. Overall, participants said that the materials were helpful and needed in their communities. In one community, much of the discussion was about how to continue to use the *Respiratory Health Awareness Toolkit* in their community beyond the pilot project.

In general, participants felt that the materials were well-designed and eye-catching, with a few exceptions that will be discussed in more detail in the section specific to each material. In particular, some materials (e.g., radon brochure) were not colourful enough for the Inuit community in Postville. This community also noted that small font size was an issue in some of the materials. Several comments also reflected a need for more specific cultural content, particularly for Postville, where participants felt that some of the existing materials were not specific enough to the Nunansiavut region (Labrador Inuit). For example, the syllabics in some of the existing materials included in the Toolbox were not appropriate for Labrador Inuit, whose language is written in Inuktitut. Translating the materials into Inuktitut is important because there are many across Nunansiavut whose first language is Inuktitut.

<sup>&</sup>lt;sup>6</sup> Stata statistical analysis software can be accessed at <u>www.stata.com</u>

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The reading level of the materials was deemed being appropriate. However, in Enoch, some of the material was only useful if it was read to community members, specifically Elders and seniors, and interpreted for them.

## Perceived effectiveness of the Toolbox

Community Advisory Group members reported learning new information when looking at the materials in the Toolbox. In particular, they reported learning:

- Information about radon (including where to purchase a kit)
- How to maintain a smoke-free home
- Safe burning (not to burn cardboard and driftwood, not to let a fire smolder)
- Second and third-hand smoke
- Household cleaning products
- Mould
- Scented personal products (perfume and cologne)

In general, participants thought that the Toolbox was a good tool to train and educate community members. Participants said that the information presented was new to many community members and was informative. In one community, the Toolbox was useful because there was a dedicated champion (Respiratory Health Champion) reaching out to community members and presenting the materials.

The participants thought that if the materials were used, general knowledge about respiratory health could increase to some extent. Participants felt that the effectiveness of the Toolbox to increase general knowledge and awareness on respiratory health depended on the will of the community, the availability of the Toolbox, and improving the presentation of some of the materials.

## Perceived usefulness of the Toolbox

Communities agreed to some extent that the materials in the Toolbox were designed and adapted for community needs and made some comments on how they could be improved. In particular, the Inuit community (Postville) found that some of the existing materials included in the Toolbox were not specific enough to the Nunansiavut region (Labrador Inuit). As well, the Métis community in Prince George commented that the Toolbox was a "good start" and "overcomes the barrier of not having Métis specific material" but needed more Métis images included and Métis people being interviewed. The First Nations communities generally had positive comments on the cultural adaptation of the materials.

There was some concern, particularly in Enoch, about the print materials being not accessible to some individuals in their community and a suggestion to have more oral materials available. Further ideas for digital stories and a community respiratory event in that community were expressed.

Participants thought that barriers to accessing materials and resources would be overcome if the Toolbox is made available to community members. Participants noted that the Toolbox needs to be offered in a centralized place where people come often.

# **Overall suggestions: improvement, changes or additions**

In general, the Toolbox was positively reviewed by participating communities. Community Advisory Group members made some suggestions on how the materials in the Toolbox could be improved and what materials need to be added to make the Toolbox sufficient to educate community members on issue related to respiratory health. There were many suggestions for improvements on specific materials, which will be covered in Section 2.1.2 for each individual material. Overall suggestions to improve the Toolbox included:

- Information content
  - Develop and include materials for children and youth (e.g., PowerPoint presentation)
  - Include materials for people in urban centres
  - Provide more information on woodstove and third-hand smoke
  - Provide clear instructions for cleaning mould in a separate material
  - Include information on smoke-houses, which are used in the Nunansiavut region for preserving fish
- Design
  - Develop more posters that can be seen from a distance
  - Include more small take-away items like fridge magnets
  - Enlarge the print on some of the materials
  - Incorporate more images if possible
  - o Develop more video stories
- Cultural content
  - Develop materials specific to Labrador Inuit
  - Have more materials specific to Métis
  - o Improve cultural interpretation of the French materials
  - Consider translating the Toolkit materials in other Native languages
- Improving access

- Make all materials available on a website
- Have someone within the community to distribute, champion and interpret the materials as required (Respiratory Health Champions)
- o Review the literacy level of certain materials and make it lower if necessary
- $\circ$  how to contact the Asthma Society of Canada and how to get more materials

## Summary of views on individual Toolbox items

Overall, the individual materials in the Toolbox were rated favorably, with **70% or more** rating each as good or excellent (Figure 2.1.-1). The Seven Sacred Teachings Poster was rated good or excellent by every Community Advisory Group member respondent in First Nations and Métis communities (it was not distributed in the Inuit community). There were no unsatisfactory ratings of the Asthma Triggers Booklet or the Outdoor Air Quality Fact Sheet. The mould (70%) and COPD (71%) postcards were the items with least number of good or excellent ratings.



FIGURE 2.1-1: SUMMARY OF RATINGS FOR MATERIALS INCLUDED IN THE TOOLBOX (WEIGHTED PERCENTS)

## **Outdoor Air Quality Materials**

outdoor An Quanty Fact Sheet. Summary of findings	
Overall rating from Ballot	95% good or excellent
Community members' opinions on usefulness *	51% would use
Organizations' opinion on usefulness <sup>#</sup>	41% would use
1	

### **Outdoor Air Quality Fact Sheet: Summary of findings**

\*see Results of Report Card: Respiratory Health Awareness Individual Package

<sup>#</sup>See Results of Report Card: Respiratory Health Awareness Toolkit for Community Organizations

The Outdoor Air Quality Fact Sheet was generally well-received. Participants felt that the content was informative, helpful and contained new information for many people. Most felt that this tool was attractive, bright and eye-catching, and sources for the information were clear. However, some noted that the fact sheet was too busy with too much information presented on the back of the tool, but that the "What you can do" section on the back was important. Participants noted that photos did not depict Aboriginal Elders. One community suggested that they would like to see a version directed at stakeholders, such as industry leaders, municipal leaders, and government officials.

## Air Quality Health Index (AQHI) Fact Sheet: Summary of findings

Overall rating from Ballot	81% good or excellent
Community members' opinions on usefulness *	55% would use
Organizations' opinion on usefulness <sup>#</sup>	34% would use

\*see Results of Report Card: Respiratory Health Awareness Individual Package

<sup>#</sup>See Results of Report Card: Respiratory Health Awareness Toolkit for Community Organizations

The AQHI Fact Sheet was not included in the Postville Toolbox. In other communities, participants reported that the AQHI Fact Sheet contained good information with a good reading level. They noted that many people are not aware of the AQHI, so it was considered helpful information to include. Some liked the AQHI scale presented at the back of the fact sheet. The accompanying spinning wheel developed by Environment Canada was well-liked and participants noted that it would be nice to have an Aboriginal version created.

While some reported that it was well-designed and eye-catching with appealing images, others found that it too busy with colour and text. Suggested improvements included: using less colour, and adding information on how to access the AQHI (radio, television, Internet).

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#### **Indoor Air Quality Materials**

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Overall rating from Ballot	82% good or excellent
Community members' opinions on usefulness *	57% would use
Organizations' opinion on usefulness <sup>#</sup>	31% would use
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 $^{*}$ see Results of Report Card: Respiratory Health Awareness Individual Package

<sup>#</sup>See Results of Report Card: Respiratory Health Awareness Toolkit for Community Organizations

The Healthy Home Environment Poster was generally felt to contain good, helpful information that was presented in a simple way with an attractive layout. There were positive comments about the icons and photos. However, participants noted that it was too small to be seen clearly from a distance and suggested to make it larger. Other suggestions included: adding contact details "For more information, call...", and considering alternate formats like magnets.

## Mould Card: Summary of findings

Overall rating from Ballot	70% good or excellent
Community members' opinions on usefulness *	54% would use
Organizations' opinion on usefulness <sup>#</sup>	72% would use

\*see Results of Report Card: Respiratory Health Awareness Individual Package

<sup>#</sup>See Results of Report Card: Respiratory Health Awareness Toolkit for Community Organizations

Generally, the mould card was considered useful and important. Comments from the Métis community appreciated the beading in the background and the colour selection. However, several communities commented that the font size needed to be bigger and that the card did not provide information on preventative measures and details on what to do if you find mould. Suggested improvements included: increasing font size, and develop another material on mould with detailed information on preventative measures.

