



SUMMARY REPORT

A SHARED VOICE:

Engaging First Nations and Inuit communities in the development of culturally appropriate asthma and allergy education materials and resources for youth and their families

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To:

First Nations and Inuit Health Branch, Health Canada

By:

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II. Executive Summary

The prevalence of asthma and associated allergies is substantially higher in First Nations and Inuit communities than in the general Canadian population. First Nations and Inuit community members may also be at a higher risk to develop asthma and associated allergies due to their exposure to various environmental determinants of respiratory health such as smoking, poor housing, wood burning, and poor indoor/outdoor air quality. Due to this growing concern, an exploratory study entitled “A Shared Vision” was conducted in 2009 and identified the development of culturally appropriate educational materials and resources as one of the integral factors in improving access to asthma/allergy-related health services. The main purpose of the current project was to collect background information about relevance of the existing asthma education materials and resources to First Nations and Inuit community members and identify how these materials could be adapted to be culturally appropriate and better suit the needs of these communities.

Three sources of data were used to compile the findings of this report. First, asthma assessment packages and questionnaires were developed to review and assess existing asthma educational materials and resources by the project participants divided into four categories namely children 6 to 12 years old, youth 12 years old and above, parents/grandparents, and community leaders. In total, 130 packages were distributed to First Nations and Inuit communities with 68 assessment questionnaires being completed by the community members. Second, five webinar sessions with 56 participants in total were conducted in order to assess asthma educational web-based support resources as well as materials for one on one and/or group asthma education. Third, a community Advisory Group of First Nations and Inuit community members was created to further discuss the existing asthma educational materials and resources and identify any other potential barriers/concerns related to receiving asthma education in First Nations and Inuit communities.

Important findings from this project revealed that overall, the asthma educational materials assessed were largely seen favorably by First Nations and Inuit audiences and some of them could be adapted for future use; however, several modifications that consider age, learning styles, preferred content, language, and First Nations and Inuit culture and context are required and may result in higher uptake and usability. In brief, the data have shown that all age categories valued the interactivity and the visual features of educational materials and resources, and enjoyed having personal interaction with parents or/and health care professionals while learning. It has been suggested that new materials be developed with a focus on practical, lifestyle issues that are related to asthma prevention and management by providing information on environmental control, asthma triggers, proper medication management including the use of an asthma action plan as well as unique issues faced by Aboriginal communities (e.g. road dust, forest fires, etc.). In general, respondents preferred to have a combination of traditional printed materials (booklets with pictures, factsheets) and digital resources (websites with audio features) as well as an opportunity to receive in-person education via asthma information nights and/or support groups while exploring an option of receiving in-person group education via webinars. Cultural relevance could be improved by implementing several strategies such as including appropriate images/pictures related to Aboriginal culture, featuring real-life personal stories of native people managing well their asthma, making core materials available in Aboriginal languages, and offering information about traditional healing approaches and their potential

combination with conventional medicine. The importance of community awareness about asthma was greatly emphasized with educational activities targeting the community as a whole along with the focus on developing educational programs for children and their extended families in order to address the significant concern of childhood asthma within the First Nations and Inuit communities.

The data from this project also support previous observations about major gaps in health care and community resources for coping with and managing asthma and associated allergies such as: a lack of educational resources available at the community level; a lack of community awareness about asthma; limited access to health care services and/or ineffective communication with health care providers; insufficient coverage for asthma medication and devices, and a lack of professional development programs on asthma for health care providers. Further, there are environmental issues that affect proper asthma management and prevention namely poor housing, poor outdoor/indoor air quality, and community-wide exposure to second-hand smoke.

The findings from this project support five key recommendations, providing the ground work for further community-based research in the area of respiratory health and education (e.g. focus groups) as well as the guidance on the development of culturally appropriate asthma educational materials and resources for First Nations and Inuit community members in order to ultimately help address asthma in their communities leading to its proper management and prevention with a potential reduction in asthma rates.

Firstly, there should be a focus on the development of culturally appropriate asthma educational materials and resources by modifying existing resources and/or designing the new materials along key characteristics identified during the project (e.g. preferred learning style, format, core elements, desirable content, cultural context, etc.).

Secondly, implementation of asthma educational activities for children and their extended families should be a priority with considerations to be given to adapting existing child-friendly educational programs (e.g. RAP “*The Roaring Adventure of Puff*” program).

Thirdly, education should not only target people with asthma and their caregivers but also aim to increase community awareness about asthma amongst broader community members in order to normalize asthma within the community and create supportive environments for each and every community member directly or indirectly affected by asthma.

Along with the development of appropriate asthma materials and resources, a fourth recommendation is to ensure appropriate access to these resources in the actual communities (e.g. at schools, community centres, health clinics, etc.). Comprehensive dissemination and community uptake strategies should be developed and implemented to ensure the right materials reach the right audiences.

Finally, it is crucial to continue engaging First Nations and Inuit community members in the development/adaption of new asthma educational materials and community-based programs. A National Framework (e.g. National Aboriginal Asthma Council) developed and implemented by Aboriginals has been recommended as a way of moving forward to improve asthma education

and care for First Nations and Inuit youth affected by asthma and their extended families. First Nations and Inuit communities should work in partnership with organizations responsible for Aboriginal Health to develop a shared strategy to improve cultural appropriateness of existing asthma educational materials and develop new resources that are relevant to these communities and their unique issues. This process could be facilitated by disease organizations such as the Asthma Society of Canada.

The project also creates an opportunity for further community-based initiatives that should be considered and included in the development process of new materials and resources. More in-depth reviews of the materials that were consistently rated most favourably by multiple groups should be conducted to complement the findings of the current project and identify “best practices” in asthma education and awareness for First Nations and Inuit communities.

III. Introduction

Asthma and associated allergies represent a significant issue for First Nations and Inuit communities with the prevalence of asthma estimated being 40% higher in First Nations and Inuit communities than in the general Canadian population.¹ It is also well known that First Nations and Inuit communities may be more at risk to develop asthma and associated allergies due to their exposure to various determinants of respiratory illness such as smoking, poor housing, wood burning, and poor indoor/outdoor air quality.

The Asthma Society of Canada (ASC)² has a special interest in helping adults and children with asthma and associated allergies in remote communities to achieve a symptom-free life by providing them with up-to-date information about asthma and its management, and empowering them to strive for better asthma control through the understanding of asthma as a chronic disease and connections between environmental factors and respiratory health. Therefore, the ASC took the lead on a research project and completed a baseline assessment of asthma and allergy programs and resources available in First Nations and Inuit communities, as well as identified needs and gaps in asthma/allergy programs. The project was implemented in collaboration with the Assembly of First Nations (AFN)³ and Inuit Tapiriit Kanatami (ITK)⁴ and supported by Allergen NCE Inc.⁵, the National Centre of Excellence for allergy and asthma research and the First Nations and Inuit Health Branch (FNIHB), Health Canada. The report “A Shared vision: Ensuring quality of life for adults and children with asthma and allergies in First Nations and Inuit Communities in Canada”⁶ was released in January 2009 and presented to all participating stakeholders with a copy publicly available on the ASC and AFN websites.

The ASC is using its experiences and expertise gained during the project to continue conducting community-based initiatives in First Nations and Inuit communities to improve respiratory health awareness and education amongst community members specifically youth affected by asthma and associated allergies and their extended families. Taking into consideration the findings from the “A Shared Vision” report, the ASC is acting upon the first of the five recommendations: the development of culturally appropriate asthma/allergy education for First Nations and Inuit community members.

Development of culturally appropriate materials was also recognized as the top priority by participants at the Asthma Expert Advisory Forum⁷ that was organized by the First Nations and Inuit Health Branch (FNIHB), Health Canada in Winnipeg (December 08&09, 2009). The Forum indicated that the development of culturally appropriate resources for youth and families affected by asthma in First Nations and Inuit communities should be driven by the community in order to be successful. At the Forum, it was also suggested to move forward by soliciting Aboriginal community members' input on how to make asthma educational materials relevant to First Nations and Inuit communities and meet their unique learning and cultural needs.

IV. Project Description

1. Background

Cultural practices and behaviors are essential for First Nations and Inuit community members and embedded in their everyday activities. It is important that they are taken into consideration when developing any health-related educational interventions and materials. Proper community engagement plays a crucial role in success of any community-based initiatives and should be considered as a first step in the development process of educational materials and resources.

Currently, there is a lack of culturally appropriate educational materials and resources on asthma and associated allergies that are tailored to the needs of Aboriginal people including youth and their families. This has been identified as the key existing barrier to accessing community resources and getting proper information/education on asthma and allergies. Based on the findings from the "A Shared Vision" report (2009), 80% of participants from First Nations and Inuit communities agreed that children and the elderly were mostly affected by asthma and associated allergies. Furthermore, the majority of participants (63%) indicated that culturally appropriate asthma education would help children and their families to identify and manage their asthma, and would be most effective in helping communities to address asthma in the future leading to its proper management and prevention with a potential reduction in asthma rates.

The project under description has been 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 kinds of programs and materials they feel will be beneficial for their communities taking into consideration unique cultural characteristics and learning preferences of community residents.

2. Project Objectives

Overall, the aim of the project was to complete ground work that would inform implementation of future initiatives related to the development of relevant asthma educational materials and resources for First Nations and Inuit community members as well as prepare community residents for their effective participation in focus groups and other community-based programs. As well, project implementation was aimed to facilitate establishing connections with people suffering from asthma and associated allergies that reside in First Nations and Inuit communities mostly focusing on youth, their families and caregivers. The project was also designed to help identify broader priorities for action in regards to establishing community support resources for

Aboriginal youth with asthma and their families that could be clarified and narrowed down by conducting focus groups and community surveys in the future. The main goals of the implemented project “A Shared Voice: Engaging First Nations and Inuit Communities in the development of culturally appropriate asthma and allergy educational materials and resources for youth and their families” can be presented as follows:

- Engage key informants from First Nations and Inuit communities including youth, their extended families (elders), and caregivers (e.g. teachers, primary health care providers) as well as community leaders (elders) in reviewing and assessing existing asthma and allergy educational materials/resources
- Prepare a package of existing asthma educational materials that are identified as being appropriate for First Nations and Inuit community residents to be presented and discussed further during focus groups
- Identify what kind of asthma support resources (e.g. web-based forums, peer-to-peer support and education, etc.) are required and will work well with First Nations and Inuit youth and their families in order to empower them to better manage their asthma and associated allergies on a daily basis
- Identify Aboriginal community members’ main issues regarding proper asthma management and determine priority actions
- Compile a “wish list” of support resources that are appropriate to implement in First Nations and Inuit communities to be discussed further during focus groups
- Establish a community Advisory Group from First Nations and Inuit community representatives and other stakeholders to guide and advise on next steps and initiatives to ensure proper community engagement in future activities related to improvement of asthma education and care for First Nations and Inuit youth affected by asthma and their extended families

To meet the aforementioned objectives, the ASC engaged First Nations and Inuit youth with asthma, their extended families and community leaders in review and assessment of disease management tools, educational materials and resources available in English. Based on our environmental scan, educational materials on asthma and allergy in First Nations and Inuit languages are not in existence so they cannot be evaluated as part of this project.

3. Main Project Activities and Findings

The ASC conducted outreach to First Nations and Inuit youth with asthma and associated allergies and their families and engaged them in review/assessment of existing English language asthma educational materials and resources. This initiative represented the first step towards developing culturally appropriate asthma education materials and support resources, and will inform other initiatives to be implemented in the next two years. The project activities were conducted over a period of one month, beginning February 1, 2010. Project analysis was

conducted in April and May of 2010, and the final report preparation was completed in June of 2010.

In order to meet the project objectives, the project undertook the following activities, which can be divided into three main components: A) Review and assessment of existing asthma educational materials and resources; B) Assessment of web-based resources and material for one-on-one and/or group asthma education (webinar sessions); and C) Creation of the community Advisory Group.

A) Review and assessment of existing asthma educational materials and resources

Feedback on the current asthma materials was gathered by applying a multi-method approach and collecting both quantitative (e.g. ranking) and qualitative (e.g. comments/opinions) input. An environmental scan of available asthma materials and resources across Canada and internationally was conducted in order to generate a broad selection of asthma materials ranging in style, format, and content. An assessment package of printed asthma educational materials was developed for four target groups to ensure a wide community representation. The following target groups were identified who would review and assess the asthma educational package:

- Children ages 6 to 12
- Children and teenagers ages 12 and above
- Parents and grandparents
- Community leaders and a broader group of caregivers (e.g. school teachers, primary care nurses, etc.)

The assessment packages were assembled and distributed to a diverse group of community residents by community outreach workers and community contacts who served as community liaisons for this project (see Appendix 1 for a brief description of the materials included in the packages). Community outreach workers were appointed by the ASC to help establish connections with youth affected by asthma and their families and ensure their proper participation in the project. A specially designed questionnaire was included in the package to standardize the assessment process and identify elements that make educational materials culturally sensitive to First Nations and Inuit youth affected by asthma and their families. The package also contained a list of web-based materials, and participants were asked to evaluate these resources as well. All correspondence, evaluation forms and questionnaires were provided in English. Potential participants were asked to seek help from family members, friends and/or community leaders if they required any assistance with translation. Community outreach workers were also available to help with translation if necessary.

The ASC conducted outreach to First Nations and Inuit communities with the aim of distributing 100 assessment packages/questionnaires to youth, their extended families (including elders), caregivers (e.g. teachers, primary health care providers) , and community leaders with the goal of collecting 50 questionnaires back (considering a typical response rate of 50%). The ASC used its existing partnerships with the AFN and ITK, connections established during the preparation

of the “A Shared Vision” report and at the Asthma Expert Advisory Forum as well as the ASC’s contacts through its membership patient group, the National Asthma Patient Alliance (NAPA)⁸.

