Asthma Education on Triggers, Environmental Control and Asthma Management: Two Tools Designed by and for First Nations Communities

FINAL REPORT

January 2011 through April 30, 2012

By:

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Funded by the First Nations, Inuit Health Branch, Health Canada

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Executive Summary

The need to develop culturally appropriate asthma educational materials to educate First Nations and Inuit children and their families and to empower them with proper asthma management and prevention was identified by both "A Shared Vision" (2009) [i] and "A Shared Voice" (2010) reports prepared by the ASC. The findings from both reports provide important insights and guidance on the development of culturally appropriate asthma educational materials and resources for First Nations community members in order to ultimately help address asthma in their communities. The "A Shared Voice" (2010) report helped gain a better understanding about "best practices" in asthma educational materials that are relevant to First Nations and Inuit community members as well as to identify the main characteristics of effective asthma educational and support resources.

The first recommendation of the report focuses on developing culturally appropriate asthma educational materials and resources by modifying the existing materials and/or designing new ones. The report also gives directions on the format and the content of educational materials that should be available for First Nations community members to meet their unique educational needs and reflect on the preferred learning practices. The second recommendation suggests the development of asthma educational programs for children and their families by modifying the existing "Roaring Adventures of Puff" (RAP)[ii] program to make it more relevant for First Nations communities.

"Asthma Education on Triggers, Environmental Control, and Asthma Management: Two Tools Designed for and by First Nations Communities" was a response to address the first two recommendations from the "A Shared Voice" report (2010) by:

1. Modifying the ASC booklet on asthma triggers "Triggers Asthma Basics #2", rated as the most highly preferred resource by parents, grandparents and community leaders, to be current and relevant to several First Nations communities in Canada.
2. Enhancing the Alberta Asthma Centre's (AAC) "Roaring Adventures of Puff" (RAP) program (including games and activities), a program with a proven record of empowering children and their families to better manage their asthma, to ensure it is appropriate and relevant for use in targetted First Nations communities.

The mentioned above activities represent an important step in creating culturally appropriate educational materials and resources for First Nations communities across Canada. These materials will be added to the inventory of asthma and asthma related materials of the project partners and will enhance future programming to First Nations communities beyond the current project.

"Asthma Education on Triggers, Environmental Control, and Asthma Management: Two Tools Designed for and by First Nations Communities" was conducted January 2011 through April 30, 2012. As indicated by the title, the project comprised of two components, developed and implemented simultaneously. The modification and development of the "Asthma Triggers" booklet into a resource for First Nations communities (Component 1) was directly led by the ASC. The adaptation, development and piloting of the "Roaring Adventures of Puff" program into a version appropriate for First Nations communities (Component 2) was contracted to the AAC by the ASC.

Component 1: Modification and Development of the Asthma Triggers Booklet for First Nations communities

To guide the ASC during the development process, a development team of First Nations key informants was established to ensure the newly developed booklet was appropriate for a variety of First Nations communities, working together to develop the core content. This development team consisted of First Nations cultural experts (*e.g.*, medical anthropologist, language expert), health care providers with experience working in First Nations communities (*e.g.*, respirologist, allergists, Certified Asthma Educator (CAE) and nurse practitioner) and First Nations community members (*e.g.*, Elders, community leaders and First Nations families) from across Canada.

The feedback from the communities and the development team was collated and analyzed by the ASC with revisions made to the draft booklet based on the key feedback from the communities. The most significant revisions were included into the next draft of the Asthma Triggers booklet at this stage with the modified draft submitted to FNIHB with the progress report in June 2011. The additional booklet revisions were based on the input from the communities obtained during the initial evaluation. The finalized draft of the Asthma Triggers Booklet was then provided to the development team for final review and approval. Finally the ASC piloted the Asthma Triggers Booklet in selected First Nations communities, evaluated the results and developed the final product.

The ASC also worked with a graphic design company and photographer with strong ties to First Nations culture, as well as with First Nations photographers in order to develop culturally appropriate pictures and images. The result is a booklet which provides information on indoor and outdoor triggers, unique issues for First Nations communities, a brief overview on "what is asthma" and information on asthma medications at the end of the booklet.