#### **Radon Brochure: Summary of findings**

Overall rating from Ballot	85% good or excellent
Community members' opinions on usefulness *	34% would use
Organizations' opinion on usefulness <sup>#</sup>	55% would use

\*see Results of Report Card: Respiratory Health Awareness Individual Package

<sup>#</sup>See Results of Report Card: Respiratory Health Awareness Toolkit for Community Organizations

In general, participant comments on the information content of the Radon Brochure were positive. It was seen as new and important information presented in a brief way that gave people the tools they needed. Participants in First Nations and Métis communities expressed that they liked the simple design and colours while members of the Inuit community found it too dull.

Initially, the brochure was designed for the First Nations and Métis communities only and was distributed to the Inuit community to get additional feedback. Participants also commented that the inside image effectively described radon without words. The Métis community liked seeing the Métis symbolism incorporated, but noted that the house should have had a chimney.

#### **Smoking Materials**

#### Seven Sacred Teachings Poster: Summary of findings

Overall rating from Ballot	100% good or excellent
Community members' opinions on usefulness *	51% would use
Organizations' opinion on usefulness <sup>#</sup>	66% would use

\*see Results of Report Card: Respiratory Health Awareness Individual Package

<sup>#</sup>See Results of Report Card: Respiratory Health Awareness Toolkit for Community Organizations

The Seven Sacred Teachings Poster was the most well received material in the Toolbox. This poster was not included in the Postville packages because it did not culturally pertain to the Inuit community. The comments from the Community Advisory Groups were overwhelmingly positive. People liked the approach, colours, drawings and content. Comments reflected a sentiment that the Seven Sacred Teachings approach was culturally appropriate in both First Nations and Métis communities. Many commented that they learned new cultural information that they did not know.

# BREATHE "Making Healthier Communities" Magazine: Summary of findings

Overall rating from Ballot	95% good or excellent
Community members' opinions on usefulness *	n/a
Organizations' opinion on usefulness <sup>#</sup>	32% would use

<sup>\*</sup>see Results of Report Card: Respiratory Health Awareness Individual Package

<sup>#</sup>See Results of Report Card: Respiratory Health Awareness Toolkit for Community Organizations

Participants liked the content, layout and design of the BREATHE magazine. They found the magazine informative and they liked the stories, the "little quotes" and the in-depth presentations. Participants liked that it was uncluttered and had large print. Participants commented on the images included in the magazine. For example, the wagon and house photo did not "convey the feeling of home" and should be potentially replaced with a warmer image (e.g., a family siting together at the dinner table). In regard to the cultural aspects of the content, the Metis community would like to see more Métis-specific content and images.

#### Knowledge on Chronic Respiratory Disease Materials

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# Asthma, Allergies, Anaphylaxis Chart: Summary of findings

Overall rating from Ballot	88% good or excellent
Community members' opinions on usefulness *	67% would use
Organizations' opinion on usefulness <sup>#</sup>	87% would use

\*see Results of Report Card: Respiratory Health Awareness Individual Package

<sup>#</sup>See Results of Report Card: Respiratory Health Awareness Toolkit for Community Organizations

Participants found the Asthma, Allergies and Anaphylaxis Chart very detailed with a lot of information. While some felt that the information was useful in helping people understand the differences, others felt that the Chart needed to be less detailed or made into a different format. The design and the colours of the Chart were liked, as was the matte finish (versus shiny). One commented that it was a good tool for parents or children to keep on-hand. Suggestions for improvement included: changing the format to something that could be used in a newsletter or a fridge magnet, making poster bigger and adding pictures if possible.

## Asthma Triggers Poster: Summary of findings

so / good of excellent
53% would use
57% would use
53 57

\*see Results of Report Card: Respiratory Health Awareness Individual Package

<sup>#</sup>See Results of Report Card: Respiratory Health Awareness Toolkit for Community Organizations

Participants found this poster useful and informative. It included things that some people would not normally consider asthma triggers, such as animals, pollen and home cleaning products.

People liked the layout and the balance between images, text and whitespace. However, some felt that the text was too small to be seen clearly from a distance.

## **COPD Card: Summary of findings**

Overall rating from Ballot	71% good or excellent
Community members' opinions on usefulness *	37% would use
Organizations' opinion on usefulness <sup>#</sup>	51% would use

\*see Results of Report Card: Respiratory Health Awareness Individual Package

<sup>#</sup>See Results of Report Card: Respiratory Health Awareness Toolkit for Community Organizations

The only discussion about the COPD card happened in Postville, where they liked the information, layout and amount of detail. They suggested that the questions approach used on the card would be helpful on other material as well.

## **Conversational Cards: Summary of findings**

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Overall rating from Ballot	81% good or excellent
Community members' opinions on usefulness *	n/a
Organizations' opinion on usefulness <sup>#</sup>	n/a

\*see Results of Report Card: Respiratory Health Awareness Individual Package

<sup>#</sup>See Results of Report Card: Respiratory Health Awareness Toolkit for Community Organizations

Most of the communities found that the conversational cards were useful tools that presented information in conversation and was not overly technical. The Postville Community Advisory Group did not like the box provided with the cards and also suggested that the cards would be laminated to be more useful. Another suggestion was to make them smaller and include in a display box that could be placed at dinner tables at community events.

## Report Card: Respiratory Health Awareness Individual Package

The Report Card (Appendix 40) for Respiratory Health Awareness Individual Packages was included in the individual packages that were distributed to community members in participating communities. The Report Cards asked respondents for their overall opinions on the materials on a scale that included 'very poor', 'poor', 'unsure', 'good', and 'very good'. Respondents were also asked which of the specific materials included in the package they were most likely to use and whether or not there were important topics that were not covered. Respondents also rated their willingness to use specific information included in the package on a scale that included: willing to use, willing to try, unsure, willing to consider trying, and not willing to use.

In total, there were **307** Report Cards for Respiratory Health Awareness Individual Packages received from participating communities (Table 16 in Appendix 65). In certain communities, some of the materials were not included in the packages distributed. Thus, these communities were excluded from questions that asked about those specific materials. These communities and their excluded materials were as follows.

- Inuit: Air Quality Health Index Fact Sheet, Radon Brochure, Do You Know the Difference Posters, and Seven Sacred Teachings Poster
- French-speaking First Nations community: Do You Know the Difference Posters, Door Knob

Submitted cards were manually entered into Microsoft Access using a data entry form constructed for this purpose. Data were extracted and imported into Stata statistical analysis software, Version 7. As the number of forms varied by community (Appendix 65), weighted average percentages were calculated to represent the overall findings. For the free text responses, comments were extracted into Microsoft Word and manually summarized for each question.

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Where responses were similar, they were combined. For lists, comments were presented in order of their frequency when applicable.

## **Overall opinion**

Overwhelmingly, respondents expressed a positive opinion on the materials (Figure 2.2-1). Approximately **9** in **10** respondents rated their first impression, the overall design of the materials, the cultural imagery used and the language level as 'good' or 'very good'.



**FIGURE 2.2-1**: SUMMARY OF RESPONDENTS' OVERALL OPINION ON THE RESPIRATORY HEALTH AWARENESS INDIVIDUAL PACKAGE MATERIALS

## **Opinion on specific materials**

The most useful materials overall are shown in Figure 2.2-2 according to their overall ranking. The highest ranking material was the Asthma, Allergies and Anaphylaxis Chart, which 67% of respondents reported that they would use.

These responses differ by community and the lists below show the top three ranked materials by community:

Postville (Inuit)

- Asthma, Allergies and Anaphylaxis Chart (86%)
- Mould Card (81%)
- Reasons for Keeping our Home Smoke-Free Magnet (67%)



**FIGURE 2.2-2**: WEIGHTED PERCENTAGE OF RESPONDENTS WHO REPORTED THAT THEY WOULD USE EACH MATERIAL FROM THE INDIVIDUAL PACKAGES.