In total, **130** assessment packages/questionnaires were distributed amongst the identified target groups, and **68** completed questionnaires were received back at the ASC. This was consistent with the expected response rate. For the distribution of the questionnaires received, organized by province and target group, please refer to Appendix 2.

3.1. Findings

The majority of project participants amongst all age categories reported that they had received asthma and/or allergy information/education from various sources. Most children in both age categories (children ages 6 to 12 and children ages 12 and above) learned about asthma and/or allergies from their mother (64.3% and 55.6%, respectively) or received information from a physician/nurse (57.1% and 44.4%, respectively). The majority of parents/grandparents in the study (70.0%) felt that they had a good understanding about asthma and associated allergies, which they attributed to information provided by various health care professionals including physicians (45.5%); nurse practitioners (40.9%), and pharmacists (27.3%). Further, the majority of children ages 12 and above (60%) and all parents were shown the proper way to use an asthma inhaler/spacer mostly by a physician (50% and 45.5%, respectively) followed by a nurse or nurse practitioner (38.9% and 50.0%, respectively). Older children in the study were also educated on how to use their puffers by family members (16.7%).

When asked about Internet access, most respondents ages 12 and above as well as parents/grandparents reported having access to the Internet on a regular basis (85.7% and 76.2%, respectively). However, Internet access was limited for children ages 6 to 12, in which group the majority have access to the Internet once a week (84.6%).

Based on findings, the following phrases describe the main themes most relevant for each target group:

- Children ages 6 to 12- ***“Fun and Interactive”***
- Children and teenagers ages 12 and over - ***“Engaging and Exciting”***
- Parents and grandparents – ***“Informative and Culturally Appropriate Education”***
- Teachers and community leaders – ***“References to Aboriginal culture and Traditional Healing Information”***

Overall, the educational materials assessed were highly favored by participants among all age categories. The majority of parents/grandparents and community leaders/teachers believed that existing asthma educational materials could be adapted to suit the needs of Aboriginal communities and modified to make them relevant to Aboriginal culture. To make newly developed materials culturally appropriate, both parents and community leaders suggested having more pictures/images that related to their culture (45.5% and 42.9%, respectively), followed by more real life stories of Aboriginal people living with asthma (36.4% and 50.0%, respectively), and make the material available in their spoken language (22.7% and 35.7%, respectively). It was recommended to incorporate personal stories in both booklets and websites

focusing on Aboriginal people, preferable a recognizable leader, who lives with asthma and manage it well. Adding real-life success stories will help Aboriginal people to relate better to their own communities and empower them to cope well with asthma. The stories will also help promote community awareness surrounding asthma and its management. Further, the addition of more pictures reflective of the Aboriginal culture, possibly developed by a well-known Aboriginal artist, will also help make the material more culturally relevant.

Besides making the materials more culturally appropriate, the development of new asthma educational materials should be age specific and take into consideration the learning styles of First Nations and Inuit community members that were identified during the project. When asked about their learning preferences, children ages 6 to 12 indicated their preference to learn through play (71.4%), while older children, parents/grandparents, and community leaders indicated a preference for visual learning through pictures/diagrams, images on the Internet, etc. (44.4%, 77.3%, 78.6%, respectively). Additionally, younger children appreciated the materials for their fun, engaging, and interactive elements as well as pictures, while older children were looking for more substantial content to further their knowledge about asthma and allergies. Parents/grandparents and community leaders were also looking to have materials which contained activities (games, puzzles, storytelling, etc.) for children in their care.

Based on the learning preferences and identified preferred material format and style, implications for the development of new asthma educational material and resources can be made for children in each age category (ages 6 to 12; 12 and above) as described below. Results indicated that children ages 6 to 12 enjoyed learning through interactive activities either available on the websites (e.g. virtual games) or paper-based (e.g. booklets with games, puzzles, etc.) as well as booklets with pictures. In addition, this group expressed a need for personal interaction while learning about asthma and allergies. Therefore, a combination of educational materials (booklets with pictures) and activities (paper-based and/or virtual) supported by in person education provided by parents and/or health care professionals would be suitable for this age group. Data showed that children ages 12 and above preferred a combination of more content heavy traditional materials (e.g. booklets, factsheets) and digital materials (e.g. websites, CD game) for their educational needs. Further, the majority of children ages 12 and above liked the idea of getting health related information in the form of a factsheet (83.3%) and rated factsheets on their wish list (61.1%) as the most preferred way of receiving information (e.g. Information on how to use asthma medications properly). From the sampled factsheets, the *Asthma and Smoking* factsheet (refer to Appendix 1) was rated the highest inferring that this topic could be of special interest for this age group. The second preference from their wish list was to have a CD with audio lessons on asthma, which were chosen almost by half of the participants (44.4%). Asthma diaries were one format of the material that was ranked poorly among children in both age groups. Along with having more information/content in printed materials (e.g. booklets, brochures, etc.), older children expressed an interest in having more pictures in newly developed materials, which is similar to the younger audience.

Recommendations for the development of new asthma educational material and resources can be made for parents/grandparents and community leaders/teachers based on their preferences from the reviewed materials as well as suggestions on how to make the materials more culturally appropriate. Parents/grandparents indicated booklets, checklists/factsheets, and asthma action

plans/emergency cards as the “most likely to be used” materials from the sample as well as the preferred format for receiving asthma information. Further, most parents (90.9%) and all community leaders reported that they liked the idea of getting health related information in the form of a factsheet. It is important to note that although both groups rated websites high, that format was not chosen as a preferred method of receiving asthma information, perhaps taking into consideration not universal accessibility of web-based resources. In addition, community leaders would like to have materials geared to the community such as activities for children in their care and community posters.

In regards to the content of future materials, parents/grandparents and community leaders would like to learn more about asthma triggers/allergies and how to control their environment (e.g. the *Triggers Asthma Basics #2* booklet; refer to Appendix 1) as well as receive lifestyle related asthma information (e.g. pets, smoking, exposure to second-hand smoke, mould, exercise, etc.). In addition, more than half of the parents (54.5%) and the majority of community leaders (85.7%) suggested that the newly developed materials should cover unique issues to Aboriginal communities (e.g. road dust, forest fire smoke, etc.) as well as provide information about native remedies (68.2% and 64.3%, respectively) and holistic approaches (54.5% and 71.4%, respectively). In addition, all participants who reviewed materials on asthma medication (e.g. older children, parents/grandparents and community leaders) found it helpful to have information on how to use asthma medication (93.3% and 94.7%, respectively) and indicated that they would like to have information on proper medication usage either in a factsheet or book format.

One specific material format, an Asthma Action Plan (AAP), was confirmed by all age categories as the material that they would like to use as a way of managing their asthma better. Almost all of the younger children (92.9%) liked the idea of an AAP to help know which medication to take and when to take it. The majority of older children and parents/grandparents had never been given an AAP before (70.6% and 81.3%, respectively), however found that the AAPs would help them take better care of their asthma. The majority of them also indicated that they would use an AAP and follow its recommendations (83.3% and 95.5%, respectively). Further, 91.7% of community leaders agreed that parents in their community would use an AAP and follow its recommendations to manage their children’s asthma. From the AAP sampled, older children preferred the *Children’s Asthma Education Centre (CAEC) AAP* (87.6%) (refer to Appendix 1), with suggestions of more pictures, information, and a section to record information. Although parents/grandparents did not have a favourite AAP, two asthma action plans (*A Little Asthma Plan (6-8 years old)* and *Breathe- Asthma Action Plan (9-14 years old)*) (refer to Appendix 1) were deemed to be age specific and possibly used as a starting point in the development of an AAP that would be age appropriate and specific to Aboriginal communities. In addition to AAPs, the idea of a portable emergency card was popular among parents/grandparents and community leaders, with 94.4% of the parents/grandparents and all community leaders reporting that they would like to have an asthma emergency card available in their communities.

In summary, appropriate images/pictures related to Aboriginal culture, personal stories of native people living with asthma, and materials on issues specific to Aboriginal communities including traditional healing information about native remedies and approaches and how they could be combined with the conventional medicine were suggested as ways of developing new asthma

educational materials that will be relevant to First Nations and Inuit communities. Further, the content of the newly developed material should focus on asthma triggers/allergies, unique lifestyle issues that exist in Aboriginal communities, and proper asthma management (e.g. medication usage, AAPs, etc.). In addition, interactive activities, booklets with pictures and factsheets with information on asthma, and a preference for visual methods of learning was apparent among the participants and should be considered when developing new asthma educational materials.

B) Assessment of web-based resources and material for one-on-one and/or group asthma education (Webinar Sessions)

Webinar technology was used to assess First Nations and Inuit communities' preferences of the existing support resources (e.g. websites, E-learning module, etc.) and materials for one on one and/or group education. This technology was used in order to make this activity accessible for people in remote places while enabling proper interaction.

Webinars were organized for children, youth, their extended families, and community leaders and caregivers (e.g. health care providers, community workers, and teachers) to solicit their opinion about existing web-based resources and group educational sessions. Webinar sessions were organized under two categories as follows: asthma educational sessions (group educational session about asthma to assess how asthma education/information could be delivered to First Nations and Inuit community members), and website webinars (informational session to discuss and evaluate existing asthma web-based resources and materials). In total, five webinar sessions lasting for 60-90 minutes each were conducted with **56** participants from First Nations and Inuit communities as follows:

- One educational session for children 6 to 12 years of age
- Two educational sessions for parents/grandparents/community leaders and children 12 years old and above
- Two website informational sessions for parents/caregivers, community leaders and children 12 years old and above

Please refer to Appendix 3 for a provincial distribution of webinar participants. A description of the webinar sessions conducted is presented below:

Educational session for parents/grandparents and community leaders

A Certified Asthma/Respiratory Educator (CAE/CRE) delivered a short educational session through a PowerPoint presentation on the main aspects of asthma and its management to parents/grandparents and community leaders. Participants were given the opportunity to ask questions pertaining to asthma and had an open discussion through a live chat with the CAE/CRE. Asthma action plans were also reviewed at the end of the webinar session followed by an open discussion on participants' preferences about the plan design.

Educational session for children

The educational webinar session for children was conducted by a “*Roaring Adventures of Puff*” (RAP)⁹ trained facilitator to give children ages 6 to 12 the opportunity to participate in a group educational session. During this session, the RAP instructor gave a presentation using asthma materials and the design of the RAP program, focusing on the topic related to asthma medications. Throughout the session children were able to ask questions through the live chat room and were involved in answering poll questions that were asked at the end of the session. During the session, the children were also able to communicate amongst each other allowing for peer support.

Websites webinar sessions

The website webinar session was designed to show various websites from lung health organizations and hospitals that have materials and resources about asthma and allergies, as well as present a web-based module (the E-learning module) to find out if this educational tool would be helpful and/or appealing for First Nations and Inuit community members. Background information about current web-based resources was provided to potential participants ahead of time to give them an opportunity to review them thoroughly. During the session, participants were given the opportunity to visit the websites and follow the presenter who navigated through each of them. They were also able to ask questions through the live chat room and answered poll questions about each of the websites, as well as provided their own opinion on what they found to be useful or not.

3.2. Findings

During the webinar sessions, the live chat dialogue was recorded and transcribed. Further, participants were involved in answering poll questions throughout the webinar session. The webinar findings are therefore separated into two main categories: Dialogue Findings and Poll Findings as presented below.

3.2.1. Dialogue Findings

Appendix 4 presents a summary of the desirable program/materials elements (‘best practices’) identified by webinar participants. The “best practices” can be categorized into four areas as follows: content, design, format, and delivery/promotion.

- **Content**

Participants’ recommendations for educational content emphasized both the use of ‘real life’ stories as well as information that differentiates between myths and facts about asthma. Participants also suggested a focus on environmental determinants of health would be particularly important for First Nations audiences, which imply recognition of the need to address and discuss issues such as housing conditions, indoor/outdoor air quality, and road dusts, which are known to be common in many Aboriginal communities. When participants were asked about their concerns surrounding asthma, 34.6% of them indicated that “smoking and asthma”

was a concern, followed by “childhood asthma”, “medication concerns”, and finally “living conditions with asthma” and “community awareness about asthma”. As a result of this, the content for the development of new material should be structured around the above mentioned areas. Further, 22.2% mentioned they would like to learn about “native remedies and their potential role in asthma management”.

- **Design**

Participants recommended a number of strategies to ensure that the design of materials was ‘eye catching’. All four groups agreed that the use of age appropriate pictures and characters, as well as bright colours was important to ensure that materials maintained children’s attention. In particular, several participants agreed that the Hospital for Sick Kids website provided a good model of a ‘best practices’ in youth asthma education. Further, 44.4% of participants indicated that they were interested in learning through pictures.

- **Format**

All three adult groups saw interactivity as the key ‘best practice’ in program delivery, suggesting recognition that digital formats such as websites were both appropriate and widely accepted in Aboriginal communities. However, at least one participant cautioned that accessibility may pose a barrier as not everyone has easy access to a computer or an Internet connection. Other specific format features recommended included the use of storytelling, live chat, and games and puzzles. When participants were asked about their preferred format for the development of new asthma material, 23.4% indicated preference for a Video/DVD, followed by activities for kids. Posters, calendars, websites/Internet, and webinars were also mentioned.

- **Delivery/Promotion**

Finally, all three adult webinar groups were enthusiastic about implementing strategies to communicate programs and materials as widely as possible in the community. Participants wanted to ensure that proper information reach the people that would benefit from the information and education. Community awareness was of top priority, and it was suggested that an “asthma information night” be conducted in schools and community settings. Two groups mentioned that material delivery should be mediated by health care professionals to ensure appropriate information was being provided and discussed.

