National Lung Health Framework

Phase I Lung Health Program

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

Executive Summary

Lead Organization: Asthma Society of Canada

Partners: Assembly of First Nations, Inuit Tapiriit Kanatami, Métis Nation British Columbia, AllerGen NCE Inc.

Supporting Partners: National Collaborating Centre for Aboriginal Health

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Area of Focus: Awareness of Risk Factors for Respiratory Disease

Target Groups: First Nations, Inuit and Métis communities

Timeline: February – August 2010

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

needs to be developed to meet the unique needs of Aboriginal communities. Another goal of the project was to help gain a better understanding about how the existing materials can be further adapted and/or modified to be culturally relevant for First Nations, Inuit and Métis communities.

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

Important findings from this project revealed that overall there was low level of awareness and knowledge on the social determinants of health and how they can affect respiratory health. Overall, there was a strong sense among project participants that respiratory health was an important issue facing their communities. However, the level of awareness and detail of respiratory knowledge (e.g. respiratory conditions, risk factors, and disease management) among individuals varied greatly as many participants indicated surprise, confusion, and in some cases, communicated misinformation about some of the specific topics. Based on the project findings, one of the main barriers in accessing information on respiratory health is a lack of information and resources available at the community level. Even though some materials and resources are available, many community members also did not know about their existence and how to access appropriate resources and support required for dealing with issues related to respiratory health. The project findings confirmed that there was a strong need for more information on the prevention (e.g. the risk factors) and management of chronic respiratory disease in their communities, and identified potential educational and awareness strategies that could be implemented to bring the right information and resources to Aboriginal community members and make them more relevant to their culture and traditional practices. As a main project outcome, a community outreach and engagement model that could be effective, culturally appropriate and sensitive to the needs of First Nations, Inuit and Métis communities has been developed based on the project findings and results.

The findings from this project support six key recommendations related to the potential implementation of the designed community outreach and engagement model as well as to the development and/or adaptation of educational materials on respiratory health and the risk factors

for chronic respiratory disease and other educational strategies to be applied during the model implementation.

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

1) Pilot the designed community outreach and engagement model
2) Develop core materials and resources to be used under the main model components
3) Develop a comprehensive dissemination network for materials and resources on respiratory health
4) Develop tools to engage, train and support community leaders in delivering respiratory health education messages
5) Develop strategies/tools to ensure adequate participation of community-based healthcare providers/representatives
6) Develop tools and resources to ensure broader community involvement in awareness initiatives

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

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

materials do not currently exist; group discussions series on respiratory health topics that can be offered by trained healthcare professionals (e.g. community health representatives, nurse, etc.) and/or community leaders; and public services announcements for local TV and radio channels.

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

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

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

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

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

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