## Prince George (Métis)

- Healthy Home Environment Poster (53%)
- Asthma, Allergies and Anaphylaxis Chart (53%)
- Asthma Triggers Poster (53%)

Wendake (First Nation, French-speaking)

• Reasons for Keeping our Home Smoke-Free Magnet (75%)

- Healthy Home Environment Poster (67%)
- Air Quality Health Index Fact Sheet (61%)

## Conne River (First Nation)

- Asthma, Allergies and Anaphylaxis Chart (85%)
- Mould Postcard (69%)
- Outdoor Air Quality Fact Sheet (59%)

## Saddle Lake (First Nation)

- Seven Sacred Teachings Poster (76%)
- Outdoor Air Quality Fact Sheet (65%)
- Reasons for Keeping Our Home Smoke-Free Magnet (62%)

## Enoch (First Nation)

- Asthma, Allergies and Anaphylaxis Chart (59%)
- Seven Sacred Teachings Poster (55%)
- Healthy Home Environment Poster (54%)

## Suggestions for improvement and additional information

Overall, 20% of respondents said that there were important topics that should be added to Individual packages. Suggestions for additional topics to be included the following:

- Cigarette smoking
  - o Information on what cigarettes contain
  - Information on smoking in vehicles and public spaces
  - o More information on second-and third-hand smoke exposure
- Chronic respiratory disease
  - More information on COPD
  - o Information on long-term effects of respiratory illness
  - o Information on misuse and overuse of inhalers
  - More information on outdoor allergens
  - Information on how to prevent respiratory illness in children
- Home Environment

- Information on quality of home construction
- o Using linoleum or wooden floors instead of carpet
- More detailed information on mould cleaning and prevention
- Information on commonly used scented products (e.g., perfume, air fresheners, hand sanitizers, etc.)
- More information on formaldehyde

Community members would also like to see materials developed for children and for people who are illiterate. They also were interested to have materials about exercise and use of traditional medicine. The Inuit community would like to see materials available in Inuktitut.

#### Willingness to use information

Overall, respondents reported high levels of willingness to use the information found in the Individual packages to make changes in their lives. As Figure 2.2-3 indicates, respondents were most likely to say that they were willing to use the information on how to prevent, detect and clean mould (95% were willing to use or to try to use the information). The least likely changes were related to use of wood stoves and idling; however, over 60% were willing to use or try to use this information.

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**FIGURE 2.2-3**: DISTRIBUTION OF WEIGHTED AVERAGE RESPONSES TO "HOW WILLING ARE YOU TO USE THE INFORMATION FOUND IN THE MATERIALS FOR THE FOLLOWING ACTIONS" (EXCLUDING "NOT APPLICABLE" RESPONSES, SIX COMMUNITIES INCLUDED)

The majority of respondents (80%) said that the changes they would make by using the information provided in the Toolkit would have a positive impact on their communities. Respondents said that these impacts would come through the following actions:

- Improving one's own personal and family health
- Modeling positive behaviours, especially for young people
- Setting examples where others will follow when they see positive changes
- Increasing awareness by sharing new information, and paying attention to earlier detection of respiratory illness
- Improving indoor air quality (e.g., reducing mould)

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Some participants (20%) expressed concerns that the changes resulting from the materials would not make an impact in the community dues to a variety of reasons, including lack of community support, reluctance of community members to change, and financial constraints.

## **Report Card: Respiratory Health Awareness Distribution Toolkit**

In addition to the individual packages, participating communities received a Respiratory Health Awareness Toolkit for Community Organizations (Distribution Toolkit) that also included a Report Card (Appendix 39). The Report Card for Organization Toolkits asked respondents for their overall opinions on the materials on a scale that included 'very poor', 'poor', 'unsure', 'good', and 'very good'. Respondents were also asked which of the specific materials included in the package they were most likely to use to educate their members. They were provided an opportunity to comment on the materials in the Distribution Toolkit, ways in which they intended to use the materials, and whether or not there were important topics that were not covered.

A total of **16** Organization Report Cards were received from Postville (5 cards), Prince George (4 cards) and Conne River (7 cards) communities. The types of organizations which responded were from diverse sectors, including business, government, health, housing, education, and non-profit. As the number of forms varied by community, weighted average percentages were calculated to represent the overall findings. In certain communities, some of the materials were not included in the packages distributed. Thus, these communities were excluded from questions that asked about those specific materials. These communities and their excluded materials were as follows.

- Postville: Air Quality Health Index Fact Sheet, Mould and your Health, Do you Know the Difference Posters, Seven Sacred Teachings Poster, It's Time.
- Prince George: Your Health At Home, Mould and your Health.

In addition, the Postville community received four materials included in their Distribution Toolkit that were not included in the others: Our Ancestors Never Smoked, Staying a Non-Smoker, Why Quit? and Are You Ready to Quit Smoking?

## **Overall opinion**

The materials in the Distribution Toolkit were well received, though not as highly rated as the materials in the Individual Packages (refer to Section 2.2.). Comments were positive overall and indicated that people found the Distribution Toolkit helpful. A majority of respondents supplied

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a rating of good or very good for their first impression (82%), overall design (80%), cultural imagery (74%) and language level (93%) of the materials (Figure 2.3-1). Of significant note, all of the negative (poor or very poor) opinion ratings came from the Inuit community of Postville, where the Distribution Toolkit was least well received. Comments from Postville reflected a lack of material specific to Labrador Inuit.



**FIGURE 2.3.-1**: Summary of respondents' overall opinions on the Respiratory Health Awareness Toolkit for Community Organizations

## Use of materials

Respondents selected the Distribution Toolkit materials that their organizations were most likely to use for educating their members (Figure 2.3-2). At least **80%** of respondents indicated that their organization was likely to use the 'Asthma, Allergies, and Anaphylaxis Chart', 'Your Health at Home', and 'Staying a Non-Smoker'. In addition, over half of respondents indicated they would be likely to use the 'Mould Card', 'Mould and Your Health', 'Asthma Triggers Poster', 'Seven Sacred Teachings Poster', 'Door knob', 'Why Quit Smoking', 'Radon Brochure', 'Do you know the differences? Poster', 'It's Time' program, and the 'COPD Card'. There was substantial variation between the communities in their expected use of the materials.

For instance:

• The Mould Postcard was most well-liked in all communities: Prince George (100%), Postville (60%) and Conne River (57%).

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- In Conne River, the Blue Light Program Postcard was seen as useful by 71% of respondents
- Prince George respondents expected to use the BREATHE Magazine (100%), but this percentage was lower in Conne River (57% of respondents)
- The Radon Brochure was most highly regarded in Postville (60%) and Prince George (75%) but not as likely to be used by Conne River community organizations (29%).



**FIGURE 2.3-2**: Weighted percentage of respondents who reported that they would use each material from the Organization Toolkits to educate members

Community organizations reported that they intended to use the Toolkit material for the following activities:

- Presentations
  - Education workshop on air quality
  - o Schools

- Toolkit for Tenants including housing maintenance
- Reference resource
- Education in community

## **Additional topics**

Overall, half of respondents (56%) felt that information on certain important topics should be in the Toolkit. This sentiment was more likely to come from respondents in Prince George (75%) and Postville (60%) communities. Respondents mentioned the following topics that they felt should be included or stressed more in the materials:

- Information on potential harmful effects of cleaning products
- Smoking (quit aid information, damage to lungs, more information on smoking cessation programs)
- More information on third-hand smoke exposure and smoking in closed areas with children
- Indoor air quality (pets, rodents)

## Feedback Survey: Online Information Module (Session)

Community members and other Project Partners who participated in the online information session, offered as part of the Model implementation, were asked for their feedback about the information, cultural aspects, and other features of the Module. A total of **46** Feedback Surveys (Appendix 45) were received from all seven pilot communities, as well as the Project Partners (see Table 17 in Appendix 66). There were uneven numbers of responses from each community/group, so weighted average percentages were calculated to summarize overall information.

For the first set of questions, respondents rated their opinions on various aspects of the online session as excellent, good, satisfactory, fair or poor. They also had an opportunity to provide comments and suggestions for each of the components. For the purposes of this evaluation, the excellent and good categories were combined as "good" and the fair and poor categories were combined as "poor".