Further, when participants were asked about what they enjoyed about the webinar or what their “desirable elements” were, 61.5% indicated that the visual interaction and being able to speak to a professional and receive information and answers to their questions right away was something they enjoyed. Following ‘ease of access to professionals’, the ‘information learned’ was listed as the second “liked” feature. In addition, when asked about ‘future directions’, 57.7% indicated that school programs and community information meetings about asthma would be a priority and of interest. These findings were also consistent with the insights provided by the Project Team that was involved in the webinars delivery.

3.2.2. Poll Findings

The poll findings are presented for each category of webinars conducted (Website Webinar, Children Educational Webinar, and Parents/Grandparents, Community Leaders and Children ages 12 and above Educational Webinar) as follows:

- **Website Webinar**

During the website webinar, 100% of the participants indicated that the websites sampled were engaging and interactive (refer to Appendix 5 for a description of the websites). When asked separately to rate the web resources sampled using the five-point rating scale, the *Hospital for Sick Kids* website was ranked the highest, with an average rating of 4.7 out of 5 followed by the *Asthma Society of Canada* website at 4.5 out of 5, the *Alberta Health Service-iCan* website at 4.46 out of 5, and the *E-learning module* at 4.41 out of 5 (refer to Appendix 6 for a graphical representation of results). When asked if they would use the *E-learning module* to learn about asthma, 92% of participants indicated that they would. When asked which web resource they liked the most, 77% of participants indicated the *Hospital for Sick Kids* website. When asked which web resource they disliked the most, 62% of participants indicated the *United Kingdom – Kick Asthma* website. From these findings, the *Hospital for Sick Kids* website was ranked the highest and, therefore, its features including interactivity should be considered when developing new materials and resources.

- **Children’s Educational Webinar**

During the children’s educational webinar, 100% of the participants indicated that they were told that they had asthma, allergies and/or breathing problems. When asked who told them about asthma, 75% of the participants indicated that either their parents and/or grandparents told them about asthma. When asked whether they enjoyed when someone talked to them about asthma, 100% of the participants said they did. Further, when asked who they would like to learn about asthma from, 83% of participants indicated their parents. Finally, when asked how they would like to learn about asthma, 50% of participants indicated through activities (games/puzzles), and a tie of 25% of participants indicated posters/calendars and video/CD’s. From these findings, it is apparent that the development of new asthma resources and materials should be targeted towards parents and contains activities that they can use to educate their children about asthma. Further, material should be interactive and fun (games), and have a large visual aspect to it. In addition, when participants were asked what they enjoyed about the webinar session, over half of the participants (66.7%) indicated that they enjoyed being able to receive “a lot of information”, while the second highest response revealed that they liked the webinar because “it was fun” (16.7%). After the webinar, one parent commented on how the children’s educational session had made her 6 year old child ask more questions about asthma and how “he was teaching other students at his school about asthma – all because of the webinar session”. Another mother who was starting nursing school found this to be educational and very important for her to know as well. Furthermore, during the children’s session, children were open to answering questions on medication and how often they used their inhalers and were honest about not knowing the inhaler technique.

- **Parents/Grandparents, Community Leaders and Children Ages 12 and above Educational Webinar**

During the parents, grandparents, community leaders and/or children ages 12 and over educational webinar, 100% of participants believed that asthma and/or breathing problems were a concern in their community. When asked to rate asthma action plans using the five-point scale, the asthma action plan from the CHEO was ranked the highest at 4.16 out of 5 followed by a tie at 4 out of 5 for the two asthma action plans from the Alberta Health Services (*A Little Asthma Action Plan* and *Asthma Action Plans – youth and adults*) (refer to Appendix 7 for a graphical representation of results). When asked which asthma action plan they liked the most, 38% of participants indicated the *Breathe Asthma Action Plan* from the ASC (Appendix 8). When participants were asked whether they had ever used an asthma action plan before, 84% of participants indicated no. When they were asked whether the use of an asthma action plan would help take better care of a child(ren) with asthma and/or breathing problems, 100% of participants said “yes”. In addition, when asked whether they would use an asthma action plan and follow its recommendations, 100% of participants said “yes”. Finally, when asked how the asthma action plan can be modified to be more useful for First Nations and Inuit communities, 42% of participants said by adding more ‘pictures/diagrams’ followed by 38% of participants indicated to add more ‘information and/or content’. Based on these findings, any new developed material should include the development of asthma action plans for First Nations and Inuit community members to promote proper asthma control and management.

When participants were asked whether they found the webinar educational session to be engaging and interactive, 96% of participants answered “yes”. Further, when participants were asked what in particular they liked about the webinar session, 54% of participants responded ‘educational’, 23% of participants choose ‘informative’, and 15% of participants indicated ‘interactive’. When asked how they prefer to receive information about asthma and associated allergies, 54% of participants said “through virtual/audio modules” followed by “online education” and “in-person education” (27% and 19% respectively). When asked who should deliver asthma education, 60% of participants mentioned a health care professional, with the majority of participants being comfortable with education delivered in a group setting (88.9%). This feedback indicates that webinar technology as a way of delivering group asthma education by a CAE/CRE and/or other health care professionals could be a method of choice for First Nations and Inuit community members especially those living in isolated and remote places.

In summary, the findings from the webinar sessions conducted helped gain a better understanding about what kind of new asthma educational material and resources should be developed for First Nations and Inuit communities in order to reflect their cultural practices and learning preferences. Thus, the development of new material should be interactive. The majority of participants rated the *Hospital for Sick Kids* website as their greatest preference due to its interactive nature. Further, when participants were asked how they would like to receive/learn new asthma information, the majority of them indicated “virtual/audio modules”, visual learning through “pictures with bright colours”, and “activities/games” for children as their top choices. The content for the development of new asthma material should focus on asthma triggers (e.g. smoke) and environmental determinants of health, provide real-life stories and present unique issues/practices that exist in First Nations and Inuit communities (e.g. housing conditions, native

remedies, etc.). Further, new material should focus on childhood asthma and be targeted to parents and/or grandparents in order for them to educate their children about asthma as the majority of children indicated that they would like to learn about asthma and/or allergies from their parents.

The concept of an asthma action plan was highly supported by all the participants. Therefore, newly developed material should include an “Asthma Action Plan” that would be relevant to First Nations and Inuit communities in order to promote asthma self-management and control amongst community members.

Further, in order to encourage proper asthma management and control, community awareness about asthma was identified as a main priority for First Nations and Inuit communities. Community programs about asthma (e.g. asthma information night, school events, etc.) should be developed and delivered in community settings to increase community awareness about asthma and create a supportive environment within the community.

During webinar sessions, participants enjoyed webinar educational sessions for their direct access to health care professionals (CAE/CREs), since it allowed them to receive immediate feedback on their questions. In addition, the majority of participants indicated that they enjoyed the webinar for its educational aspect and being able to receive a lot of information in a short time frame. This finding reaffirms the previously made observation that interactive methods of learning work well with First Nations and Inuit community members. Further considerations are required in order to understand how the webinar technology could fit with more traditional educational approaches (e.g. printed materials) and be used to deliver group educational sessions.

C) Creation of the community Advisory Group

A community Advisory Group Meeting was organized to complement the findings of the previously described activities through an in-person discussion with Aboriginal community members in order to gather their input on existing asthma related materials, programs, and websites and relevance of these resources to the First Nations and Inuit Communities. The open discussion forum served to help determine priority actions for Aboriginal communities as well as encourage involvement in future community based initiatives (e.g. focus groups) related to the development of relevant asthma educational materials and resources. The open discussion forum also served to discuss any concerns/barriers faced by First Nations and Inuit community members regarding proper asthma management and control.

The Advisory Group Meeting was held in Ottawa, Ontario on Friday, March 26th, 2010 at the Wabano Centre for Aboriginal Healthⁱ. The ASC recruited ten Aboriginal participants, all of whom had a connection to asthma. The Wabano Centre for Aboriginal Health¹⁰ was chosen as the venue for the meeting because it provided us with an environment, which we felt was comfortable and engaging to First Nations and Inuit community members. The meeting engaged

ⁱ The Wabano Centre for Aboriginal Health is an urban health centre that delivers services to prevent, treat, and provide support for ill health. Services are offered in a culturally-sensitive way that welcomes, accepts, and represents Aboriginal people(s).

Aboriginal community members by incorporating ice breaking activities along with traditional Aboriginal opening and closing ceremonies.

In order to have an open discussion on kinds of asthma programs and materials that would be beneficial for Aboriginal communities, a sample of existing asthma educational materials and resources was prepared by the ASC to be assessed and discussed by the Advisory Group members at the meeting. The materials and resources chosen by the ASC were taken from the final inventory list of materials selected by a means of the environmental scan described earlier in the report (refer to Appendix 1). Approximately eighty percent (80%) of the items from the final inventory list were included in the sample to be reviewed at the Advisory Group Meeting. Feedback on the asthma printed and web-based materials were gathered by applying three different methods including: ballots, wish list, and open discussion. A brief description of each method is presented below:

- **Ballots:** Participants evaluated the asthma educational material and resources sampled using a five-point rating scale on a series of ballots (quantitative method), as well as by providing written comments (qualitative method). The written comments on the back of the ballot were compared with the ballot results for each category of material. A sample ballot is presented in Appendix 9.
- **Wish List:** Participants were asked to fill out their wish list of asthma educational material and resources. A wish list of asthma educational and support resources was created to understand what materials are necessary to develop for First Nations and Inuit communities. The wish list of asthma educational material and resources was designed to ask participants the following two main questions related to the desirable content and format of potential educational materials:
 - 1) *Format* - Please specify your preferred method of receiving asthma educational materials and resources (wish list of materials about asthma and/or allergies)
 - 2) *Content* -Please specify your topics of interest on asthma and/or allergies (which areas on asthma and/or allergies you would like to know more information about)
- **Open Discussion:** During the Advisory Group Meeting, the audio and video of the meeting dialogue was recorded, and written notes were taken by three individuals on how the material can be made more culturally appropriate.

3.3. Findings

The combined findings from the ballot, wish list, and open discussion attained at the Advisory Group Meeting provided valuable feedback on the existing asthma educational materials and resources sampled and their relevance to the First Nations and Inuit communities. The meeting also provided insight on future directions for development of materials and resources aimed to improve asthma management and control in Aboriginal communities.

To lead the open discussion, the following questions were asked by the ASC during the Advisory Group meeting:

- Is asthma an issue in your community?
- Are there any existing asthma services or groups available?
- What are the barriers to asthma education in your community?
- What did you like about the materials?
 - Preferred format?
 - Do you prefer learning through pictures or text?
- What did you dislike about the material?
- How can the materials be modified to be made more culturally appropriate?
 - Are these materials relevant?

From these questions, the ballot, and wish list results, the overall findings can be categorized under the following main themes: People/community perspectives on asthma; Barriers to proper asthma management; Feedback on existing educational materials/resources, and Development of new asthma materials/resources.

People/Community Perspectives on Asthma

On a general note, from the open discussion it was found that First Nations and Inuit community members think that “asthma is something that is kept quiet” in their communities and is not taken “as a serious condition, although it is”. Participants had mentioned that they keep their asthma to themselves, and do not let other people know about their condition (e.g. “I don’t advertise that I have asthma”). For instance, when around someone who smokes, instead of asking that person to put out their cigarette, they would just walk away instead of letting them know that they have asthma. Further, participants mentioned that they felt others would be afraid of them because they had asthma saying: “People who have asthma do not want to say that they have asthma because people could be scared of them”, and that children see “taking their inhaler as not cool”. Participants also mentioned that there were “some fears about western medications”, as attention and interest in “natural medicine is growing” in Aboriginal communities.

Participants also indicated that they felt asthma was not taken seriously, and that the main concern from health professionals and the communities was on other health conditions (e.g. diabetes, heart disease, etc.). Education on asthma management was also limited, as parents were unsure what to do when their child got sick and what questions to ask, and would resort to having their children miss out on sports. Participants were not aware of the available asthma educational resources, and the majority of participants mentioned that they did not know that an asthma action plan existed. The consensus from the meeting was that asthma was “being pushed aside” and “has been dormant and silent” and these negative perceptions of asthma need to be changed and that people “have to start talking about it” to normalize asthma within the community.

Barriers to proper asthma management

The meeting participants expressed many concerns related to asthma management in their communities as presented below:

1) Potential effect of traditional ceremonies and exposure to second-hand smoke

The majority of First Nations Aboriginal ceremonies involve tobacco smoke and participants raised a question whether or not these activities may be detrimental to an individual with asthma. Further, there is a concern about exposure to second-hand smoke and a lack of awareness among community residents about its harmful effects in general and on people with asthma in particular.

2) Impact by environmental factors including poor housing

Poor living conditions in some Aboriginal communities were noted as an additional concern and barrier to proper asthma control. Some residents are exposed to mold and mildew in the house. Participants also brought up an issue of pollution including “dirt roads or live near a dump”.

3) Lack of educational resources available

Another concern and barrier to proper asthma management was the fact that there were no asthma resources or information readily available in both First Nations and Inuit communities. It was noted that “community clinics do not contain information on asthma; there are no tools for asthma readily available” and “no support groups in communities or they are too far away”. As a result of this, Aboriginal community members are not well educated about asthma, including information on asthma triggers, asthma management and treatment. Further, proper medication administration/usage was identified as another concern in the community with “people not knowing how to use their asthma puffers”. It was also noted that some people were bad at keeping records, which “are the key to management from a health care provider perspective”.

4) Access to health care services

The participants mentioned that “not all Aboriginal communities have doctors readily available” and therefore not having enough health-care resources readily available was a main concern. This issue is even more pronounced in small communities with no or limited clinical services and transportation being a major challenge as well (e.g. “the nearest emergency is 6 hours away”).