Component 2: Adaption and Development of the Roaring Adventures of Puff (RAP) Asthma Educational Program for First Nations communities

As part of Asthma Society of Canada's ("ASC") implementation of recommendations from its "A Shared Voice" project, AAC was contracted to adapt the Roaring Adventure of Puff ("RAP") childhood asthma curriculum to be relevant to Canadian First Nations children. To ensure project activities were informed and community-based, AAC proposed a process that included an Advisory Group, a national workshop, on-line survey, collaboration website and community-based training and delivery. This report describes activities undertaken, additional funds acquired and products developed including the new *Legend of Tahnee, the Wolf: My Asthma Journey* activity book ("Asthma Journey book"). The section entitled "Lessons Learned" includes a summary of challenges and the considerable - and potentially novel - efforts taken to address the same. The recommendations section focuses on suggested next steps for RAP, First Nations children with asthma and their communities. Finally, this report contains a description of the beneficial effects (both anticipated and unplanned) of project activities in First Nations communities and elsewhere.

Challenges and lessons Learned

This project's biggest challenge has been to create a tool that resonates with as many First Nations communities and individuals as possible. We attempted to achieve this by including as much diversity as possible and practical in terms of design and information as well as relying on pan-Indigenous symbols and concepts as much as possible.

When developing materials, the language used should be simple, with explanations being incorporated into the content where necessary. As well, some terminology may need to be confirmed with Elders and knowledge keepers to ensure their understanding of the subject under description.

Participants from this project felt that personal stories, pictures and, if possible, real life characters that relate to their culture should be included in materials for their communities.

Materials, such as the triggers booklet, should be distributed and explained through discussion with health care providers during individual or group consultations. This ensures that community members fully understand the content of the booklet.

It is important to have proper introduction and a full relationship building process in place prior to implementing community-based activities. Communities were more readily identified and recruited in regions where provincial coordinators had previous links or relationships with First Nations communities.

Proper protocol, communication and transparency is key to achieving buy-in and success in community-based settings.

Successful participation of communities and community groups is reliant not only on financial capacity, but often human resources and knowledge. Numerous communities and individual team members advised that they were impeded by staff shortages, high staff turnover, competing demands and priorities. Although many confirmed that asthma and lung health were significant issues in their community, and initially expressed enthusiasm about the project, there were significant rates of attrition.

It is important to involve the leaders and key decision makers in the community at all levels of project and program planning (development, implementation and evaluation) to ensure the maximum success and future "buy–in".

Recommended next steps

First Nations communities are interested in receiving an asthma poster or card with key information about asthma triggers. Other format suggestions include a pamphlet style to serve as a quick reference for asthma education when needed (*e.g.,* carry-on item).

A key feature of this project has been the engagement of leaders, stakeholders and communities and the resulting collaboration and ownership. All of these groups, including the provincial coordination teams, have expressed interest and plans for extending this project and its outputs. Alberta Asthma Centre has received several requests to expand and continue to utilize and promote some or all of the project. For example, it is exploring offering the training program RAP-IT, utilizing the Funbook with their RAP sessions and teaching mentoring the enhanced RAP in the FN communities.

To maximize impact from this initial investment, the AAC feels that the RAP program and the project outputs, including the adapted RAP program, RAP-IT training course and the Asthma Activity Fun booklet now need:

1. plans to continue to build on momentum, capacity and training opportunities;
2. expanded reach by creating and implementing a dissemination plan;
3. to expand the online community of practice to facilitate ongoing review and inclusion of community input into the program;
4. to establish a systematic way of facilitating linkages to asthma education mentors and clinical teams with the program and for the community;
5. structure, staffing and supports (i.e. technological) to better enable communities to implement RAP;
6. evaluate utility and health and society impact in other aboriginal communities.

Specific recommendations include:

1. **Build on the Strengths of this Project, namely:**
    - Evidence of needs and gaps in First Nations health and asthma care;
    - Network of highly committed and knowledgeable asthma and RAP Instructors;
    - Emerging capacity of community teams, community members and provincial teams;
    - Emerging networks of community teams and asthma education mentors;

- Relationships between project team, provincial coordinators, asthma education mentors and participating communities;
- Evidence-based children's curriculum, training curriculum and activity book adapted to reflect communities' preferences and containing First Nations art, subjects and themes; and
- Evidence of community based teams learning preferences;

2. Sustain and Expand RAP Asthma Education for First Nations Children by:

- Promoting and facilitating health professionals and/or community health representatives in First Nations communities to receive RAP-IT training and deliver RAP in the community's school(s);
- Resourcing asthma education mentors' services, including RAP-IT training facilitation, teaching and support and travel time (for 1 t- 2 sessions);
- Promoting the continuing implementation and evaluation of RAP and RAP-IT to First Nations communities;
- Engaging a coordination team such as the AAC to facilitate communication, incorporate community input, activities and stories, provide annual sessions of RAP-IT and sustain the children's art contest features in The Asthma Journey book;
- Advising and consulting with communities and coordination teams about complementary FNIHB, Health Canada initiatives, funding opportunities and positions which can support RAP for example, including RAP in job responsibilities and training for First Nations health promoters.