Overall, each factor was rated as good by at least **65%** of respondents from the communities. Figure 2.4-1 below summarizes the feedback from most to least favorably viewed aspects. The

information provided during the session was viewed favorably by the highest percentage of respondents (76%). Respondents commented that the information was thorough, engaging and well explained.

When asked if the material was delivered clearly, **86%** said yes. The majority (**71%**) also said that the information provided was useful and helpful. All the responses from the community respondents reinforced this. By way of suggestions, Project Partners felt that the language was too technical and should be adjusted to be more useful to the general public, and the module could be made not so lengthy.



FIGURE 2.4-1: SUMMARIZED FINDINGS OF THE FEEDBACK SURVEY INCLUDING RESPONSES FROM EACH COMMUNITY (RESULTS ARE SHOWN IN WEIGHTED PERCENTAGES)

Almost three quarters of the participants liked the images (74%), voiceover (73%) and interactive features (72%) of the online Module. In particular, respondents liked the use of local community photos and colourful, clear graphics. The interactive features resulted in an easy-to-use online tool; however, there were some suggestions to improve the skip patterns in the post-test questions (e.g., if answer "no" to "Are you a smoker?", then skip "How often do you smoke?"). There were also some specific challenges with the voiceover audio including:

- Some respondents from three different communities were unable to hear the audio because they did not have speakers or headphones
- Project Partners commented that the male voice was not appealing or engaging, the voices did not sound "Aboriginal"

While the overall ratings were high, there is opportunity to improve the cultural content and the format of the online Module. Suggestions to improve the format of the Module came from Project Partners and included:

- Shortening and simplifying the pre-knowledge survey and allowing for a different middle-ground response like "maybe" rather than "I don't know"
- Improving the audio and the male voice

Comments from community members were positive and indicated a good balance. Overall, **66%** of the respondents from communities said that the online module was the right length. Most of the community-specific responses showed a similar pattern to the overall findings, however, there were some notable variations. The online Module was least well received in Enoch where the responses were less likely to be good and more likely to be satisfactory. The least well liked aspects of the module in Enoch were the ability of the module to engage and the voiceover.

Further, just under half (45%) of community respondents said that the voiceover should be the voice of a community member and 30% thought the voiceover should be delivered in Aboriginal languages. However, several respondents noted the diversity in languages and dialects. It would not be acceptable to simply offer the voiceover in Inuktitut or Cree without recognition of regional differences in the way it is spoken.

There was variation between communities on their feelings about the voiceover as shown in Figure 2.4-2. The Project Partners felt most strongly that the voiceover should be the voice of a community member to enhance community engagement. If the module were presented in an Aboriginal language, suggestions included: Inuktitut (local Northern Labrador dialect), Mi'gmaq, Cree (Plains Cree, Enochies "Y" dialect).



FIGURE 2.4-2: COMMUNITY VARIATION ON OPINIONS RELATED TO CULTURAL ASPECTS OF VOICEOVER

## Master Group Presentation: Satisfaction Survey

In two communities, Postville and Prince George, participants in the Master Group Presentation, offered as part of the Respiratory Health Awareness Toolkit, completed Satisfaction Surveys about the session. A total of **69** Satisfaction Surveys (Appendix 44) were received from two communities: Postville (16 surveys) and Prince George (53 surveys). Because the numbers of Satisfaction Surveys completed were different for the two communities, the overall results are presented as weighted averages. The same evaluation methods as described above were applied to analyze results of the satisfaction surveys. Respondents were asked to rate their opinion on the information, usefulness and cultural content of the session on a scale that included excellent, good, satisfactory, fair and poor. For the purposes of this evaluation, the excellent and good categories were combined to "good" and the fair and poor categories were combined to "poor". Respondents were also asked several yes/no questions and were offered the opportunity to provide comments and suggestions on all the questions.

#### **Information content**

Almost all respondents liked the presentation (99%) and 88% felt they learned new information, including information about third-hand smoke, radon and mould. Overall, most respondents felt the information provided was good (79%) and useful/helpful (78%) (Figure 2.5-1). They commented that the information was well put-together, clearly presented and contained both review and new information. Respondents also noted that the specific information on smoking and perfumed products was most useful. Suggestions for improvement included incorporating more pictures and interactivity into the presentation.

#### **Cultural Content**

The findings show an opportunity to improve the cultural content of the Master Group Presentation, particularly for Métis communities. Overall, 65% of respondents felt the cultural content used in the presentation was good (Figure 2.5-1). This varied substantially between the two communities. Respondents in Postville, an Inuit community, rated the cultural content highly, with **82%** rating it as good and only 6% rating it as poor. Comments from that community were positive; respondents liked the photos and thought that the presentation reflected life in isolated communities. Respondents from the Métis community in Prince George found the presentation less reflective of their culture with a lack of Métis-specific content (e.g., Métis food, cleaning practices, etc.).



**FIGURE 2.5-1**: SUMMARIZED FINDINGS OF THE RATED QUESTIONS FROM THE MASTER GROUP PRESENTATION: SATISFACTION SURVEY INCLUDING RESPONSES FROM POSTVILLE AND PRINCE GEORGE (RESULTS ARE SHOWN IN WEIGHTED PERCENTAGES)

#### **Impact of the Presentation**

A majority of respondents reported that they would make changes to their lifestyle (68%) or environment (72%) based on the information provided in the Master Group Presentation. For those who were not planning to make changes, the main reason was that they already practice the things outlined in the presentation. People also said that some changes were outside of their control and that they don't know how to make changes.

Planned changes to the <u>lifestyle</u> included (in order of frequency mentioned):

- Reducing smoking or making a smoke-free home
- More exercise, including walking
- Be more aware of mould
- Use fewer chemicals (e.g., cleaning products, new furniture, scented products)
- Eat healthier foods
- Burn carefully outdoors
- Reduce vehicle use and idling
- Stay indoors when air quality poor
- Note air quality index before planning outdoor activities

Planned changes to <u>the environment</u> included (in order of frequency mentioned):

- Making a smoke-free home
- Cleaning regularly or with fewer chemicals / air fresheners
- Get rid of old rugs and try to avoid carpets in the home
- Check for radon
- Prevent mould from happening (install fans)
- Use dry wood in wood stove
- Check new furniture and be aware of paint chemicals

#### **Summary of findings**

The evaluation of the *Respiratory Health Awareness Toolkit* for each community was comprised of an assessment of five components: The Master Toolbox, Individual Packages, Distribution Toolkits, the Online Information Module (Session), and the Master Group Presentation.

The Master Toolbox was well-received by Community Advisory Group members, Elders/Knowledge Keepers, and community leaders. In Individual Packages and Distribution Toolkits, the content, design and cultural images of the newly-developed materials were also well-received overall. Approximately **9 in 10** respondents rated their first impression, the overall design of the materials, the cultural imagery used and the language level as 'good' or 'very good'. Overall, respondents reported high levels of willingness to use the information provided in the Individual packages to make changes in their lives. In general, the following observations about the Toolkit were made:

- Toolkit materials were needed in the communities and helped learn new information
- Toolkit materials would be a good resource to educate community members
- Use of the Toolkit materials at the community level would increase to some extent general knowledge and awareness about respiratory health
- Availability of the Toolkit in all formats to community members would help overcome barriers accessing information on respiratory health and the risk factors for chronic respiratory disease
- Toolkit materials were designed and adapted for community needs but certain improvements could be made

Table 2.6-1 summarizes the overall opinion for each material from different sources (Community Advisory Group members, community members, and community organizations). Of note, the preferences of Community Advisory Group members, community members and organizations varied considerably.

- The top rated material by the Community Advisory Group members was the Seven Sacred Teachings Poster.
- Community members and organizations reported that the Asthma, Allergies and Anaphylaxis Chart was the most useful.
- Community members named the Healthy Home Environment Poster as the second most useful material

Respondents reported that it would be beneficial to add additional information to the Toolkit on topics such as smoking, asthma triggers, household chemicals, use of traditional medicine, among others. They also noted that materials should be made more accessible for those with low English literacy (pictures, translation to Inuktitut) and children.