5) Barrier in communicating with health care professionals

An addition concern noted at the meeting was a communication barrier when speaking to doctors/health care providers about asthma. The use of terminology was “too advanced” and this made language a barrier in understanding asthma and how to properly control it. The same concern was expressed in regards to children and the language used by doctors in dealing with them.

6) Health care professionals expertise on asthma

It was mentioned that there was a lack of professional development programs for health care providers and community workers so they do not have an opportunity to upgrade their skills related to asthma management/education.

7) Coverage for asthma medication and devices

Additional concerns mentioned at the meeting were a lack of coverage for asthma medications as “government programs no longer cover all treatment costs”.

8) Lack of asthma awareness at community level

There is a lack of advertisement related to asthma which leads to insufficient information available on asthma at community level. One participant mentioned, “You don’t see educational awareness posters (on asthma) at native health centres”. At schools, there is an alert for allergies; however, existing school programs on asthma from the Asthma Society of Canada are not tailored to the needs of First nations and Inuit communities.

Feedback on Existing Educational Materials/Resources

Education was a major topic discussed at the Advisory Group Meeting and its crucial role in proper asthma management was highly emphasized by the Advisory Group members. Education was seen as the key and a great way of “normalizing” asthma in the community, and empowering those that have asthma to strive to live symptom free. Participants agreed that education should be provided to all members of the society to increase public awareness about asthma and allergies. People also thought that education was very important to ‘empower children to make choices’ and that it should be a focus on providing training and education in schools/daycares. For example, one participant noted: “Early childhood education is where the asthma education should be. Important to have someone teach them about asthma and how to deal with it”.

After reviewing the materials, participants were asked to identify ‘negative’ elements or features that they liked the least and did not want to see in future materials. The main negative element identified by the participants was that materials were ‘too busy’ and had ‘too much writing’ so people ‘lost interest’ in reading them. Materials that were busy and had a lot of technical information were seen as being beyond ‘reading capabilities’ for First Nations and Inuit community members. Some participants do not like the idea of games for children as they thought that games could “shed light on seriousness of the disease”. The video “*Living Well with Severe Asthma*” was sought to be ‘too professional and formal’ and ‘not engaging to individuals’. It was also noted that materials did not have Aboriginal references or pictures of Native people. Although, one participant said: “Asthma is asthma, it does not matter what culture you are”.

When asked how the reviewed materials could be adapted to make them culturally appropriate and meet needs of Aboriginal communities, the meeting participants agreed that modifications to the existing asthma material should be made and making them more culturally appropriate is important. The newly developed material should be interactive and engaging to the reader, and include information relevant to Aboriginal culture and living conditions. The material should also provide Aboriginal reference (e.g. pictures) in order for the materials to be more identifiable as well as be available in Aboriginal languages for easy understanding and comprehension.

Development of new materials

After reviewing the existing asthma educational materials and resources, participants were asked about their preferences in both material content and format. In general, it was noted that newly developed materials should balance text with pictures that fit the community, be straight forward and to the point and simple, have less technical information (terminology), be interesting, and engage the reader. Specific comments about the content and format are presented below. It was also noted that health care centres and schools should have proper access to asthma materials and resources.

Content

For material content, participants were interested in receiving information that would be more practical and geared towards triggers with further information on stress and its management and smoking including information about third-hand smoke being of a particular benefit and good information to have. This finding was confirmed by the Wish List results, whereby 32% of participants were interested in receiving information regarding control of asthma triggers in their environment (Appendix 10, Figure 2), while 16% of participants were interested in practical asthma-related lifestyle information (e.g. exercise, pets, smoking, etc.) and information about asthma action plans. Information regarding the consequences/side effects of asthma medication and how to use puffers correctly was also of great interest for participants. One of the suggestions was to have “colored puffers with explanations on what each of these puffers do”. As well, it will be good to have materials that showing children how to use their inhalers and present “real-life situations that would be more engaging and identifiable to community members”. For example, the Advisory Group members suggested having a video or commercial of a child having an asthma attack and the mother teaching the son how to use the puffer to relieve the symptoms (e.g. “show real-life management of asthma and what to do in a “right” and “wrong” situation”). Additionally, they felt that proper education on the use of traditional medicine should be available for Aboriginal community members. Further, participant raised the importance of having information on asthma prevention stating that “prevention of asthma should be the number 1 on the list”. It was also mentioned that future material needs to be more culturally appropriate and available in Aboriginal languages for better clarity. These findings were also confirmed by the ballot results and written comments. The overall trend from the ballot results indicate that First Nation and Inuit community members were interested in resources surrounding asthma prevention, management, and control of triggers. Further, resources which were practical to the everyday living conditions of Aboriginal individuals were of a greater interest (e.g. asthma and smoking, reserve living conditions), as well as material relatable to their community (e.g. pictures with Aboriginal individuals, commercials of real people showing how to properly take asthma medication, etc.). A few comments were made about the material being too difficult to comprehend due to a language barrier so it was suggested that the material should be available in Aboriginal languages as well.

Format /Desirable Elements

For material format, participants were interested in interactive and engaging ways of learning. As a best practice example, participant referred to the “Hospital for Sick Kids” website that by a

general consensus was considered the best asthma information website for children as it was interactive, engaging, and easy to use. Participants also emphasized that the material should not be too busy and filled with technical information, rather should include more pictures and diagrams to help explain the content and would be “quick and easy” to review. This finding was also confirmed by the ballot results and written comments where highly interactive resources were favored, along with resources that provided more pictures and less text (less technical information). Participants agreed that it would be beneficial to have a variety of asthma materials available in different formats as everyone has different preferences and learning styles. All participants were eager to learn about asthma and/or allergies, as no participants indicated that they did not want to receive asthma education. Participants also mentioned that individuals in their communities most likely would not read pamphlets nor use an asthma diary. It was suggested that asthma information be displayed through TV commercials, posters, and games for children with references to the Aboriginal culture. This is in comparison to the wish list findings, which indicate that that 52% of participants preferred to receive their asthma and/or allergies information through printed materials (e.g. booklets, factsheets, posters etc.), followed by 26% of participants for personal interaction (including support groups, mentor etc.), and 19% of participants for audio/video means (Appendix 10, Figure 1). Further, the wish list findings also show some outliers in the results, which can be explained through experimental errors. For instance, none of participants expressed interest in receiving asthma educational information through a webinar. This finding can be explained by the fact that the Advisory Group members have not yet participated in an educational webinar, and the small population of participants sampled may have never experienced this type of education.

Other materials that were mentioned from the Advisory Group Meeting include the following:

- **Asthma emergency/info card.** Participants mentioned that they would be interested in keeping a small asthma information card on them. They noted that a wallet card or medical asthma bracelet would be good for the hospitals.
- **Asthma action plan.** It was mentioned that an asthma action plan would be a great tool for Health Centres. A newly developed plan should “have space so someone can write” (there is no space on presented asthma action plans).
- **Conversation map.** It was suggested to develop a treatment map on a large sheet for kids to be used for discussion purposes and provide an interactive way of learning. That “conversation map” would represent a “culturally appropriate road map game for childhood asthma and contain information about asthma, triggers, prevention strategies, etc.”

In summary, the main findings from the Advisory Group meeting indicate that overall, asthma is not considered as a priority in First Nations and Inuit communities where there is a lack of community awareness of asthma. The Advisory Group members agreed that asthma is something that is kept quiet and is not taken as a serious chronic condition. One of the possible explanations for this attitude towards asthma may be the fact that tools and/or resources about asthma and associated allergies and not readily available in communities. Prior to the Advisory Group Meeting, many of the participants were not aware that any of these asthma resources existed. Participants mentioned that there were few doctors available in some of the remote areas, and

that community centres did not have these asthma resources readily available. Placing similar resources in Aboriginal community centres could help increase asthma awareness and decrease the rates of asthma deaths in Aboriginal communities. The participants also emphasized the importance of normalizing asthma within the community. The latter could be achieved by gearing educational initiatives towards community as a whole and conducting community educational sessions about asthma including information about prevention, triggers and its proper management.

The overall results from the meeting (the ballot, wish list and open ended discussion results) suggest that First Nation and Inuit community members are interested in resources surrounding asthma prevention, management, and environmental control. As mentioned earlier, resources which were highly interactive were favored, along with resources that provided more pictures and less technical information and were applicable to the everyday living of community members. Participants also indicated that they were interested in having material relatable to their community (e.g. pictures with Aboriginal individuals, commercials of real people showing how to properly take their asthma medication) and potentially available in Aboriginal languages.

The Advisory Group members identified many concerns and barriers to proper asthma management as well as ways to make the asthma material more culturally appropriate and relevant to First Nations and Inuit community members. The key messages from the Advisory Group meeting are summarized below:

- Important to educate broader community members about asthma through community educational sessions and resources in order to normalize asthma within the community
- Asthma prevention, asthma triggers, medication use and environmental control are the key topics of interest for First Nations and Inuit community members
- Resources should be highly interactive, provide more pictures instead of written information, be practical, relatable, and have images identifiable by Aboriginal community members (e.g. smoking, reserve living conditions, Aboriginal ceremonies and traditions, commercials/real life stories of Aboriginal people)
- Resources should be available in Aboriginal languages
- Resources should be broadly available in the community settings including community centres and schools in order to raise awareness about asthma

Future directions for proper asthma management and control in First Nations and Inuit communities were also discussed at the Advisory Group meeting. The recommendations on the main proposed directions are as follows:

1) Increase public/community awareness of asthma

Education should not only target people with asthma and caregivers but also aim to increase awareness of asthma amongst the general public (e.g. “similar to what has been developed for diabetes”). By increasing public awareness, asthma will be normalized in the community so “community members can support each other and share their concerns”.

2) Increase access to asthma resources and materials

Asthma resources and materials should be readily available in the community (e.g. schools and health clinics). Asthma resources and materials should focus on asthma prevention, asthma triggers, and proper medication management taking into considerations the unique cultural traditions and living conditions of First Nations and Inuit communities. It is also important that newly developed asthma materials respond to the needs of Aboriginal people and be available in Aboriginal languages with references to Aboriginal culture.

3) Focus on providing education to children and their extended families

In Aboriginal communities, families are very important so “kids need to see someone who they can identify with”; therefore, newly developed material should mostly target parents, children, and extended family members. There was a consensus that new materials should aim to empower children and youth to better manage their disease. It would be preferable to have real life examples featuring Aboriginal people living with asthma. As well, there should be engaging and interesting materials targeting young children.

4) Ensure availability of in-person education

Participants were very interested in having asthma information sessions and training available at schools and community centres. Participants felt that it would be important to have a professional teaching the community about asthma in order to provide proper explanations about asthma triggers, medication use (including proper inhaler technique), and asthma management. Participants also thought that it would be beneficial to have focus groups for kids and support groups for community members.

5) Develop materials with content and format relevant to Aboriginal communities

Newly developed material should include asthma prevention, management, and control of triggers. Resources should be highly interactive, provide more pictures instead of written information, and should be practical covering unique issues faced by community members (e.g. reserve living conditions, Aboriginal ceremonies and traditions, natural remedies and traditional healing information).

The Advisory Group members agreed that First Nations and Inuit community members should be involved in the development of new materials as a way of moving forward. They thought that a National Framework should be developed and implemented by Aboriginals. They also expressed a need to have a similar meeting specifically involving youth and were interested in establishing a “Youth Advisory Group”.

V. Project Results

The main purpose of this project was to gather background information on the relevance of existing asthma education materials and resources to First Nations and Inuit community members and explore the opportunity to modify existing materials to address the needs of these communities. The project was also designed to guide the future development of culturally appropriate asthma educational materials for First Nations and Inuit community members in order to help address asthma in their communities ultimately leading to its proper management and prevention with a potential reduction in asthma rates. During the project, key informants

from First Nations and Inuit communities namely youth, their extended families, caregivers (e.g. teachers, health care providers), and community leaders were engaged in reviewing and assessing existing asthma and allergy educational materials and resources. The assessment process was divided into three main components according to the activities that were undertaken during the project implementation such as: A) Assessment of existing asthma educational materials and resources by reviewing the asthma educational packages compiled based on the results of the environmental scan of asthma educational materials available across Canada and internationally; B) Assessment of web-based support resources and materials for one on one and/or group asthma education by conducting webinar sessions; and C) Creation of a community Advisory Group to further discuss main issues regarding proper asthma management at community level and help determine priority actions going forward while ensuring proper Aboriginal engagement.

The combined findings from the three main activities revealed consistent themes and results, thereby addressing overall project outcomes that are summarized as follows:

- 1) Overall, asthma educational materials reviewed were highly favoured by participants among all age categories and the results demonstrate that the existing materials could be adapted to better suit cultural and other unique needs of First Nation and Inuit community members and make them relevant to their culture. Cultural aspects could be embedded by using pictures/images related to the culture and real life stories of Aboriginal people living and coping well with asthma, and, lastly, by making some materials available in Aboriginal languages, specifically Inuktitut. Further, cultural relevance should be supported by providing traditional healing information.
- 2) The visual learning style applied through either printed materials (e.g. booklets with pictures, checklists/factsheets, etc.) and/or virtual resources (e.g. video/DVD, webinar, etc.) seems to be a method of preference in receiving health-related information amongst older children, parents/grandparents and community leaders of First Nations and Inuit communities. Younger children prefer learning through play and interactive activities (e.g. games, puzzles, etc.) either paper-based or virtual. Older youth appear to be least enthusiastic about asthma education, which suggests for a combination of educational approaches in order to reach out to this audience and ensure their active involvement in the process of developing new materials and resources. All age categories also indicated the importance of personal interaction with parents, health care professionals, etc. in receiving asthma education and information.
- 3) For newly developed materials, features of educational materials that attracted the most support include: balanced text with pictures and less technical information, educational and right to the point content (e.g. factsheet, asthma emergency card, etc.), and information that is interesting/engaging and relatable to the reader. Interactivity was named one of the most desirable elements of educational materials and resources to be developed. Amongst traditional printed materials, the format of booklets and/or factsheets was chosen as one of the favourites by the majority of project participants. Educational webinars for both children and adults were also well received by the project participants and favoured for their interactional component and the ability to receive immediate information and answers to their questions directly from a health care professional; however, concerns were

expressed about Internet accessibility in some First Nations and Inuit communities. Similar reasons were put forward for not identifying video-based asthma educational materials as the number one choice on the wish lists because the participants feared a possibility of facing technical and other difficulties in using them.