3.* Publicize and Promote Widespread Dissemination of *Legend of Tahnee, the Wolf: My Asthma Journey

The Asthma Journey has been developed for use within the RAP curriculum and as an independent resource. As a result, it can be used to:

- increase general awareness about asthma;
- introduce the program and its potential to communities;
- provide information and skills where RAP is not currently available; and
- strengthen learning in RAP delivery.

The AllerGen proposal includes a limited budget for printing of The Asthma Journey. In light of what has been invested for development to date, additional funds for printing and dissemination would be warranted and well spent. Further evaluation of this new resource is needed.

4. Promote RAP as an Integrated, Efficient Model to Capture, Refer and Support Children with Asthma

This model uniquely captures children through their school. These children may not otherwise access services, or many access only emergency services. RAP increases their awareness, provides information to family members and provides **links to asthma education mentors, certified respiratory educators, primary care and specialists.** As well, the format of six weekly sessions, in contrast to one emergency visit or one education session, provides multiple opportunities to re-inforce the need to obtain a proper diagnosis and ensure proper medication use.

Leveraged impact of the project and deliverables

In addition to achieving the program deliverables, "Asthma Education on Triggers, Environmental Control, and Asthma Management: Two Tools Designed for and by First Nations Communities" provided an opportunity for community residents from First Nations communities to be involved in the development and further distribution of asthma education resources and materials

Requests and offers to share the project process and outputs more broadly among aboriginal communities have been extended through the AAC's networks and collaborations. Plans are being developed to share the project at various meetings with leaders, administrators, nurses and health promoters working in aboriginal communities and they have been invited to announce project resources on national websites. The AAC also plan to present the project at respiratory and aboriginal related conference, workshops and health fairs.

A greater sense of awareness of asthma and respiratory health at the community level, discussion about ways to integrate asthma and the RAP program into their long term structure has begun. This has including asthma in their chronic disease funding plan, examining staff to support the program and continuing to build relationships with outside clinical experts.

Funds provided by FNIHB made it possible to access matching dollars from AllerGen to help expand the project and be responsive to feedback. These funds and the resulting progress will help to leverage additional funds and resources from other sources with the partners that have been formed.

- For example an Alberta based grant (Alberta innovates Health Solutions) is being drafted for a large collaborative research grant that responds to needs and recommendations stimulated from this project.
- Discussions have begun about at CIHR grant and additional KT funds.

Acknowledgements

The Asthma Society of Canada wishes to acknowledge the many individuals, organizations and communities that contributed to the development of this educational resource. We are grateful to the Assembly of First Nations for their support during the workbook development.

We would like the members of the development team: Roxanne Blood, Roberta and Brent Burnstick, Elder Myrtle Calahaisen, Elder Joanna Dallaire, Myrna Daschuk, Anna and Matthew Doxtator, Jessica Demeria, Dr. Diego Garcia, Dr. B. Louise Giles, Jo-Anna Gillespie, Agnes Kanasawe, Dr. Michael Mandl, Ada Roberts, Dr. Esther Tailfeathers, Dr. Wayne Warry and Dr. Susan Wasserman.

We also wish to thank the organizations and communities who participated in the review of the workbook and contributed their feedback: At^lohsa Native Healing Services, London ON; The First Nations Quebec and Labrador Health Services Commission, Wendake, QC; The Native Women's Resource Centre, Toronto, ON; Shining Mountains Living Community Services, Red Deer, AB; Tl'etinqox-T'in Health Services, Tl'etinqox-T'in, BC; Hazelton First Nation,

Hazelton, BC; Miawpukek First Nation, Conne River, NL; Oneida Nations of the Thames, London, ON; and Whitefish Lake First Nation, Goodfish, AB.

We also wish to acknowledge the members of our production team and the artists and designers who shared their work: Sharon Anderson, Hiro Chavez, Sylviane Duval, Melanie Ferris, Audrey Huntley, Erin Marie Konsmo, Dr. Oxana Latycheva, Robert Oliphant, Zhen Liu, Rupinder Chera, Tannis Nielsen, and Sabrina Panetta.

The Alberta Asthma Centre would like to thank our dedicated and enthusiastic partners, including: Asthma Society of Canada; Assembly of First Nations; Children's Asthma Education Centre; Ontario Lung Association; Ontario Public Health School Asthma Project; asthma educators; and teams and kids from the communities.

This project was developed with support of Health Canada. The work and opinion herein are not those of Health Canada.