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**TABLE 2.6-1**: OVERALL OPINION ON THE TOOLKIT MATERIALS

	Community Advisory Group members % rated "good" or "excellent" (rank/8)	Community members % would use (rank/8)	Organizations % would use (rank/10)
Outdoor Air Quality			
Outdoor Air Quality Fact Sheet	95 (2)	51 (6)	41 (7)
Air Quality Health Index (AQHI) Fact Sheet	81 (6)	55 (3)	34 (8)
Indoor Air Quality			
Healthy Home Environment Poster	82 (5)	57 (2)	31 (10)
Mould Postcard	70 (8)	54 (4)	72 (2)
Radon Brochure	85 (4)	34 (8)	55 (5)
Smoking			
Seven Sacred Teachings Poster	100 (1)	51 (6)	66 (4)
BREATHE Making Healthier Communities Magazine	95 (2)	n/a	32 (9)
Knowledge on Chronic Respiratory Disease			
Asthma, Allergies, Anaphylaxis Chart	88 (3)	67 (1)	87 (1)
Asthma Triggers Poster	88 (3)	53 (5)	67 (3)
Asthma Triggers Booklet	95 (2)	n/a	n/a
COPD Postcard	71 (7)	37 (7)	51 (6)
Conversational Cards	81 (6)	n/a	n/a

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#### **Online Information Module (Session)**

Respondents commented that the information was thorough, engaging and well explained. The majority (70% and more) of them liked the images, voiceover and interactive features of the online Module. Participants generally liked the session, with largely positive ratings on:

- The information provided and its usefulness/helpfulness and clarity
- The format, images, voiceover and interactive features
- The length of the session

While most of the ratings were positive on the cultural content of the module, this was the area where most improvement could be made. Respondents, especially from the Inuit community, made specific comments on ways to improve the session. Communities varied in their opinion on whether or not they preferred the voice of a community member for the voiceover.

## **Master Group Presentation**

Almost all respondents liked the presentation and learned new information that was good and helpful, particularly about third-hand smoke, radon, scented household and personal products and mould. A majority of people also planned to make changes to their lifestyle (68%) or environment (72%) based on the information provided. Comments were made on how to improve the cultural content, particularly for Métis communities.

## **Project Sustainability**

# Project Sustainability beyond the funding from the Public Health Agency of Canada

March 31<sup>st</sup>, 2012 brought an end to the second phase of a two-part project by the Asthma Society of Canada (ASC) funded principally by the Public Health Agency of Canada (PHAC) (through the National Lung Health Framework), with additional financial support from AllerGen NCE Inc. The project was a pilot intervention and initial evaluation indicates that it has been highly successful, but resources beyond those of the ASC will be required to sustain the activities in the pilot communities, and a significant investment will be required to extend its reach into Aboriginal communities across the country.

The Phase I project, completed August 31<sup>st</sup>, 2010, demonstrated an urgent need to bring awareness of risk factors for chronic respiratory disease, namely social determinants of health (i.e., outdoor and indoor air quality, mould, second and third-hand smoke, etc.) to First Nations,

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Inuit and Métis communities (Asthma Society of Canada, 2010). The key recommendations from the Phase I project led to the main goals of the recently completed Phase II project which were to evaluate the effectiveness of the *Respiratory Health Awareness Community Outreach and Engagement Model* and the development and/or adaptation of educational materials on respiratory health and the risk factors or chronic respiratory disease for Aboriginal community members. Both were accomplished successfully through a pilot intervention undertaken in seven Aboriginal communities.

The Model developed by the ASC aimed to empower communities to create better awareness of lung health, to improve their knowledge about the risk factors for chronic respiratory disease, and to enable First Nations, Inuit and Métis communities to engage in capacity building and establish community-based resources on respiratory health. The project also included the development of a *Respiratory Health Awareness Toolkit* with a variety of educational resources and materials that was developed, distributed and pilot tested in the seven selected Aboriginal communities. In addition, it established a National Coordination Centre (**BREATHE** Clearing House) to provide potentially on-going administrative and resource support to the communities involved in the Model testing, as well as to distribute culturally appropriate educational materials on respiratory health to Aboriginal communities across Canada.

While culturally appropriate resources in the Toolkit now exist, and the Model has proven to be appropriate and successful in the pilot communities, the ASC currently has not got the financial means to promote the Model in communities beyond the original pilot. Some communities involved in the pilot Model implementation will sustain Model-related activities using their internal community resources and capacity that was built during the current project. The Toolkit requires revision based on the results of the pilot before a wider distribution. The ASC has applied for funding from AllerGen NCE Inc. to complete the final revisions of the Toolkit materials and resources, and finalize it for wider dissemination. In the case that this funding is secured, the ASC would still require resources to produce the Toolkit after it has been finalized. For a short period of time (up to 6 months after the project completion), the Clearing House website will be maintained by receiving in-kind support from the Division of e-Learning Innovation, McMaster University. The BREATHE information line (phone and e-mail) will be initially maintained in-kind as part of the ASC Allergy and Asthma Education and Support Program. However, in order to sustain both the website and the line in the future, core funding will be required.

Future funding will be sought from governmental sources, Aboriginal organizations, corporations, foundations and individuals who will appreciate the success of the Model, the cultural relevance of the Toolkit, the necessity of the Coordination Centre (**BREATHE** Clearing House), and the importance of improving lung health in Aboriginal communities across Canada.

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## **Priorities for future action**

Since this was by definition a pilot project, evaluation of both the *Model* and the *Toolkit* was built into the Phase II work in a systemic way. However, given the timeframe of the project (only thirteen months, including final evaluations and data analysis), comprehensive outcomes analysis and a full reach evaluation of the Toolkit has not yet been done. Evaluation of the *Model* over a longer period of time is critical given that it is an empowerment model and changes in the attitudes engendered may happen over time and need to be assessed properly. This further assessment is also important as the resources developed dependent upon the process of community involvement that was undertaken and may or may not be easily transmitted to other communities. As well, feedback from the pilot communities after the Toolkit pilot dissemination has not yet been incorporated into final resources and materials included in the Toolkit.

Subject to funding availability, immediate work identified as needing to be done includes the following:

(1) <u>Modification of the resources and materials</u> included in the *Respiratory Health Awareness Toolkit* according to the feedback received from community members during the primary pilot testing and evaluation in seven Aboriginal communities, as well as the comments provided by the main project partners (the Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK) the Métis Nation British Columbia (MNBC), and AllerGen NCE Inc.).

(2) <u>Implementation of the Model and distribution of the modified Toolkit</u> followed by a comprehensive evaluation in additional Aboriginal communities located close to the initial pilot communities (same region), using Community Respiratory Health Champions from the pilot communities and other engaged community leaders to both promote the Model and assist in Toolkit dissemination.

(3) <u>Final revision of the Toolkit</u> based on the feedback received during the extended pilot and development of a knowledge mobilization package for further Toolkit dissemination. This package with include the final version of the Toolkit materials and resources, as well as materials that will provide an explanation on how to use the Toolkit in Aboriginal communities.

(4) <u>A national consultation</u>, bringing together key Aboriginal and provincial health decision and policy makers, and program planners to exchange knowledge and information about the Model and Toolkit in order to gather insights, share resources, plan effective strategies, and determine next steps for the broader implementation of the Model in Aboriginal communities across Canada.

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(5) <u>Full implementation of the Model</u> and distribution of the finalized Toolkit in additional Aboriginal communities located in Provinces and Territories other than those involved in the initial pilot, followed by comprehensive evaluation on health outcomes, capacity building and program reach.

(6) <u>Seek long-term funding for incorporation of the Model</u> in all interested Aboriginal Communities in Canada, widespread distribution of revised, culturally appropriate materials in the Toolkit in among both urban and non-urban Aboriginal people, and a fully functioning National Coordination Centre currently named *BREATHE (Building Respiratory Education and Awareness for First Nations, Inuit and Métis: Tools for Health Empowerment)* to promote lung health in the Canadian Aboriginal population.

The long-term goal for the ASC and key project partners is to work collaboratively with communities to create a self-sufficient and sustainable outreach and engagement system that facilitates greater access to community level respiratory health educational materials and resources and improve respiratory health.