- 4) The content of the newly developed material should focus on practical elements of asthma management specifically by providing information about asthma triggers including environmental determinants of health; asthma prevention; and proper medication usage including information on how to use an Asthma Action Plan (AAP). Materials also should cover unique lifestyle issues of Aboriginal communities (e.g. housing conditions, road dust, forest fires, traditional ceremonies using tobacco smoke, etc.) as well as offer information on holistic approaches and the use of natural remedies in treatment of asthma and allergies and their potential combination with the conventional medicine.
- 5) The concept of an asthma action plan was highly supported by all the participants who indicated a willingness to use it to improve asthma self-management. Amongst assessed AAPs, no one was selected as the plan that could be used by First Nations and Inuit community members with some asthma action plans being seen as a possible starting point in developing a special plan for First Nations and Inuit community members.
- 6) The importance of proper community awareness on asthma was emphasized by all the project participants noting that the development of awareness materials and resources should be considered in order to help “normalize” asthma within the community and create a supportive environment for all community members with any connections to asthma (e.g. people with asthma, parents, family elders, friends/family members of individuals with asthma, community leaders, etc.) Asthma information nights at schools and other community settings delivered by health care/community workers should be considered for implementation in order to provide personal interaction and help increase community awareness about asthma. Further, the primary focus of all educational activities within the community should be on implementing resources for childhood asthma by targeting parents and/or grandparents in order for them to educate their children about asthma and allergies.

VI. Project Recommendations

Major barriers to proper asthma education within the Aboriginal communities identified include: lack of educational resources readily available; communication challenges with health care professionals, limited access to health care services; lack of professional development programs on asthma for health care providers; insufficient coverage for asthma medication and devices, and lack of asthma awareness at the community level. The project participants also mentioned a significant impact by environmental factors such as poor housing and exposure to second-hand smoke. In order to help address asthma in First Nations and Inuit communities as well as improve asthma education, management and prevention, the findings from all project activities support five key recommendations as follows:

1) Focus on developing culturally appropriate asthma educational material and resources by modifying some of the existing materials and/or designing new ones

Based on the material rated the highest/most liked by most respondents in each group, ‘best practices’ materials across conventional and digital-media educational materials (some examples are presented below) should be selected for further evaluation and adaptation as well as used as a basis for developing new materials. During the development/adaptation of asthma educational materials, it is essential to ensure that newly developed materials are tailored appropriately to audiences based on their age, gender, and relationship to the individual experiencing asthma within the family or community. The adapted and newly developed materials and resources also should incorporate the following key characteristics and elements:

- Material format and core elements

In general, materials and resources should be highly interactive and interesting to the learner as well as focus on visual elements by providing more pictures/diagrams instead of written text/technical information. An emphasis should be placed on developing/modifying traditional printed materials while exploring how new digital means could be adopted for implementation in First Nations and Inuit communities. Based on the project findings, it is recommended to have a combination of traditional printed materials with pictures and personal stories that provide adequate information to help learn about asthma (factsheets and booklets) and digital resources (websites potentially with audio lessons/asthma podcast, virtual learning modules, etc.). Activities/games (paper-based and/or web-based) and booklets with pictures drawn by well-known artists should be developed for younger kids to address their learning preferences.

- Material content

Material content should focus on practical asthma-related lifestyle issues faced by First Nations and Inuit community members and include information on asthma prevention, proper medication management, and control of triggers, as well as environmental determinants of health, which are relevant to many First Nations and Inuit communities, including road dust, housing conditions, second-hand smoke, etc. The highly preferred booklet “*Triggers Asthma Basics#2*” should be considered for adaptation/modification and serve as a basis to design a similar material with focus on unique environmental needs of First Nations and Inuit community members. In the same way, the “*Asthma Medication Information*” (see Appendix 11) factsheet should be adapted for parents and grandparents as an easy-to-follow instruction guide providing information on the proper use of asthma medications including inhaler technique.

- Cultural context

Newly developed and adopted materials should be relatable and identifiable to First Nations and Inuit community members. Cultural appropriateness could be improved by implementing simple strategies such as the following: use images/pictures relevant to Aboriginal culture (e.g. Aboriginal art, photography, etc.); include real life stories/testimonials of First Nations and Inuit people living well with asthma (e.g. recognizable leaders within the community featured in commercials), and have references to Aboriginal ceremonies and traditions. Further, some materials should be translated and available in Aboriginal languages, specifically Inuktitut as well as provide information about traditional healing practices and their possible combination with conventional medicine approaches.

- Delivery method

It is important to use in-person interaction with health care/community workers when educating First Nations and Inuit community members about asthma and associated allergies in order to provide proper explanations about asthma triggers, medication use, and asthma management. In-person education should be considered as one of the possible delivery methods with asthma information sessions and support/focus groups for kids and adults available at schools and community health centres. Alternatively, considerations should be given to delivering in-person education via webinar sessions for communities with adequate Internet access and limited resources to organize in-person group education sessions. Webinar sessions could be organized for adults at home/community settings and children at schools providing them with proper information about asthma and instant access to a health care professional while maintaining the interactive nature of in-person education. A prospect of developing and organizing webinar sessions that meet educational needs of First Nations and Inuit community members should be explored further by conducting a pilot in the chosen First Nations and Inuit communities across Canada to determine whether educational webinars are a preferred way of receiving asthma information for First Nation and Inuit community members.

- Materials on asthma self-management

Empowering children and adults with asthma living in First Nations and Inuit communities to deal with asthma and manage it properly deems to be of a greater importance for community members. An Asthma Action Plan (AAP) should be designed specifically for Aboriginal community members in order to promote proper asthma self-management and help achieve optimal asthma control. The existing AAPs (e.g. *the Children's Asthma Education Centre* asthma action plan (see Appendix 12), *A Little Asthma Action Plan*, etc.), which were highly rated by the project participants, could be used as a starting point for future design. The newly designed plan could provide a single page, colour-coded algorithm that can be reviewed in a short amount of time with copies kept in convenient places that are often seen by children and youth (e.g. school locker, refrigerator, and bedroom) and have more space to record personal information. A consideration also should be given to the development of an asthma emergency card, which could be used along with the asthma action plan.

2) Develop and implement asthma educational programs mainly focusing on children and their families

Childhood asthma appears to be of a greatest concern for First Nations and Inuit community members warranting a focus to be placed on educating children and their extended families and empower them to better manage their disease. Families are very important in Aboriginal communities and children stated a preference to learn about asthma from their parents so *family-oriented education* should be considered as a choice of educating children in First Nations and Inuit communities. The existing RAP “*Roaring Adventure of Puff*” program could be modified to be used by parents in educating their children about asthma. In this case, parents would be educated by health care professionals utilizing a specially designed training version of the RAP program (the trainer-the trainer model). Both RAP versions should be available online and an opportunity should be explore of delivering the trainer version of the program using the webinar technology.

3) Increase public awareness of asthma by developing and implementing awareness programs and materials

Education should not only target people with asthma and caregivers but also aim to increase awareness about asthma amongst the broader community members and the general public leading to normalizing asthma within the community and creating supportive environment for all community members directly and/or indirectly affected by asthma. Community awareness could be improved by implementing several strategies. For example, a community model used to increase awareness about diabetes could be considered for adaptation. The Asthma Society of Canada (ASC) is also in the process of designing a community outreach model suitable for Aboriginal communities that could be applied to increase awareness about asthma. Implementation of asthma community information nights at schools or other community settings should be included in the chosen outreach model. Awareness materials should be available in traditional formats (e.g. community posters that are relevant to Aboriginal culture) as well as be designed using innovative technological approaches. For example, the ASC *E-learning Module* (see Appendix 13), a sophisticated online educational tool that makes use of a speaking avatar to guide the user through information, was highly regarded by community leaders and teachers and could be modified to be used as an educational, informational, and support tool available for broader community members.

4) Ensure appropriate access to asthma educational resources and materials

Asthma educational resources and materials should be readily available in the actual communities (e.g. at schools, community centres, health clinics, etc.) to ensure their accessibility to community members. If web-based materials are taken into consideration for future development, adequate Internet/computer access should be available for the majority of community residents in each given community. It is also crucial to ensure that appropriate mechanisms are in place to disseminate materials that are suitable (i.e. languages) and appropriate (i.e. computer accessibility) to a particular First Nations or Inuit community. Several dissemination strategies should be developed and employed with a focus on seeking ‘champions’ at the community level to promote uptake of the materials; establishing and strengthening linkages with health care services and community programs, and creating and sustaining strong connections with disease organizations such as the Asthma Society of Canada (ASC).

5) Continue engaging First Nations and Inuit community members in the development/adaptation of asthma educational resources

There is a consensus among the project participants that Aboriginal community members should be involved in the development of new materials as a way of moving forward. The Asthma Society of Canada (ASC) recommends a creation of a National Framework (e.g. National Aboriginal Asthma Council) that should be developed and implemented by First Nations and Inuit community members. The Council could be established based on the community Advisory Group, members of which are very interested to continue working on future initiatives and be involved in the development of new materials and programs aimed to improve asthma education and care for First Nations and Inuit youth affected by asthma and their families. The Asthma Society of Canada (ASC) would also use linkages of the community Advisory Group and other

partnerships established throughout the implementation of the “A Shared Vision report” and the current project to access appropriate First Nations and Inuit groups (e.g. Assembly of First Nations Youth Council, the ITK Nation Inuit Committee on Health, etc.) to advise on adaptation and development of new asthma educational materials and resources. Youth are the population group that is usually at highest risk of asthma-related morbidity and mortality so it is also advisable to establish a “Youth Panel” of the Advisory Group to get their input on developing new asthma materials and resources.

Further, the Asthma Society of Canada (ASC) could take a lead and build on its strong existing partnerships with organizations responsible for Aboriginal health (the AFN, ITK, the FNIHB) and work closely with them to develop a shared strategy to support and guide the adaptation/development of new culturally appropriate asthma educational materials and resources to First Nations and Inuit audiences along dimensions identified by project participants (e.g. format, core elements, cultural context, content including environmental determinants of asthma, etc.).

VII. Appendices

Appendix 1 - Description of Selected Materials for Assessment

Booklets

Asthma Active: Learning About Asthma

“Asthma Active: Learning About Asthma” is a booklet developed by the Ontario Lung Association (OLA). This booklet contains information and games that provide information on asthma to kids ages 6 to 12 years old. There are a multitude of activities that educate kids about what is asthma, its triggers, and how to control their asthma.

Call Me Brave Boy

Call Me Brave Boy is a storybook of a boy dealing with his asthma developed by the Ontario Lung Association (OLA) in consultation with Sick Kids. It is designed to help kids deal with asthma when they are first diagnosed with their disease.

Be a secret Asthma Agent (Kids Asthma Basics)

“Be a secret Asthma Agent” is a booklet designed by the Asthma Society of Canada to educate kids about asthma and help them develop a better understanding of what are the causes of their disease. It also contains information on different medications available to control asthma and how to take them properly. This booklet contains information for both kids and parents.

Asthma Story Board - Taking Control of Asthma (Follow the Circle of Care)

The Circle of Care Asthma Storyboard is a booklet developed by a group of stakeholders and supported by AstraZeneca Canada Ltd. The booklet provides information on asthma including facts, triggers, medication use, and asthma action plans.

The Story of Asthma in Pictures

The Story of Asthma in Pictures is provided by the Ontario Lung Association (OLA). It briefly talks about what is asthma, asthma triggers, and how to control it.

Asthma Basics #2: Triggers (Manage Your Environment)

“Asthma Basics #2: Triggers” is a booklet provided by the Asthma Society of Canada, and contains information on asthma triggers and allergies. In addition, it contains information on how to avoid these triggers and manage your environment.

Asthma and Children

“Asthma in Children” booklet is provided by the Lung Association, and contains information on asthma, its triggers, and the different medications available. In addition, it contains “My Asthma Action Plan” and “My Asthma Diary”.

Questions and Answers about Asthma

“Questions and Answers about Asthma” is a booklet developed by the Hospital for Sick Children and the Ontario Lung Association (OLA). It provides information for parents on childhood

asthma and the medications available to control the disease. Also, the booklet includes a calendar and an asthma action plan to help keep track of a child's medication use.

Brochures

Sara's Ready... Are you?

"Sara's ready...Are you?" brochure is provided by the Asthma Society of Canada. It contains information on asthma for kids and how to deal with their symptoms while at school.

Control Asthma Now!

"Control Asthma Now!" brochure is provided by Alberta Health Services (Calgary Health Region). This brochure provides information on asthma, asthma medication, and asthma management. In addition, this brochure contains "'A little Asthma Action Plan" which is designed to help keep track of symptoms and medication use.

Asthma: What You Need to Know (BCLA)

"Asthma: What You Need to Know" is provided by the British Columbia Lung Association. This brochure contains information on asthma and the available treatment options.