I. 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 all Aboriginal communities, including First Nations communities than in the general Canadian population.[iii] It is also well known that First Nations 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 and/or outdoor air quality.

The Asthma Society of Canada (ASC)[iv] 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 connections between environmental factors and respiratory health. In 2010, the ASC took the lead on a project and completed an assessment of asthma and allergy educational materials and resources by First Nations and Inuit communities to identify their relevance to community members.

The project was also designed to understand how these materials could be modified to better suit the needs of these communities and implemented in collaboration with the Assembly of First Nations (AFN)[v], Inuit Tapiriit Kanatami (ITK)[vi], and AllerGen NCE Inc.[vii], and supported by the First Nations and Inuit Health Branch (FNIHB), Health Canada. The 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" [viii] was released in June 2010 and main findings were presented to FNIHB.

The findings from "A Shared Voice" (2010) supported five key recommendations:

1. Focus on developing culturally appropriate asthma educational material and resources by modifying some of the existing materials and/or designing new ones.
2. Develop and implement asthma educational programs mainly focusing on children and their families.
3. Increase public awareness on asthma by developing and implementing awareness programs and materials.
4. Ensure appropriate access to asthma educational resources and materials in communities.
5. Continue engaging First Nations and Inuit community members in the development and/or adaptation of asthma educational resources.

"Asthma Education on Triggers, Environmental Control, and Asthma Management: Two Tools Designed for and by First Nations Communities" was a response to address the first two recommendations from the "A Shared Voice" report (2010) by:

3. Modifying the ASC booklet on asthma triggers "Triggers Asthma Basics #2", rated as the most highly preferred resource by parents, grandparents and community leaders, to be current and relevant to several First Nations communities in Canada.
4. Enhancing the Alberta Asthma Centre's (AAC) "Roaring Adventures of Puff" (RAP) program (including games and activities), a program with a proven record of empowering children and their families to better manage their asthma, to ensure it is appropriate and relevant for use in targetted First Nations communities.

The mentioned above activities represent an important step in creating culturally appropriate educational materials and resources for First Nations communities across Canada. These materials will be added to the inventory of asthma and asthma related materials of the project partners and will enhance future programming to First Nations communities beyond the current project.

II. Project Description

Background

The need to develop culturally appropriate asthma educational materials to educate First Nations and Inuit children and their families and to empower them with proper asthma management and prevention was identified by both "A Shared Vision" (2009) [ix] and "A Shared Voice" (2010) reports prepared by the ASC. The findings from both reports provide important insights and guidance on the development of culturally appropriate asthma educational materials and resources for First Nations community members in order to ultimately help address asthma in their communities. The "A Shared Voice" (2010) report helped gain a better understanding about "best practices" in asthma educational materials that are relevant to First Nations and Inuit community members as well as to identify the main characteristics of effective asthma educational and support resources.

The first recommendation of the report focuses on developing culturally appropriate asthma educational materials and resources by modifying the existing materials and/or designing new ones. The report also gives directions on the format and the content of educational materials that should be available for First Nations community members to meet their unique educational needs and reflect on the preferred learning practices. The second recommendation suggests the development of asthma educational programs for children and their families by modifying the existing "Roaring Adventures of Puff" (RAP) [x] program to make it more relevant for First Nations communities.

Cultural practices and behaviours are very essential for First Nations communities and embedded in their everyday activities. It is important that they will be taken into consideration when

modifying and/or developing any health-related educational interventions and materials. Currently, there is a lack of culturally appropriate educational materials and resources on asthma and associated allergies that are tailored to the needs of First Nations people including youth and their families. "Asthma Education on Triggers, Environmental Control, and Asthma Management: Two Tools Designed for and by First Nations Communities" focused on the development of culturally appropriate asthma educational materials and resources based on the key characteristics identified during the "A Shared Voice" project (*e.g.*, preferred learning style, format, core elements, desirable content, cultural context, *etc*.).

Proper community engagement plays a crucial role in success of any community-based initiative and was considered as a first necessary step in the development process. "Asthma Education on Triggers, Environmental Control, and Asthma Management: Two Tools Designed for and by First Nations Communities" focused on engaging First Nations community members, particularly youth and their families, in the development of asthma educational initiatives and materials by gathering their input on the materials under development.

Key community members who participated in the "A Shared Voice" project (2010) who expressed their interest to be involved in future development of educational materials were consulted to provide their feedback on the draft materials developed as well as to ensure cultural appropriateness of newly developed materials and their relevance to First Nations communities and their unique issues.