## Strengthening organizational capacity and expertise

This project was conducted by the Asthma Society of Canada (ASC) in close partnership with the Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK), the Métis Nation British Columbia (MNBC), AllerGen NCE Inc., the National Collaborating Centre for Aboriginal Health (NCCAH), Social Support Research Program, University of Alberta (SSRP), the Canadian Action Network for the Advancement, Dissemination and Adoption of Practice-informed Tobacco Treatment (CAN-ADAPTT), the Division of e-Learning Innovation, McMaster University and Healthy Indoors Partnership (HIP).

Building on previous projects with Aboriginal communities and people, this project furthered the capacity of the ASC to work collaboratively with complex organizations developing a collaborative, participative model of community engagement both accepted and appreciated by Aboriginal leadership, health practitioners, community leaders and community members. Further, expertise was gained by the ASC in the development of resource, materials, and on-line tools that are culturally relevant and accepted by First Nations, Inuit and Métis communities.

Technical expertise was gained by the ASC in current tobacco reduction strategies, indoor air quality, mould, outdoor air quality and other factors in the development and management of asthma and other chronic respiratory illnesses.

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Special expertise was also gained in conducting and evaluating population-based, complex intervention and developing evaluation tools. Working closely with PHAC, the PHAC Community Capacity Building Tool (CCBT), 2007 (Appendix 46) was modified to meet the needs of the Model implementation and made it more appropriate for use in Aboriginal communities. Based on the Multidimensional Sense of Community Scale (Prezza *et al.*, 2009) and other frameworks to assess community capacity on dealing with health-related issues, Community Respiratory Health Awareness and Support Scales, 2011 were specifically designed by the ASC Project Team for evaluation of the model-related activities to understand the level of community resources and attention to respiratory health issues before and after the intervention. These evaluation tools and the modified CCBT (Appendix 47) now form part of the ASC's set of evaluation tools that can be used for other population-based interventions.

Relationships formed with the key Project Partners and other stakeholders have raised both the visibility of the ASC among those groups and have changed the nature of the way ASC will undertake its advocacy, educational, program development, policy and research work in both Aboriginal communities and other Canadian communities considered to be "at risk" or vulnerable populations for respiratory illness. Our approach will be more community-based, collaborative, iterative and respectful of traditions and cultural practices.

# Support from the Public Health Agency of Canada

The Public Health Agency's (PHAC) support was instrumental in the successful completion of this project. It maintained effective timely and constant communication with the ASC Project Team. It supported and helped with budget transfer submissions and all other administrative requests. Furthermore, all arising issues were discussed and addressed in a timely and effective manner, as were other requests.

Although the support received was substantial, the PHAC future funding programs and processes could be enhanced in several ways. The project conducted by the ASC was extensive and involved an implementation and evaluation component. With this type of project, the PHAC may want to consider providing more time to complete data analysis and final report preparation. The request for multiple hard copies of documents is time consuming, so we suggest providing either additional time to provide these or the submission of only one hard copy. Finally, this project has heightened the participating communities' respiratory health awareness and a desire for continued support. To accommodate this request, the PHAC could establish processes and ways to ensure long-term sustainability. This could include programs aimed at providing additional funding to sustain or expand highly successful pilot projects.

The funding program provided several beneficial outcomes. Firstly, this funding program allowed the ASC Project Team to conduct a pilot intervention and assess its outcomes while directly building capacity and improving lung health awareness in pilot communities. Further, the ASC Project Team was given the opportunity to develop and implement unique project evaluation tools. Lastly, and perhaps most importantly, it facilitated the opportunity to work with multiple stakeholders, which included a wide array or partners and communities.

## Recommendations

The Respiratory Health Awareness community outreach and engagement Model (Model) developed by the ASC aimed to empower First Nations, Inuit, and Métis communities to create better awareness of lung health, to improve their knowledge about the risk factors for chronic respiratory disease, and to enable these communities to engage in capacity building and establish community-based resources on respiratory health. The project also included the development of the *Respiratory Health Awareness Toolkit* (Toolkit) with a variety of culturally appropriate educational resources and materials that was developed, distributed and pilot tested in the seven selected Aboriginal communities (5 First Nations, 1 Inuit, and 1 Métis). Moreover, during the project implementation, a National Coordination Centre (**BREATHE: Building Respiratory Health Awareness for First Nations, Inuit and Métis: Tools for Health Empowerment Clearing House) was established to provide on-going administrative and resource support to the communities involved in the Model testing, as well as to distribute culturally appropriate educational materials on respiratory health to Aboriginal communities across Canada as requested.** 

In general, the pilot Model implementation worked well in participating communities. The process of implementing the Model incorporated substantial community engagement and capacity building activities. The participating communities showed high interest levels towards the project, were fully engaged in the process, and indicated that Model-related activities were positively received by, and were appealing, to community members.

Overall, participating communities experienced increased levels of respiratory health awareness and knowledge about risk factors that can impact respiratory health after the Model implementation. In addition, community support for respiratory health increased in most communities. The project results demonstrated improved community members' perceptions of the programs and help on respiratory health available at the community level, specifically for someone with a chronic respiratory health problem.

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Participating communities showed marked progress in the development of community capacity to address respiratory health issues. Key findings demonstrate improved perceptions about community commitment and social climate in regard to dealing with issues related to community respiratory health, as well as increased conversation about respiratory health at the community level. There was also improved integration or linkages of respiratory health programs with existing community structures and organizations.

Further, there was greater awareness and increased perceived availability of appropriate community-based resources and materials on respiratory health at a variety of places within the communities. Community leadership on respiratory health was enhanced and there was increased availability and awareness of support and information offered by community leaders among community members post-Model implementation. Community members also indicated the increased comfort level in sharing information about their respiratory health and the ability to contact a community member for information and support. Additionally, participating communities showed their increased willingness to help reduce negative effects of open burning and to provide help in improving indoor air quality in homes of community members.

The Toolkit materials and resources were well-received, deemed to be good for educating community members, and were appreciated for the helpful, useful and interesting information, appropriate content and reading level, appealing design, locally and culturally relevant images, and the intergenerational applicability of the materials. The Master Toolbox, Distribution Toolkits and Individual Packages were adapted to the community's needs and were used to improve access to information on respiratory health, potentially overcoming barriers to accessing this type of resources.

While culturally appropriate resources in the Toolkit now exist, and the Model has proven to be appropriate and successful in the pilot communities, further work needs to be done on finalizing the Toolkit materials and resources based on the feedback obtained during the pilot testing, as well as developing a plan for implementing the Model in other Aboriginal communities. Proposed recommendations presented below are related to further modification of the resources and materials included in the Toolkit, implementation of the Model-related activities and distribution of the modified Toolkit in additional Aboriginal communities, and comprehensive evaluation of these interventions over a longer time period allowing to observe changes in people's behaviour and community practices. Proposed recommendations are informed by lessons learned and experiences during the pilot Model implementation, through analysis of the Model and Toolkit evaluation results, as well the feedback provided by Project Partners and the National Advisory Committee (NAC) members during the project evaluation workshop (March 19<sup>th</sup>, 2012).

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

# 1. Modify the resources and materials included in the Respiratory Health Awareness Toolkit

It is recommended that modifications be made to the newly-developed Toolkit materials and resources, according to the feedback received from community members during the primary pilot testing and evaluation in seven Aboriginal communities, as well as the comments provided by the main project partners (the Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK) the Métis Nation British Columbia (MNBC), and AllerGen NCE Inc.). Suggestions have been made to further modify the following materials and resources in the Toolkit:

## **1.1.** Toolkit printed materials

Modifications should include changes to the newly developed educational materials according to the comments received during the initial pilot testing to further improve their appropriateness and relevance to Aboriginal cultures and traditions. Some materials should be reviewed and revised in regard to their language level to make them more accessible to people with low literacy abilities. Special considerations should also be given to translating some materials into Aboriginal languages, specifically Inuktitut. Subject to funding availability, additional materials could be developed to target children and youth, as well as provide additional information on the topics of greater interest identified during the Phase II project (smoking and third-hand smoke exposure, asthma triggers, household chemicals, use of traditional medicine, among others).