Asthma and Physical Education – "Daily Physical Activities for Everyone" (Teacher's Package)

"Asthma and Physical Education" is developed by the Ontario Physical Health Education Association (OPHEA) in partnership with the Ontario Lung Association (OLA), the Public Health School Asthma Pilot Project, and the Asthma Society of Canada. It contains information that pertains to asthma and physical activities at school.

Asthma in the Classroom: What Teachers Need to Know (Teacher's Package)

"Asthma in the Classroom: What Teachers Need to Know" is provided by OPHEA, and the Public Health School Asthma Pilot Project, in partnership with the Ontario Lung Association (OLA) and the Asthma Society of Canada. It is designed to educate teachers about asthma and how to deal with asthma related situations that may arise in the classroom.

Asthma: Managing Real Life Situations (Teacher's Package)

"Asthma: Managing Real Life Situations" is provided by OPHEA, and the Public Health School Asthma Pilot Project, in partnership with the Ontario Lung Association (OLA) and the Asthma Society of Canada. It contains information for teachers on how to respond to asthma emergencies.

Asthma: Is Your Asthma Well Controlled? (OLA)

"Asthma: Is Your Asthma Well Controlled?" is provided the Ontario Lung Association (OLA), and helps determine whether one's asthma is well controlled, as well as some tips on how to improve asthma control.

Smoke Free Home Environment

"Smoke Free Home Environment" is provided by the Ontario Lung Association (OLA) and

contains information on the dangers of second hand smoke, as well as steps to help make any home smoke free.

Checklist/Factsheets

Asthma Diagnosis Checklist

This checklist provided by Alberta Health Services (Calgary Health Region) can help understand if symptoms that someone experiences may be related to asthma.

Asthma and Exercise

The “Asthma and Exercise” factsheet is provided by the Ontario Lung Association (OLA) and contains information on how to manage your asthma while exercising.

Asthma and Pets

The “Asthma and Pets” factsheet is provided by the Ontario Lung Association (OLA). It contains information on pets and asthma, and how to avoid pet triggers.

Asthma and Smoking

“Asthma and Smoking” is provided by the Ontario Lung Association (OLA). It contains information on smoking, asthma, and resources to help quit smoking.

What is Asthma

“What is Asthma” is a factsheet provided by the Ontario Lung Association (OLA). It contains information on asthma and its causes.

Childhood Asthma

“Childhood Asthma” is a factsheet provided by the Ontario Lung Association (OLA). It contains information on childhood asthma, and the medications available to control it.

Some Common Triggers and How to Protect Against Them

“Some Common Triggers and How to Protect Against Them” is a factsheet provided by the Alberta Lung Association and contains information on controlling asthma.

The Basics of Asthma, Allergies, and Anaphylaxis (Teacher’s Package)

“The Basics of Asthma, Allergies, and Anaphylaxis” is provided by OPHEA, and the Public Health School Asthma Pilot Program, in partnership with the Ontario Lung Association (OLA) and the Asthma Society of Canada. It answers common questions on asthma, allergies, and anaphylaxis.

Preparing for My Asthma Appointment

“Preparing for My Asthma Appointment” is a checklist provided by Alberta Health Services and is designed to help prepare for the next doctor’s appointment.

Childhood Asthma

“Childhood Asthma” is a factsheet provided by the Ontario Lung Association (OLA) and it contains information that pertains to asthma, triggers, and medications.

Asthma Triggers in the Home Environment

“Asthma Triggers in the Home Environment” is a factsheet provided the Canadian Lung Association and contains information on asthma triggers.

Asthma Action Plans

A Little Asthma Plan

A little Asthma Plan is provided by the Alberta Health Services (Calgary Health Region), as part of ICAN (I Can Control Asthma Now). This asthma action plan contains a calendar to help keep track of symptoms and medication use. In addition, it contains an easy way for kids to remember their triggers and remember when to take their medication.

My Asthma Action Plan (CLA)

“My Asthma Action Plan” is provided by the Canadian Lung Association. This plan is designed to aid in the monitoring of asthma and its related symptoms.

My Asthma Action Plan (CHEO)

“My Asthma Action Plan” is provided by CHEO (Children’s Hospital of Eastern Ontario). This plan is designed to help monitor peak flow, and have planned responses in various situations.

Asthma Action Plan (CAEC)

“Asthma Action Plan” is provided by CAEC (The Children’s Asthma Education Centre). CAEC is from the Department of Pediatrics and Child Health at the Children’s Hospital of Winnipeg. It is designed to monitor the level of asthma control and help have a planned response in case of emergency.

Breathe – Asthma Action Plan (Your Asthma Is As Unique As You Are) (ASC)

“Breathe – Asthma Action Plan (Your Asthma Is As Unique As You Are)” is provided by the Asthma Society of Canada. This Action Plan is designed to help learn the steps to managing asthma, and living symptom free.

Asthma Action Plan (ICAN)

“Asthma Action Plan” is provided by the Alberta Health Services in partnership with the Canadian Lung Association. This action plan is designed to help keep track of asthma symptoms, keep the asthma under control, and plan the appropriate response in each situation.

The Lung Association’s Asthma Action Plan (OLA)

“The Lung Association’s Asthma Action Plan” is provided by the Ontario Lung Association and is designed to help keep asthma under control.

Student Asthma Management Plan (Teacher’s Package)

“Student Asthma Management Plan” is provided by the Lung Association in partnership with the Public Health Asthma Project. It is designed to help keep track of asthma triggers and planning appropriate emergency responses.

Asthma Diaries

My Asthma Calendar

“My Asthma Calendar” is provided by Alberta Health Services- “I Can Control Asthma Now” (ICan). The calendar is designed to help children keep track of their asthma symptoms and medication use.

The Children’s Asthma Education Centre Diary

“The Children’s Asthma Education Centre Diary” is provided by CAEC (The Children’s Asthma Education Centre). CAEC is from the Department of Pediatrics and Child Health at the Children’s Hospital of Winnipeg. It is designed to keep track of your symptoms, peak flow, and medication use.

My Asthma Diary Card (OLA)

“My Asthma Diary Card” is provided by the Ontario Lung Association (OLA). It is designed to keep track of your symptoms, peak flow, and medication use.

Community Pediatric Asthma Service Asthma Diary (ICAN)

“Community Pediatric Asthma Service Asthma Diary” is provided by Alberta Health Services and is designed to help keep track of asthma symptoms.

Asthma Video and CD

Quest for the Code

“Quest for the Code” is an interactive online game provided by the Starlight Children’s Foundation. “Quest for the Code” is an asthma game, which is geared for children and teens to help manage their asthma. The game provides asthma education, including medication use, allergies, proper asthma control, and how to use an asthma action plan.

Taking Control: Living Well with Severe Asthma

“Taking Control: Living Well with Severe Asthma” is a video provided by the Asthma Society of Canada. It explains the medications used to treat asthma, discusses how allergies may be a factor contributing to asthma symptoms, and provides tools for asthma control.

Managing Asthma in our Schools (Teacher’s Package)

“Managing Asthma in our Schools” aims to help create an asthma-friendly school by providing educators with knowledge to support students in managing their asthma independently, and by enhancing educator’s understanding and confidence to respond to asthma-related situations. This DVD was developed by OPHEA in collaboration with Public Health School Asthma Project. In addition, it comes with a brochure, “Creating Asthma Friendly Schools”, which contains information on asthma, its symptoms, and triggers.

Asthma Websites and the E-Learning Module

Asthma Society of Canada – www.asthma.ca

The central website of the Asthma Society of Canada provides information about asthma, treatment, and symptom management. The ASC has various interactive links for kids and youth such as (asthma kids) <http://www.asthmakids.ca/> and (air square) <http://www.airsquare.ca/main.html> these websites are geared towards children and youth to learn about asthma and how to manage it effectively through interactive games and stories. There are online stories from children and youth who have a history of asthma. There are also links for Parents and Children to ask Certified Asthma Educators questions/concerns they might have about their asthma or their child(ren)'s Asthma. The website also provides several educational materials and resources which can be downloaded for personal use such as: asthma action plan, booklets, etc. or they can be ordered online.

Asthma Kids – www.asthmakids.ca

Asthma Kids is a link that can be found on the Asthma Society of Canada webpage www.asthma.ca.

This link open up to interactive games and activities for children to play surrounding asthma, and includes information for parents, as well as “Stories” from children/peers that have asthma.

Air Square – www.airsquare.ca

Air Square is a link that can be found on the Asthma Society of Canada webpage www.asthma.ca.

This link is for youth and young adults – it is an interactive way to learn about asthma and its related causes and management. On this website, you are able to choose one of four virtual characters, which lead you to discuss various aspects of asthma. The webpage talks about activities that young youth and adults are engaged in, including sports, shopping, and arcade games, all which is tied to messages that surround asthma.

I can Control Asthma Now – www.calgaryhealthregion.ca/ican/kids_home.html

The ICAN (I can Control Asthma Now) is a website provided by Alberta Health Services which targets kids targets children (anywhere form toddlers to elementary aged children), teenagers, parents, teachers and coaches and health care providers. For children there are several games/puzzles, and videos with stories from children or youth who have asthma, as well as different reading levels (from toddlers to teenagers). The website provides educational materials and resources which can be downloaded for personal use such as asthma action plan or even an asthma diary. There are links to how to manage a child's asthma by showing proper methods on how to use inhalers and spacers. The site has instructional videos and interactive games for kids to learn and enjoy.

Hospital for Sick Kids – www.aboutkidshealth.ca/JustForKids/asthma_cons.aspx

This link is associated with the Hospital for Sick Children: it is an Interactive learning module- where information about asthma for children aged 5 to 8, 7 to 10 and 8-13 can be found. There are interactive games, puzzles and quizzes about asthma.

Canadian Lung Association – www.lung.ca

The Canadian Lung Association has links to information on asthma as well as a resource center on their home page which opens up to information on asthma, work, and allergy etc. Further, the webpage provides the option to order or download brochures, fact sheets or booklets on how to manage or control your or your child's asthma. In addition, there is a link to activities and games for children in various grade levels, (under Lung 101) as well as information for students, including a diagram of the respiratory system. Also has a link to games for kids <http://www.lung.ca/children/games/index.html>.

Teen Asthma – www.teenasthma.ca

Teen Asthma website is developed by the Ontario Lung Association with help from the Ontario government. This website contains information on asthma for teens as well as several interactive activities they can enjoy.

Kick Asthma – www.kickasthma.org.uk

Kick asthma is an international asthma website in the United Kingdom. This website gives information to children, youth, parents, and teachers about asthma in children, asthma in adults, or asthma at work. Kick Asthma has an arcade centre for children to play games, as well as health centre where children can email a nurse if they have any questions about their asthma. Kick Asthma also provides important family days and holiday's for children with asthma, with the intent of creating asthma peer groups. You can also find an asthma dictionary on the website as well as a problem pages for friends and family, spare time and school. This link could be accessed from www.asthma.org.uk.

E-Learning module: Taking Control of Your Asthma – www.takingcontrolofyourasthma.ca

The E-learning module is provided by the Asthma Society of Canada and McMaster University. The module consists of animations and illustrations on the respiratory system, showing step by step an illustration on how asthma affects the lung system, this helps you understand how to take control of your asthma. The module is an electronic way of delivering asthma education materials by walking you through information through an audio individual. The audio individual speaks to you about your asthma, including causes, triggers, and proper control and management. There is also a section on myths and facts on asthma, to help better understand which areas of asthma you need more information about.

Teen Asthma – www.teenasthma.ca

Teen Asthma – asthma games and quizzes - linked to the Ontario Lung Association – services is temporarily unavailable.

Asthma Posters

Breathe

“Breathe” poster is provided by the Asthma Society of Canada. This poster is designed to encourage people to visit the doctor if they are poorly managing their asthma symptoms.

Bill of Rights Poster

“Bill of Rights” poster is provided by the Asthma Society of Canada.

A Child is Having an Asthma Attack (Managing Asthma Episodes)

“A Child is Having an Asthma Attack” poster is provided by the Lung Association in partnership with OPHEA and Public Health School Asthma Project. This poster provides information on appropriate emergency responses.

The Basics of Asthma, Allergies, and Anaphylaxis (Teacher’s Package)

“The Basics of Asthma, Allergies, and Anaphylaxis” is provided by OPHEA and the Public Health School Asthma Pilot Program, in partnership with the Ontario Lung Association (OLA) and the Asthma Society of Canada. It answers common questions on asthma, allergies, and anaphylaxis.

Asthma Games and Puzzles

Paper Game

This is a simple game created by the Alberta Asthma Centre designed to teach kids myths and facts about asthma.

Coloring

A booklet from SickKids for kids to color.

Asthma Word search

A word search designed by SickKids that has asthma terminology for kids to learn.

Edible Airways activity

An activity for kids to create and learn about airways.

Additional Materials

Medication Information

The Medication Information sheet is provided by the Asthma Society of Canada. This sheet contains information on the different types of medications available and how to use them.

Asthma Action Facts (MDI)

Asthma Action Facts sheet is provided by the Ontario Lung Association (OLA), and contains information on the metered dose inhaler.

My Emergency Asthma Information

“My Emergency Asthma Information” card is provided by ICAN of Alberta Health Services. It used to help build a response in advance for emergency situations.

Diary Card (Fridge Magnet)

This asthma diary is designed to help keep track of medication use

Appendix 2 - Total number of completed questionnaires received, by province and target group

Target Group	Province						Total
	ON	QC	NS	NL	SK	NU	
Children Ages 6 to12	9	1	0	2	0	2	14
Children Ages 12 and above	9	0	2	4	0	3	18
Parents & Grandparents	10	3	3	3	0	3	22
Teachers & Community Leaders	8	0	1	3		2	14
Total	36	4	6	12	0	10	68

Appendix 3 - Total number of participants in webinar sessions, by province

Province	Webinar Sessions			Total
	Educational Session for Children 6 to 12 years of age (March 31 st 2:00 pm)	Educational Sessions for Parents/Grandparents, Community Leaders and Children 12 and above (March 31 st 4:00 pm and 6:00 pm)	Website Webinar Session (March 29 th 4:00pm and March 30 th 2:00pm)	
Ontario	11	16	11	38
Quebec	0	0	1	1
Alberta	0	15	0	15
Nunavut	0	0	2	2
Total	11	31	14	56

Appendix 4 - Best practices (desirable elements) in program content, design, format, and delivery/promotion as identified by webinar participants.