Project Goals

"Asthma Education on Triggers, Environmental Control, and Asthma Management: Two Tools Designed for and by First Nations Communities" was developed and implemented as a response to the first two recommendations from the "A Shared Voice" report (2010), focusing on developing culturally appropriate asthma educational resources by modifying some of the existing asthma educational materials and programs. This project aimed to achieve 2 goals:

1. To adapt and modify the existing ASC booklet on asthma triggers "*Triggers Asthma Basics #2*" chosen because it was rated as the most highly preferred resource by parents, grandparents and community leaders. (Component 1)

2. To develop and pilot an asthma educational program based on the RAP curriculum, which aimed to empower children and their families to better manage their asthma. (Component 2)

Project Overview

"Asthma Education on Triggers, Environmental Control, and Asthma Management: Two Tools Designed for and by First Nations Communities" was conducted January 2011 through April 30, 2012. As indicated by the title, the project comprised of two components, developed and implemented simultaneously. The modification and development of the "Asthma Triggers" booklet into a resource for First Nations communities (Component 1) was directly led by the ASC. The adaptation, development and piloting of the "Roaring Adventures of Puff" program into a version appropriate for First Nations communities (Component 2) was contracted to the AAC by the ASC.

Component 1: Modification and Development of the Asthma Triggers Booklet for First Nations communities

To guide the ASC during the development process, a development team of First Nations key informants was established to ensure the newly developed booklet was appropriate for a variety of First Nations communities, working together to develop the core content. This development team consisted of First Nations cultural experts (*e.g.*, medical anthropologist, language expert), health care providers with experience working in First Nations communities (*e.g.*, respirologist, allergists, Certified Asthma Educator (CAE) and nurse practitioner) and First Nations community members (*e.g.*, Elders, community leaders and First Nations families) from across Canada.

The feedback from the communities and the development team was collated and analyzed by the ASC with revisions made to the draft booklet based on the key feedback from the communities. The most significant revisions were included into the next draft of the Asthma Triggers booklet at this stage with the modified draft submitted to FNIHB with the progress report in June 2011. The additional booklet revisions were based on the input from the communities obtained during the initial evaluation. The finalized draft of the Asthma Triggers Booklet was then provided to the development team for final review and approval. Finally the ASC piloted the Asthma Triggers Booklet in selected First Nations communities, evaluated the results and developed the final product.

The ASC also worked with a graphic design company and photographer with strong ties to First Nations culture, as well as with First Nations photographers in order to develop culturally appropriate pictures and images. The result is a booklet which provides information on indoor and outdoor triggers, unique issues for First Nations communities, a brief overview on "what is asthma" and information on asthma medications at the end of the booklet.

Component 2: Adaption and Development of the Roaring Adventures of Puff (RAP) Asthma Educational Program for First Nations communities

As part of Asthma Society of Canada's ("ASC") implementation of recommendations from its "A Shared Voice" project, AAC was contracted to adapt the Roaring Adventure of Puff ("RAP") childhood asthma curriculum to be relevant to Canadian First Nations children. To ensure project activities were informed and community-based, AAC proposed a process that included an Advisory Group, a national workshop, on-line survey, collaboration website and community-based training and delivery. This report describes activities undertaken, additional funds acquired and products developed including the new *Legend of Tahnee, the Wolf: My Asthma Journey* activity book ("Asthma Journey book"). The section entitled "Lessons Learned" includes a summary of challenges and the considerable - and potentially novel - efforts taken to address the same. The recommendations section focuses on suggested next steps for RAP, First Nations children with asthma and their communities. Finally, this report contains a description of the beneficial effects (both anticipated and unplanned) of project activities in First Nations communities and elsewhere. (See Appendix 38 for the Final Report from Component 2)

III. Project Objectives, Core Activities and Results - Component 1 "Modification and Development of the new Asthma Triggers Booklet":

Objectives for Component 1

- Adapt and modify the existing booklet *"Asthma Triggers Basics#2"* based on the main findings of the "A Shared Voice" report (2010) and taking into consideration the preferred content, design, and cultural practices identified by First Nations community members.
- Engage First Nations community members in the adaptation process by establishing a Development Team consisting of key informants from First Nations communities including youth, their extended families (family Elders), caregivers (*e.g.*, teachers, primary health care providers), community leaders (Elders), partner representatives and other stakeholders.
- Conduct an initial evaluation of the newly developed material before pilot production and distribution to ensure its cultural appropriateness and relevance by gathering feedback from community members.