## **1.2.** Master Group Presentation

This presentation was delivered during health and wellness fairs, and other community events and programs during the pilot Model testing and was extremely well-received by community members due to its interactive nature and the useful content. The majority of participants reported willingness to make changes in their lifestyle and environment based on the information provided in the presentation. Suggestions were made to make a version of the Master Group Presentation that would be suitable for the younger audience (children and youth). Other further modifications would include adding Métis-specific images to improve relevance of the presentation for this community.

## **1.3.** Online information Module (session)

An online train-the trainer instructional Module (session) was developed to train community leaders, Knowledge Keepers, and Elders to become Respiratory Health Champions in their communities, and deliver key educational messages on respiratory health by using a "word-of-mouth" approach. Involving Elders or Knowledge Keepers in Model-related and community-

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based activities was considered to be one of the key success factors in Model implementation. The pilot intervention also confirmed potential benefits of online resources and information for respiratory health education. It is recommended to revise the Module based on the feedback received from Project Partners and participating communities, in particular, by clarifying some of the information provided (e.g., include more details on radon sources) and including more images related to Inuit traditional activities (e.g., fishing, hunting, etc.). Special consideration should be given to changing the voice used for the voiceover in the Module to be represented by the voice of a community member.

## 1.4. Digital stories

Digital stories developed by participating communities based on people's personal experiences living with chronic respiratory disease and dealing with several environmental issues are to be posted on the **BREATHE** website. If any comments are received on the stories through a feedback form available online, these suggestions would be incorporated before including the digital stories in the modified Toolkit.

# 2. Further implement the Model and the modified Toolkit (Modified Pilot)

Another recommendation is to implement the Model and distribute the modified Toolkit in additional Aboriginal communities located close to the initial pilot communities. The communities involved in the initial Model pilot would be used to showcase and introduce the Model and would also distribute the Toolkit to nearby communities located in the same region. Respiratory Health Champions from the pilot communities and other engaged community leaders could help both promote the Model and assist in Toolkit dissemination to additional communities that were not involved in the initial development of the Toolkit. As a next step, it is recommended to extend the Model implementation to **15** communities in the same regions. If future funding allows, considerations should be given to extending the pilot implementation to Aboriginal communities in another province that was not involved in the initial pilot (e.g., Ontario or Nova Scotia).

This intervention should be associated with a comprehensive, extensive evaluation of the Toolkit in these communities. This additional evaluation is necessary to ensure broader applicability of the Toolkit and its relevance to other Aboriginal communities, and is crucial to support its future use Canada-wide and internationally. Further comprehensive evaluation is also necessary to better understand if the developed materials in the Toolkit and other Model-related activities resonate with the target audience and assess their cultural relevance and appropriateness by gathering feedback from community members, healthcare professionals, representatives from community organizations, community leaders, Elders and Knowledge Keepers who were not

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involved in the initial development of the Toolkit. Such evaluation is critical to determine the role and importance of local development of tools and materials as compared to the simple transferability and usability of culturally appropriate tools in communities not involved in their development. Evaluation tools that were developed or used during the initial Toolkit evaluation would be applied to conduct further assessment of the Model-related activities and the modified Toolkit. Activities that are proposed to be conducted during the modified pilot are listed below:

# 2.1. Gathering feedback on the Toolkit printed materials and the Master Group presentation

In order to evaluate the modified Toolkit materials, the report card developed for the initial evaluation would be reapplied and included in the Distribution Toolkits and Individual Packages to collect feedback from community members, community organizations and healthcare settings. To better understand if the modified Toolkit resonate with the target audience in the communities involved in the modified pilot, it is also recommended to conduct focus group discussions and ensure representation from various community groups, including health care professionals, Health Directors, representatives from community organizations, community members at large, community leaders, Elders and Knowledge Keepers. The modified Master Group Presentation would be evaluated by applying the satisfaction survey developed for the initial pilot testing. The survey contains quantitative questions based on the *Likert Scale* and offers an opportunity to provide written comments as well.

## 2.2. Obtaining feedback on the digital stories included in the Toolkit

A selection of personal stories from each of the three cultural communities was developed during the pilot project to 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.). The evaluation of the digital stories was not completed during the pilot project; therefore, it is suggested that the effectiveness of digital stories in conveying key respiratory health messages should be assessed by conducting community meetings and applying a "direct audience response" method (Miller *et al.*, 2003) to provide community members with the opportunity to rate the relative strengths of the messages portrayed in the stories in real time.

## 2.3. Assessing the effectiveness of the modified Online Information Module

To determine further if the online training Module could be a useful and acceptable method of training in Aboriginal communities, the modified online training Module will need to be piloted in additional communities. Community leaders, Elders and Knowledge Keepers in these communities will be recruited and trained to become *Respiratory Health Champions* by using the revised online training Module. Upon module completion, they would be asked to provide detailed feedback about the session by completing certain surveys. Trained Respiratory Health

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Champions would distribute, champion and interpret the Toolkit materials in their communities. At the end the pilot, they would be also asked to share their insights and ideas on potential Module roll-out to Aboriginal communities across Canada, as well as practical approaches that need to be applied to ensure its overall success and effectiveness.

Based on a request to continue training in the initial pilot communities, additional Respiratory Health Champions would be recruited and trained in these communities as well, subject to funding availability.

## 2.4. Evaluating the overall effectiveness of the Model and Toolkit implementation

To understand the overall impact of the initiative at the community level, it is recommended to organize reflective community nights to discuss the Toolkit and Model-related activities. Additionally, a questionnaire needs to be designed to investigate changes in community members' self-reported knowledge, attitudes and intentions to modify their behaviors following the Toolkit dissemination. This survey would be administered to all community members and be developed based on Kirkpatrick's conceptual framework (Watkins *et al.*, 1998). To identify successful implementation strategies, another set of interviews is proposed to be conducted with community leaders, Elders, Knowledge Keepers, and trained Respiratory Health Champions about their experiences and satisfaction with the Model and the modified Toolkit implementation. These interviews will help define the necessary strategy to be included in the knowledge mobilization package to be developed at the end of the modified pilot.

When conducting the modified pilot, focus should also be placed on assessing changes in community capacity on respiratory health. According to several research studies (Hawe *et al.*, 1998; Anderson *et al.*, 2007; MacLelland-Wright *et al*, 2007), community capacity could be considered as a proxy measure for community health. Communities involved in further implementation of the Model would be asked to complete data collection tools to gather information about community capacity on respiratory health before and after conducting Model-related activities and using materials from the modified Toolkit. The data collection tools that were designed or adapted during the pilot Model testing (Phase II project) will be applied (e.g., PHAC Community Capacity Building Tool (CCBT), 2007; Community Respiratory Health Awareness and Support Scales, 2011).

# 3. Finalize the Respiratory Health Awareness Toolkit

Based on the feedback received during the extended (modified) pilot, final revision to the Toolkit will be made. In addition, it is recommended to develop a knowledge mobilization package to facilitate further Toolkit dissemination and introduction to other Aboriginal communities across Canada. This package would include the final version of the Toolkit materials and resources, as

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well as materials that will provide an explanation on how to use the Toolkit at the community level. The package would also contain information on practical approaches that need to be applied to ensure successful and effective Toolkit implementation. The main outcome of this initiative will be the finalized *Respiratory Health Awareness Toolkit* specifically designed and tested to empower First Nations, Inuit and Métis communities to create better awareness of lung health, improve community members' knowledge about the social determinants of health as risk factors for chronic respiratory disease, as well as to enable access to community-based resources on respiratory health rooted in culturally relevant formats and tailored according to the unique community's priorities and needs.

The finalized Toolkit and Model-related activities would be available for use in Aboriginal communities across Canada, as well as other vulnerable populations (i.e., communities affected by poverty, poor housing, low socio-economical level, and multicultural communities).

## 4. Conduct a national consultation with key opinion leaders

To ensure the success of the Canada-wide Model implementation, another recommendation is to bring together key Aboriginal and provincial health decision and policy makers, and program planners to exchange knowledge and information about the Model and the Toolkit in order to gather insights, share resources, plan effective strategies, and determine next steps for the broader implementation of the Model in Aboriginal communities across Canada. Such a consultation would help assess the capacity of Aboriginal organizations or regional health authorities to lead future Model implementation through knowledge translation and mobilization. Key informant interviews could be conducted by phone or in person with decision makers to gather insights on potential Model implementation strategies in Aboriginal communities across Canada. Participating provincial and/or regional organizations will be collaboratively identified by working with the AFN, ITK, and MNBC.