Best Practice/element	March 29	March 30 4 p.m.	March 31 2 p.m.	March 31 6 p.m.
Content	*Use of life stories – particularly ‘real’ life rather than fictional ones *Extra resources	*Myths and facts about asthma		*Informative *Environmental determinants of asthma
Design	*Use of ‘cute’ characters *Cartoons, animation, video, artwork, *Ease of navigation	*Characters *Bright colours *Eye catching *Generally, Hospital for Sick Kids website seen as best	*Pictures, games, cartoons (with First Nations kids)	*Pictures, models
Format	*Interactivity – games, stories, drama lessons *Concerns about accessibility to computers *Should be vetted by physicians	Interactivity, including games, quizzes Virtual learning Live chat and sound/voice Storytelling Fun Accessibility		*Interactive – e.g. digital stories
Delivery/Promotion	*Community awareness (e.g. asthma information night), school based delivery, and training of peers on symptoms	*Outreach and advertising of websites		*Outreach – community learning *Access to a professional for Q & A
Other comments	*Tragically, one participant recounted a story of a boy in her community who died from an asthma attack			

Appendix 5- Website Descriptions, Website Webinar Session

E-Learning module: Taking Control of Your Asthma – www.takingcontrolofyourasthma.ca

The E-learning module is provided by the Asthma Society of Canada and McMaster University. The module consists of animations and illustrations on the respiratory system, showing step by step an illustration on how asthma affects the lung system, this helps you understand how to take control of your asthma. The module is an electronic way of delivering asthma education materials by walking you through information through an audio individual. The audio individual speaks to you about your asthma, including causes, triggers, and proper control and management. There is also a section on myths and facts on asthma, to help better understand which areas of asthma you need more information about.

Asthma Society of Canada – www.asthma.ca

The central website of the Asthma Society of Canada provides information about asthma, treatment, and symptom management. The ASC has various interactive links for kids and youth such as (asthma kids) <http://www.asthmakids.ca/> and (air square) <http://www.airsquare.ca/main.html> these websites are geared towards children and youth to learn about asthma and how to manage it effectively through interactive games and stories. There are online stories from children and youth who have a history of asthma. There are also links for Parents and Children to ask Certified Asthma Educators questions/concerns they might have about their asthma or their child(ren)'s Asthma. The website also provides several educational materials and resources which can be downloaded for personal use such as: asthma action plan, booklets, etc. or they can be ordered online.

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Air Square is a link that can be found on the Asthma Society of Canada webpage www.asthma.ca. This link is for youth and young adults – it is an interactive way to learn about asthma and its related causes and management. On this website, you are able to choose one of four virtual characters, which lead you to discuss various aspects of asthma. The webpage talks about activities that young youth and adults are engaged in, including sports, shopping, and arcade games, all which is tied to messages that surround asthma.

I can Control Asthma Now – www.calgaryhealthregion.ca/ican/kids_home.html

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how to use inhalers and spacers. The site has instructional videos and interactive games for kids to learn and enjoy.

Canadian Lung Association – www.lung.ca

The Canadian Lung Association has links to information on asthma as well as a resource center on their home page which opens up to information on asthma, work, and allergy etc. Further, the webpage provides the option to order or download brochures, fact sheets or booklets on how to manage or control your or your child's asthma. In addition, there is a link to activities and games for children in various grade levels, (under Lung 101) as well as information for students, including a diagram of the respiratory system. Also has a link to games for kids <http://www.lung.ca/children/games/index.html>.

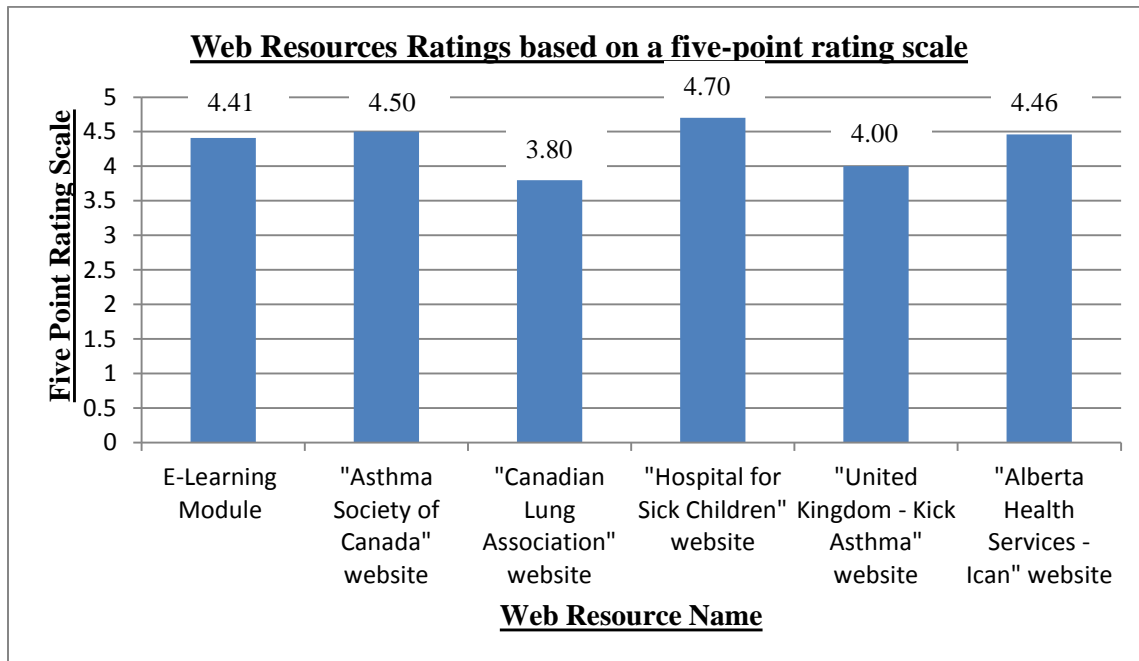
Hospital for Sick Kids – www.aboutkidshealth.ca/JustForKids/asthma_cons.aspx

This link is associated with the Hospital for Sick Children: it is an Interactive learning module- where information about asthma for children aged 5 to 8, 7 to 10 and 8-13 can be found. There are interactive games, puzzles and quizzes about asthma.

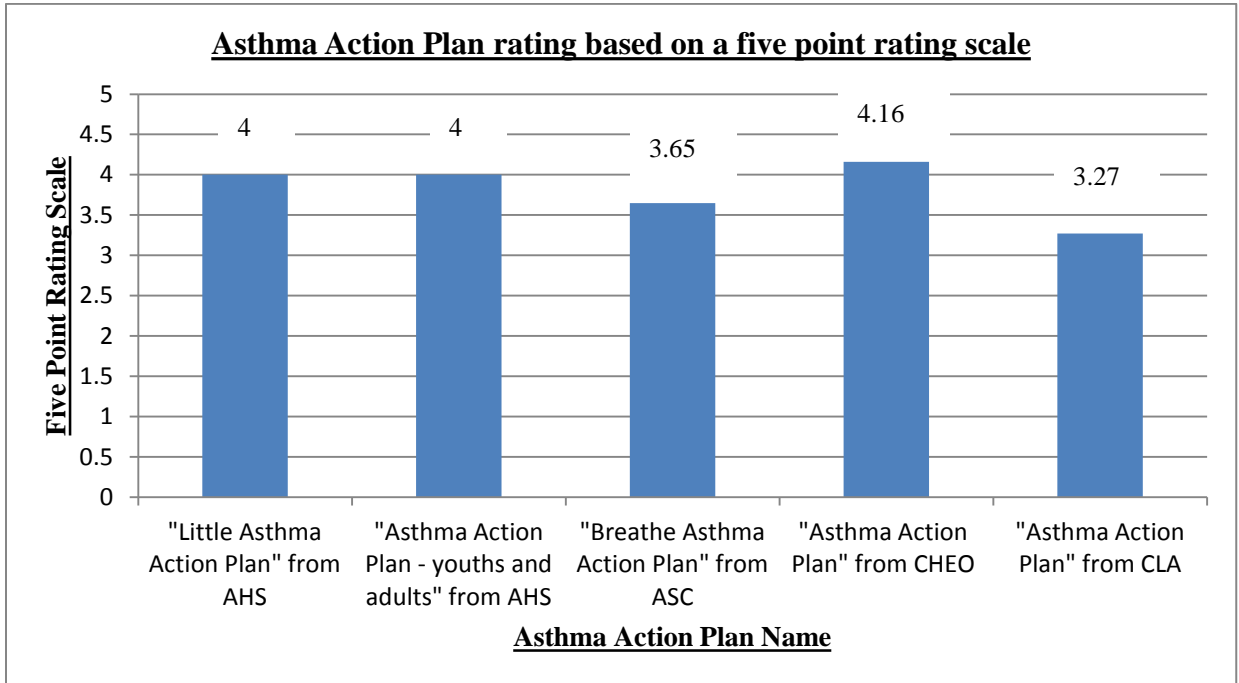
Kick Asthma – www.kickasthma.org.uk

Kick asthma is an international asthma website in the United Kingdom. This website gives information to children, youth, parents, and teachers about asthma in children, asthma in adults, or asthma at work. Kick Asthma has an arcade centre for children to play games, as well as health centre where children can email a nurse if they have any questions about their asthma. Kick Asthma also provides important family days and holiday's for children with asthma, with the intent of creating asthma peer groups. You can also find an asthma dictionary on the website as well as a problem pages for friends and family, spare time and school. This link could be accessed from www.asthma.org.uk.

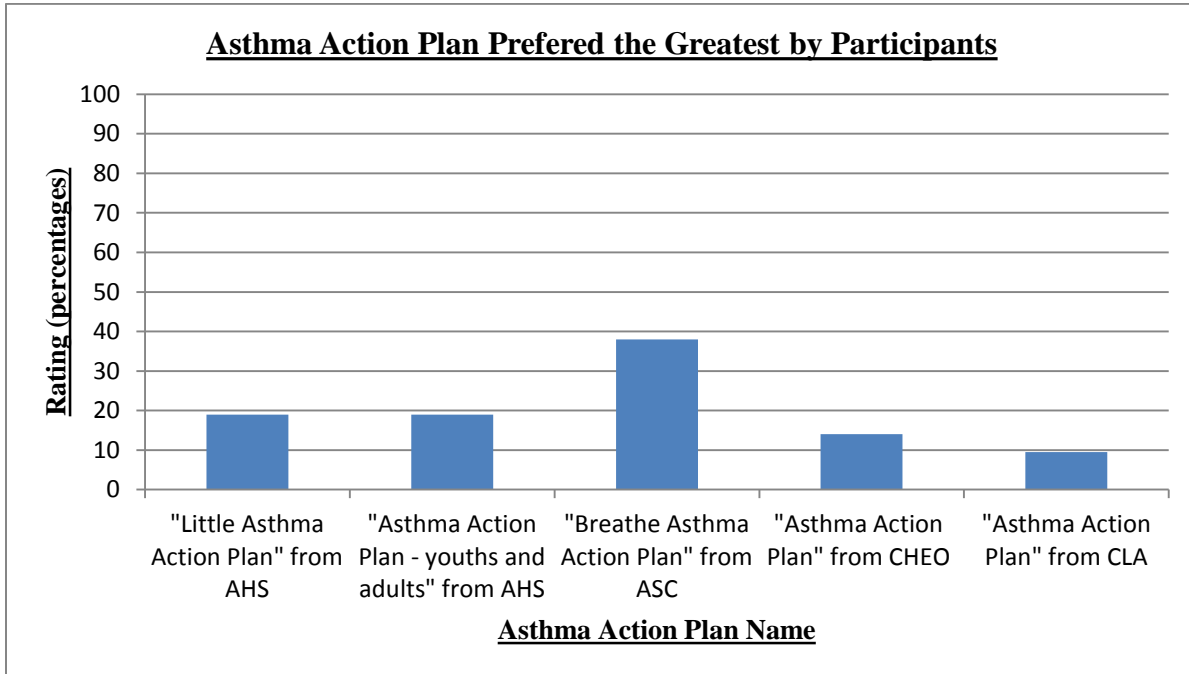
Appendix 6- Website Poll Results (Webinar Sessions)



Appendix 7 –Poll Results, Asthma Action Plan (Webinar Sessions)



Appendix 8 –Asthma Action Plan Preference (Webinar Sessions)