Core Activities and results for Component 1

The Creation of the Development Team and Initial Development of the Core Content and Design of the Draft Asthma Triggers Booklet

A Development Team of First Nations cultural experts, health care professionals working in these communities, and First Nations community members was established in order to maintain appropriate guidance during the course of the project, namely the modification and development of the draft Asthma Triggers Booklet. Members of the Development Team provided the ASC with integral feedback on the content and cultural relevance of the Asthma Triggers booklet as well as took part in the revisions of the booklet after initial evaluation.

- Development Team Recruitment and Participation

Letters of invitation were sent to potential participants of the development team via email. Potential participants were chosen based on existing ASC contacts as well as through collaboration with key project partners such as the AFN. The invitation letter described the purpose of the project and explained the team members' potential role in the project.

The development team is comprised of three categories of team members; First Nations cultural experts, health care professionals, and First Nations community members. The list of development team members with their affiliation and province of residence is presented in Appendix 1. The development team also includes the ASC project staff, a professional writer and representatives from partner organizations (the AFN, AllerGen NCE Inc.)

These individuals were chosen to be part of the development team based on their connection to asthma and associated allergies as well as their experience in working in First Nations communities. Further, these individuals were from across Canada allowing for a nation-wide representation of First Nations communities in the development team. A First Nations graphic designer was recruited to help create images and layout of the draft Triggers booklet based on the feedback and suggestions of the ASC and the development team.

- Development of the draft Core Content and Design of the Draft Asthma Triggers Booklet

The initial development of the Asthma Triggers booklet began with the ASC compiling the content from the Asthma Basics booklet series. Additionally, the ASC conducted detailed searches of information on asthma triggers and irritants available from other sources such as Canadian and provincial Lung Associations. Further, the ASC collected information on unique issues specific to First Nations communities, such as road dust, forest fires, mould and traditional and non-traditional tobacco use by reviewing multiple sources (*e.g.*, internet websites, resources available from the government agencies, material developed by organizations working in the smoking cessation field, *etc.*).

Upon completion of a detailed search on asthma triggers, irritants as well as avoidance strategies, the ASC compiled the gathered information into four key sections, namely: "What is Asthma?", "Asthma Triggers", "Avoidance Strategies", and "Asthma Medication" as follows:

- The information in the first section, "What is Asthma?" was mainly taken from the Asthma Basics: Diagnosis booklet[xi] available through the ASC.
- The information in the second section, "Asthma Triggers", was compiled from the Asthma Basics: Triggers booklet[xii] offered through the ASC, as well as other sources on asthma triggers which would be relevant to First Nations communities. The second section includes detailed definitions of various allergic and non-allergic triggers (irritants) in paragraph format which are grouped under respective headings.
- The information in the third section, "Avoidance Strategies", was compiled from the ASC's Asthma Basics: Triggers booklet as well as other sources. The ASC created an "Avoidance Strategy" chart with instructions on how to avoid main asthma triggers. In the chart, instructions are further divided into the following headings: "What to avoid", "How to prevent" and "What else can you do?".
- The information in the fourth section, "Asthma Medication", was compiled from the ASC's Asthma Basics: Medication booklet[xiii] and prepared in chart format. This document also includes important questions and answers related to medications and their use.

The ASC and the development team worked closely to finalize the core content and design of the Asthma Triggers booklet. Ongoing communication took place via email and regular phone calls as well development team meetings which were conducted via conference calls separately with the First Nations cultural experts and health care professionals as well as the First Nations community members. The ASC organized three meetings in March 2011 with the development team via conference calls to discuss in detail the core content for the draft Triggers Asthma booklet.

A specific issue discussed was whether or not to keep the information on "Asthma Triggers" and "Avoidance Strategies" as two separate sections. The decision was made to present that information separately. Further, the ASC consulted with the development team on how to incorporate a holistic approach into the booklet. A draft Asthma Triggers booklet was then prepared by the ASC based on the feedback received from consultations with the development team.

Initial Evaluation of the Draft Asthma Triggers Booklet by First Nations Communities

The initial evaluation of the draft Triggers booklet was conducted by First Nation communities in order to gain integral feedback from community members. The ASC recruited five First Nations communities to participate in the initial evaluation. These communities were chosen in

order to ensure a nation-wide representation of First Nation communities in the development of the new booklet.

1. Miawpukek First Nations (Conne River, Newfoundland)
2. Whitefish Lake First Nations (Goodfish, Alberta)
3. Oneida Nation of the Thames (London, Ontario)
4. Hazelton First Nations (Hazelton, British Columbia)
5. First Nations Quebec and Labrador Health and Social Services Commission (Wendake, Quebec).

First Nations community health directors from the above listed communities were approached to assist with the initial evaluation of the draft Asthma Triggers booklet to their respective community members. Communities took a lead in recruiting participants to be involved in the initial evaluations. Proper community agreements were signed with the communities once they agreed to participate in the project (Appendix 2). The ASC also appointed community based project managers to facilitate the initial evaluation at the community level.