# 5. Ensure full implementation of the Model and distribution of the finalized Toolkit

After the Toolkit is finalized, the knowledge mobilization package is prepared, and implementation strategies are defined, it is recommended to implement the Model and distribute the Toolkit in additional Aboriginal communities located in Provinces and Territories other than those involved in the initial or modified pilots, followed by comprehensive evaluation on health outcomes, capacity building and program reach. The ASC is planning to seek long-term funding for incorporation of the Model in all interested Aboriginal Communities in Canada, widespread distribution of revised, culturally appropriate materials in the Toolkit in among both urban and non-urban Aboriginal people, and a fully functioning National Coordination Centre (Clearing

House) currently named **BREATHE** (Building Respiratory Education and Awareness for First Nations, Inuit and Métis: Tools for Health Empowerment) to promote lung health in the Canadian Aboriginal population. The Clearing House will allow to have one point contact for all information and resources to the Toolkit dissemination, as well as give the opportunity to obtain the resources directly from the **BREATHE** website.

The wide-spread Model implementation will continue to be based on the principles of a participatory approach (Rossi *et al.*, 2004; Agency for Healthcare Research and Quality, 2004; CIHR, 2007), wherein Aboriginal communities are engaged in all aspects of the Toolkit use and application. This approach recognizes the ability of community members to understand their community strengths, practices, and needs, fostering sustainable strategies that build community capacity and, eventually, leading to improved health outcomes (Edwards *et al.*, 2008).

*In conclusion*, the long-term goal for the ASC and key Project Partners is to work collaboratively with First Nations, Inuit, and Métis communities across Canada to create a self-sufficient and sustainable outreach and engagement system that facilitates greater access to community level respiratory health educational materials and resources and improve respiratory health at the population level.

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(Available upon request to the Asthma Society of Canada)

April 30<sup>th</sup>, 2012

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APPENDIX 58 RESULTS DISSEMINATION AND COMMUNICATION PLAN

APPENDIX 59 COMMUNITY FEEDBACK REPORT TEMPLATE

APPENDIX 60 THE NUMBER OF RESPIRATORY HEALTH AWARENESS SCALES COMPLETED BEFORE AND AFTER MODEL IMPLEMENTATION, PER COMMUNITY

APPENDIX 61 THE NUMBER OF RESPIRATORY HEALTH SUPPORT SCALES COMPLETED BEFORE AND AFTER MODEL IMPLEMENTATION, PER COMMUNITY

APPENDIX 62 COMMUNITY RESPONSES TO QUESTIONS IN THE RESPIRATORY HEALTH SUPPORT SCALE RELATED TO THE COMMUNITY ABILITY TO WORK TOGETHER ON ISSUES RELATED TO RESPIRATORY HEALTH, BASELINE (ALL COMMUNITIES COMBINED)

APPENDIX 63 COMMUNITY RESPONSES TO QUESTIONS IN THE RESPIRATORY HEALTH SUPPORT SCALE RELATED TO THE COMMUNITY SUPPORT TOWARDS SMOKE-FREE HOMES AND CHRONIC RESPIRATORY DISEASE TESTING, BASELINE (ALL COMMUNITIES COMBINED)

APPENDIX 64 THE NUMBER OF BALLOTS COMPLETED, BY COMMUNITY

APPENDIX 65 THE NUMBER OF REPORT CARDS FOR RESPIRATORY HEALTH AWARENESS INDIVIDUAL PACKAGES COMPLETED, BY COMMUNITY

APPENDIX 66 THE NUMBER OF FEEDBACK SURVEYS RECEIVED FROM INDIVIDUALS WHO PARTICIPATED IN THE ONLINE INFORMATION MODULE (SESSION), BY COMMUNITY

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# The Respiratory Health Awareness community outreach and engagement model in First Nations, Inuit and Métis communities: Pilot Intervention

LIST OF ATTACHMENTS

(Available upon request to the Asthma Society of Canada)

April 30<sup>th</sup>, 2012

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Asthma Society of Canada

124 Merton Street, Suite 401

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Funded by the Public Health Agency of Canada, Lung Health Program

### ATTACHMENTS

#### ATTACHMENT 1. COMMUNITY ASSESSMENT GUIDE (FIRST NATIONS, INUIT AND MÉTIS)

ATTACHMENT 2 . INFORMATION <u>PACKAGE, COMMUNITY ADVISORY GROUP</u> (GUIDE TO ESTABLISH COMMUNITY ADVISORY GROUPS)

## ATTACHMENT 3. LIST OF RESOURCES COMPILED FROM ENVIRONMENTAL SCAN

#### ATTACHMENT 4 POST-WORKSHOP REPORT - PHASE II PROJECT IMPLEMENTATION WORKSHOP (MAY 2011)

#### ATTACHMENT 5 NEWLY DEVELOPED MATERIALS ON OUTDOOR AIR QUALITY:

a. Outdoor Air Quality Fact Sheet (First Nations, Inuit, Métis and English)

b. AQHI Fact Sheet (First Nations and Métis)

#### ATTACHMENT 6 NEWLY DEVELOPED MATERIALS ON INDOOR AIR QUALITY

a. Mould postcard (First Nations, Inuit and Métis)

b. Healthy Home Poster (English, French)

c. Radon brochure (French, English)

#### ATTACHMENT 7 SEVEN <u>SACRED TEACHINGS POSTER (NEWLY DEVELOPED</u> <u>MATERIAL ON TRADITIONAL AND COMMERCIAL TOBACCO USE, ENGLISH</u> <u>AND FRENCH)</u>

ATTACHMENT 8 BREATHE MAGAZINE (NEWLY DEVELOPED MATERIAL ON SECOND AND THIRD HAND SMOKE EXPOSURE, ENGLISH, FRENCH AND CREE)

#### ATTACHMENT 9 NEW <u>DEVELOPED MATERIALS ON KNOWLEDGE OF</u> <u>CHRONIC RESPIRATORY DISEASE:</u>

a. COPD card (First Nations, Inuit and Métis)

b. Asthma Triggers Poster

c. Asthma, Allergies and Anaphylaxis chart

#### ATTACHMENT 10 COVERSATIONAL CARDS (ENGLISH)

ATTACHMENT 11 CONVERSATIONAL CARDS (FRENCH)

ATTACHMENT 12 MASTER GROUP PRESENTATION (ENGLISH AND FRENCH)

ATTACHMENT 13 INFORAMTION PACKAGE, DIGITAL STORIES

ATTACHMENT 14 **INFORMATION <u>PACKAGE</u>**, <u>COMMUNITY RESPIRATORY</u> <u>HEALTH CHAMPIONS (RECRUITMENT PACKAGE)</u>

ATTACHMENT 15 INFORMATION PACKAGE, COMMUNITYARTWORK CONTEST

ATTACHMENT 16 INDIVIDUAL PACKAGES (FIRST NATIONS ENGLISH)

ATTACHMENT 17 INDIVIDUAL PACKAGES (INUIT)

ATTACHMENT 18 INDIVIDUAL PACKAGES (MÉTIS)

ATTACHMENT 19 INDIVIDUAL PACKAGES (FIRST NATIONS FRENCH)

ATTACHMENT 20 INFORMATION PACKAGE, COMMUNITY EVENTS AND PROGRAMS

ATTACHMENT 21 **PRESENT<u>ATION FROM THE UNIVERSITY OF NORTHERN</u>** BRITISH COLUMBIA MEETING

ATTACHMENT 22 A <u>SCREENING BROCHURE DEVELOPED BY THE WENDAKE</u> FIRST NATION (FRENCH SPEAKING FIRST NATIONS COMMUNITY)

ATTACHMENT 23 INFORMATION PACKAGE PROJECT EVALUATION GUIDE

ATTACHMENT 24 EVALUATION WORKSHOP NOTES ON THE PROJECT TOOK-KIT OVERVIEW AND EVAULATION

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