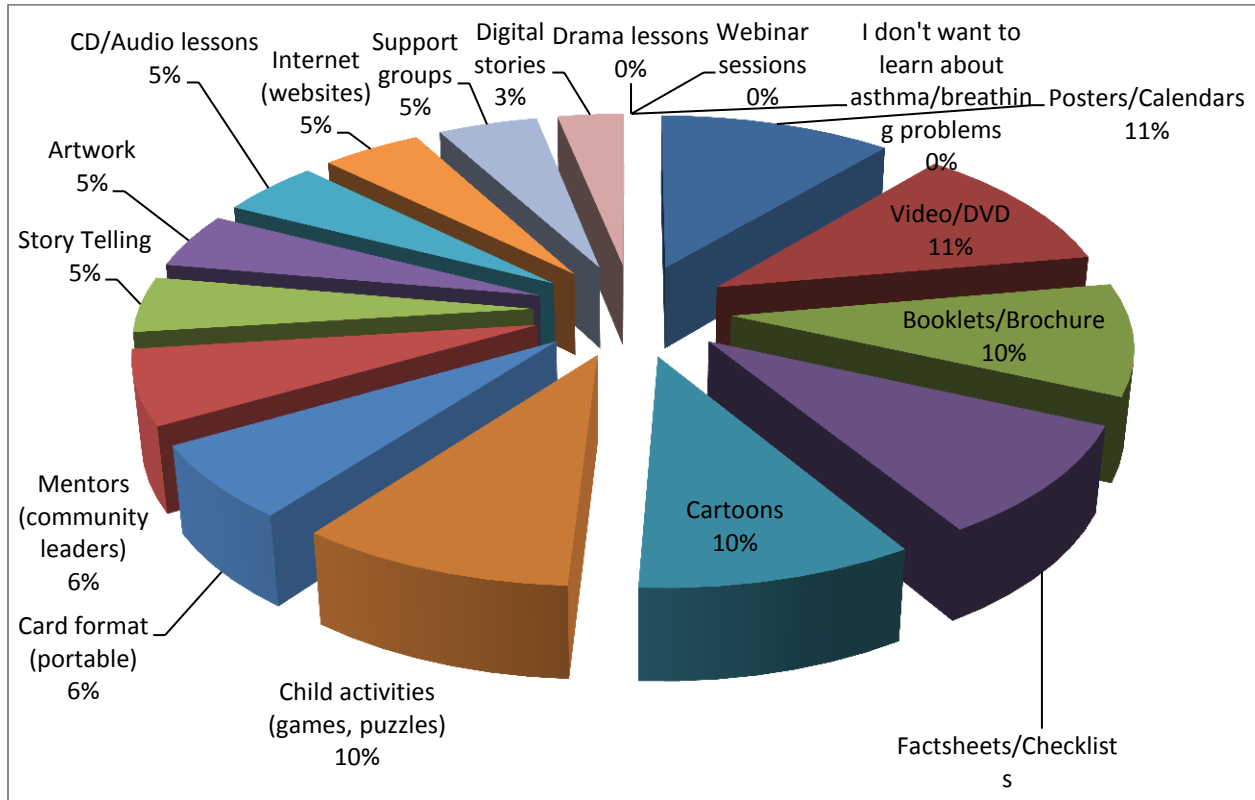
Appendix 9- Sample Ballot, Booklets (Advisory Group Meeting)

BOOKLETS

Favourite	BOOKLETS	Excellent	Good	Fair	Poor	Very Poor
	Asthma Basics 1-Be a Secret Asthma Agent					
	Asthma Basics 2- Manage your Environment					
	Asthma Action- The Story of Asthma in Pictures					
	Taking Control of Asthma (Asthma StoryBook)					
	Asthma Active – Learning about Asthma					
	Call me Brave Boy					
	Questions and Answers about Asthma					
	Asthma and Children					

Appendix 10- Wish List Results (Advisory Group Meeting)

Figure 1 - Preferred Method of Receiving Asthma Educational Materials and Resources



Printed Materials

- Posters/Calendar (11%), Factsheets/Checklists (10%), Booklets/Brochure (10%), Cartoons (10%), Card Format (6%), Artwork (5%) = **52%**

Personal Interaction

- Child activities (10%), Mentor (6%), Storytelling (5%), Support Groups (5%), Drama Lessons (0%) = **26%**

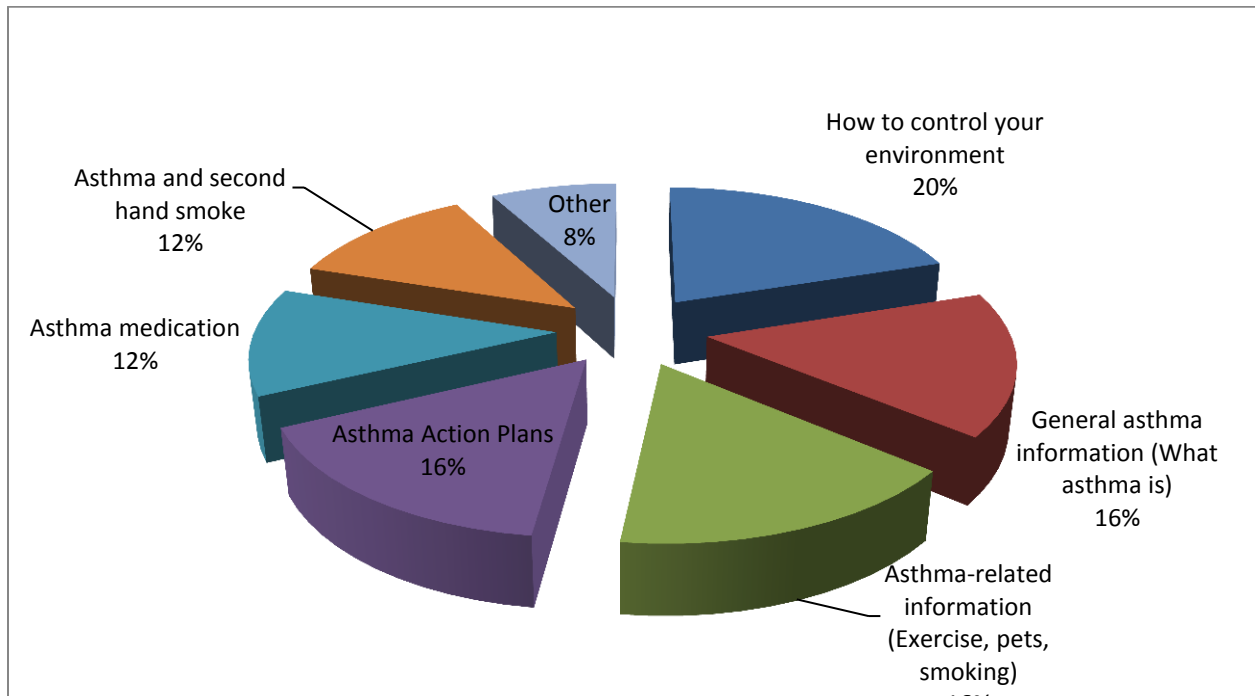
Audio/Video

-Video/DVD (11%), CD/Audio Lessons (5%), Digital Stories (3%) = **19%**

Internet Based

-Internet Websites (10%), Webinar Session (0%) = **10%**

Figure 2 – Topics of Interests on Asthma and/or Allergies



Asthma Triggers

-How to control your environment (20%), asthma and second hand smoke (12%) = **32%**

Asthma-Related Information

-Asthma and Exercise, Pets, Smoking = **16%**

General Asthma Information

-What is Asthma? = **16%**

Asthma Action Plans

-Information on Asthma Action Plans = **16%**

Asthma Medication

-Asthma Medication Information = **12%**

Other = **8%**

4% - Resources used by health care professionals for teaching about asthma in a clinical setting (e.g. Professional Asthma Education Courses)

4% - Information on asthma and Stress

Appendix 11- Asthma Medication Information

Asthma Medication Information. Educational material rated as ‘good’/’excellent’ by most parents and grandparents. (Asthma Society of Canada)

Medications: Asthma Basics Booklet

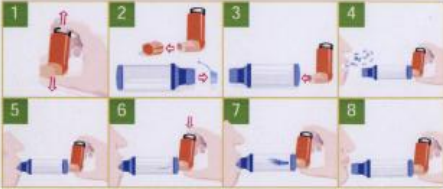
Asthma H1

MDI and spacer

The Asthma Society recommends that anyone, of any age, using an MDI should consider using a spacer. Spacers are available for purchase from pharmacies.

To use your MDI with a spacer:

- 1 Shake the inhaler well before use (three or four shakes)
- 2 Remove the cap from your inhaler, and from your spacer, if it has one
- 3 Put the inhaler into the spacer
- 4 Breathe out, **away** from the spacer
- 5 Bring the spacer to your mouth, put the mouthpiece between your teeth and close your lips around it
- 6 Press the top of your inhaler once
- 7 Breathe in **slowly** until you've taken a full breath
If you hear a whistle sound, you are breathing in too fast. **Slowly** breathe in
- 8 Hold your breath for about ten seconds, then breathe out



18 © Asthma Society

MDI (puffer)

You should follow the instructions packaged with your medication. The following is one way to use your inhaler.


To use your MDI without a spacer:

- 1 Shake the inhaler well before use (three or four shakes)
- 2 Remove the cap
- 3 Breathe out, **away** from your inhaler
- 4 Bring the inhaler to your mouth. Place it in your mouth between your teeth and close your mouth around it.
- 5 Start to breathe in **slowly**. Press the top of your inhaler **once** and keep breathing in **slowly** until you've taken a full breath
- 6 Remove the inhaler from your mouth, and hold your breath for about ten seconds, then breathe out

If you need a second puff, wait 30 seconds, shake your inhaler again, and repeat steps 3-6.

Always write down the number of puffs you've taken so that you can anticipate when you need to refill your prescription.

Store all MDI's at room temperature.



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Appendix 12 – The Children’s Asthma Education Centre (CAEC) Asthma Action Plan

Educational material most ‘liked’ by older youth ages 12-18. (Children’s Asthma Education Centre, 2001).

C4

**THE CHILDREN’S ASTHMA EDUCATION CENTRE
ASTHMA ACTION PLAN**

Name: _____
Date: _____

IS ASTHMA UNDER CONTROL?

- Normal breathing
- No cough or wheeze
- Normal activity
- Normal sleep
- Reliever medicine used no more than 3 times a week for symptoms

Keep Up The Good Work!

Green Level—Good Control

WHAT SHOULD I DO?

CONTROLLER

MEDICINE	PUFFS/DOSE	TIMES/DAY

- Use your **Reliever** medicine _____ as needed before exercise or for asthma symptoms (cough, wheeze, difficulty breathing).

TIME TO TAKE ACTION!

- Cold symptoms
- Symptoms at night
- Symptoms with activity
- Reliever medicine used more than once a day or more than 3 times a week for symptoms

- Start or increase **Controller** medicine at earliest sign
- When better return to Green Level

Yellow Level—Caution

CONTROLLER

MEDICINE	PUFFS/DOSE	TIMES/DAY

RELIEVER

	As needed
--	-----------

- During Yellow Level you may need to use your **Reliever** medicine more often.
- If **Reliever** medicine is needed every 4 hours, call your doctor.
- See your doctor if asthma symptoms are not improving after two days.

GET HELP!

- Reliever medicine needed in less than 3 hours
- Reliever medicine does not begin to relieve asthma symptoms in 10 minutes

RED LEVEL—DANGER

GO TO THE CLOSEST EMERGENCY DEPARTMENT IMMEDIATELY!

- Use **Reliever** medicine _____ as much as needed on the way to the **Emergency Department!**

Comments: _____

Doctor: _____ Phone Number: _____

Monitor your asthma control using the Asthma Tracker, visit www.asthma-education.com

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The Children’s Asthma Education Centre 2001, 2004, 2006[®]

Appendix 13 – E-Learning Module

E-learning Module. Educational material rated as ‘good’/’excellent’ by most teachers/community leaders. (Asthma Society of Canada; www.takingcontrolofyourasthma.ca)

The screenshot displays the 'Taking Control of Your Asthma' e-learning module. The interface includes a top navigation bar with links for 'GLOSSARY', 'ORIENTATION', 'RESOURCES', and 'SEND LINK'. The main content area features a large title 'Taking Control of Your Asthma' and a congratulatory message: 'Congratulations! By completing this module you are taking an important step towards understanding your asthma better and how you can partner with your doctor to get it in control.' Below this, a section titled 'We'll discuss:' lists topics: 'Asthma and Your Lungs', 'Avoiding Your Triggers and Monitoring Your Symptoms', 'How Your Medications Work and Why You Should Take Them', and 'Asthma Control and Partnering with Your Doctor'. A sidebar on the left contains a table of contents with items like 'Did You Know?', 'Asthma Myths & Facts', 'Being Diagnosed with Asthma', 'A Little Puzzled?', 'Asthma Control', 'Treating Your Asthma', 'Medication Know How', and 'Asthma Myth? Or Fact?'. A bottom control bar shows 'SLIDE 1 OF 28', 'PLAYING', and a timer '00:12 / 00:33'. The Asthma.ca logo and 'Asthma Society of Canada' are visible in the bottom right corner.

VIII. References

- ¹ “Life and Breath: Respiratory Disease in Canada:”, the Public Health Agency of Canada, 2007 Available at www.phac-aspc.gc.ca/publicat/2007/lbrdc-vsmrc/index-eng.php
- ² Asthma Society of Canada (ASC) <http://www.asthma.ca/adults/>
- ³ Assembly of First Nations (AFN) <http://www.afn.ca/>
- ⁴ Inuit Tapiriit Kanatami (ITK) <http://www.itk.ca/>
- ⁵ AllerGen NCE Inc. www.allergen-nce.ca/index.html
- ⁶ “A Shared Vision: Ensuring quality of life for adults and children with asthma and allergies in First nations and Inuit Communities in Canada”, the Asthma Society of Canada (2009) Available at www.afn.ca/misc/ASV.pdf
- ⁷ “Chronic Disease Prevention-Asthma Expert Advisory Forum Meeting Summary Report”, submitted to the First Nations and Inuit Health Branch (FNIHB), Health Canada (December 2009) provided by the FNIHB
- ⁸ National Asthma Patient Alliance (NAPA) <http://www.asthma.ca/napa/>
- ⁹ “The Roaring Adventures of Puff” program. Available at <http://www.educationforasthma.com>
- ¹⁰ Wabano Centre for Aboriginal Health: <http://www.wabano.com>