The ASC applied a mix-method approach to initial evaluation of the draft Asthma Triggers booklet. Quantitative and qualitative methods were used to conduct the initial evaluation as follows:

Community Survey

A community questionnaire (Appendix 3) was developed by the ASC based on the core content and design of the draft Asthma Triggers booklet. The purpose of the questionnaire was to gain feedback on the cultural appropriateness of the Asthma Triggers booklet for First Nations communities. The questionnaire also addressed questions on core content, layout, format, and images. Questions about areas of improvement and suggestions were also included in order to further modify the draft booklet during its final revision.

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The questionnaires were distributed to the appointed First Nations community based project managers to distribute to their respective community members (See Table 1 for results). The draft Asthma Triggers booklet was attached to the questionnaire. Questionnaire packages were mailed out with accompanying prepaid envelopes which were to be mailed back to the ASC after survey completion.

Table 1 Number of completed questionnaires received by the ASC, by First Nations community

First Nations Community	Number of Questionnaires Completed
Miawpukek First Nations (Conne River, Newfoundland)	5
Whitefish Lake First Nations (Goodfish, Alberta)	2
Oneida Nations of the Thames (London, Ontario)	4
Hazelton First Nations (Hazelton, British Columbia)	4
Total	**15**

Community-Led Discussion Groups

In order to gather feedback and suggestions from community members, community-led discussion groups were organized. The communities choose to conduct and organize their own discussion groups, with the discussion be conducted by a community health care professional who would be responsible for gathering feedback and input from participants.

All participating communities chose their own community facilitator to conduct and organize the group discussion who was also responsible for participant recruitment. In the Whitefish Lake First Nations community, Alberta, the discussion group was organized with support from the Social Support Research Program, University of Alberta. Necessary documents were created by the ASC to help guide communities during the discussion groups. The documents provided to the communities included:

- Discussion participants consent form (Appendix 4)
- Discussion group participants checklist outlining important questions for discussion (Appendix 5)
- Facilitators guide for each discussion including detailed questions on core content, avoidance strategies and cultural relevance of images and booklet design (Appendix 6).

Community-led discussion group participants included First Nations adults with asthma and/or associated allergies, including, community leaders, band council members and youth (aged 20 and above). In total, 26 First Nations individuals participated in the community discussion groups as outlined in Table 2.

Table 2 Number of Participants who attended Community Discussion Groups, by First Nations community

First Nations Community	Number of Participants
Miawpukek First Nations (Conne River, Newfoundland)	5
Whitefish Lake First Nations (Goodfish, Alberta)	11
Oneida Nations of the Thames (London, Ontario)	5
Hazelton First Nations (Hazelton, British Columbia)	5
Total	**26**

Interview with Health Directors and/or Health Care Professionals

The third method used to collect feedback and suggestion on the draft booklet was interviews with the First Nations community health directors and/or health care professionals. Materials such as the draft booklet and the interview guide developed by the ASC (Appendix 7) were provided to health directors and/or health care professionals prior to a scheduled conference call with the ASC project staff. During interviews, health directors and/or health care professionals were encouraged to give the ASC their personal opinion, feedback as well as suggest possible changes that would be relevant in the further modification of the booklet. In total, **4** health directors and **2** health care professionals were interviewed.

Analysis of the Initial Evaluation Results and Suggestions for Improvement

Feedback from the initial evaluation was recorded by community representatives, transcribed by the ASC and the Social Support Research Program staff, and analyzed using manual coding by at least two independent individuals from the ASC project staff. The key findings of the initial evaluation are summarized below under the two main categories as follows:

Qualitative Results and Recommendations

Feedback on the booklet and recommendations for further revisions were very consistent based on the initial evaluation of qualitative results obtained by the means of community-based discussion groups, interviews with health directors and/or other health care professionals, on-going communication with the development team as well as written comments provided in community surveys.

Content

Positive Aspects

- *Core content very well researched and included necessary information*

The major finding based on the feedback from the community surveys, interviews with community health directors and/or other health care professionals, community-lead discussion groups and development team discussions was that the information and core content of the draft Asthma Triggers booklet was very appealing, well done, and researched. Participants found that the content was very interesting, informative, and the description of asthma and its triggers was clear. The core content was very detailed and covered all the necessary information and discussion topics pertaining to asthma, including information on "What is Asthma", "Triggers", "Irritants", "Avoidance Strategies", and "Medication Usage".

Participants particularly enjoyed the section on *Exercise and Physical Activity*, and agreed that this topic should be emphasized. Participants felt that it was necessary to get the message across to First Nations individuals that people can and are encouraged to continue exercising even if they do have asthma. In addition, participants favored the section on *Non-traditional Tobacco use*, as they felt that smoking was very prevalent in First Nations communities and could be a significant trigger of asthma. Information on *Stress,* as well as *Unique Issues* pertaining to First Nations communities including mould, road dust, forest and grass fires and outdoor burning, were also favoured.

> "I think this is a really good book with a lot of information. [The content is] very good, [it] explains what asthma is very well, and tells you what causes breathing problems"
>
> -First Nations community member

- *Core content was accurate and relatable to First Nations community issues and concerns*

When participants were asked whether they felt that the community would respond well to the material, the majority agreed that the booklet could be used as a "handy resource" in various community settings. Participants felt that the information pertaining to First Nations communities was presented accurately and was relevant to the issues and concerns faced by their communities. However, First Nations community members suggested that changes would need to be made in order to make the resource more useful for the community.

Suggestions for Improvement

- *Be more precise (avoid too much information)*

The major negative aspect expressed by the community members regarding the content of the material was that the material contained too much detail and was too wordy to be easily digested by community members. It was also felt that too much information could potentially take away from the public interest in reading and/or using the booklet. Therefore, it was suggested that only

the main messages and key points be included and emphasized in order for the material to be more concise and right to the point. Further, it was also suggested to have a short "snapshot" text at the beginning of each section.

- *Simplify the Language*

Another major negative feature of the draft booklet was that the material was presented at high literacy level. It was deemed that the booklet was written more for healthcare professionals, and would not be readable by the majority of First Nations community members. It was suggested that the language be brought down to a Grade 6-7 literacy level in order for the material to be easily understandable by the majority of community members and reviewed by Elders and knowledge keepers to ensure understanding of the subject. Further, it was recommended that explanations should be included next to the information presented to ensure that the message has been understood. In addition, it was suggested that there should be a detailed description of allergies, and thorough and clear explanations about the difference between "allergic" and "non-allergic" triggers.

Additional suggestions on elements and topics to be incorporated and/or clarified in the final draft of the booklet

The incorporation of personal stories and real life experiences about First Nations community members living well with asthma.

This incorporation of personal success stories was highly favoured by participants as it will introduce a sense of community as well as feeling of empowerment that people can control their asthma. It was also recommended to include pictures of the individuals who provided their personal stories.

Detailed information about existing support resources

- More emphasis should be placed on providing contact information for the asthma help and/or support line offered by the ASC. This information will allow First Nations community members to get in contact with a Certified Asthma/Respiratory Educator (CAE/CRE) should they have any non-emergency questions and/or concerns regarding asthma. It could also serve as a support resource for the emotional stress associated with caring for a child with chronic disease, asthma in particular.
- Further, content should be altered to provide more information on additional resources available at the community level and how they can be accessed. For instance, it should be stated that individuals need to contact their Band Council and/or healthcare centre if they require further information on asthma and the environmental control. Proper explanations should be made on when community members should be contacting the Environmental Health Officer.

Specific changes to the booklet sections

- "What is Asthma" should start as a story leading into the booklet.
- "Triggers" should provide basic suggestions on how to avoid the trigger (*e.g.*, quick tips on each trigger). The order of the triggers should be in the order of importance and relevance to First Nations individuals. It was suggested that *Outdoor Triggers* (*e.g.*, forest fires, road dust) should be presented before *Indoor Triggers*. Further, information on tobacco, smudge, dust, and the flu should be closer to the top of the list. Additional triggers to be added to the list include: grass and hay (common allergies in the community); dust mites; smudging; scented items (*e.g.*, candles with sage smell, etc.); trees, and toxic chemicals especially in school environments (portables). Community members would also like to see information on asthma and allergy-friendly products (*e.g.*, mattress covers, stuffed toys, *etc*.)
- "Irritants" should include information not only on traditional tobacco, but also on cedar, sage, and sweet grass. There should be a note about West Coast practices as they do not widely use the traditional tobacco. There also should be mentioning of smoke house, chimney smoke, wood burning stoves, and idling especially during the winter. Further, outdoor burning, forest fires, and occupational irritants (*e.g.*, cleaning products) should be added to the list where appropriate. It was also suggested to add information on cough suppressants as potential asthma triggers.
- "Medication" should include the following points: checking expiry dates, not storing medication in bathrooms, keeping prescriptions up to date and having an additional puffer on hand. It also needs to give advice on how to help children remember to take their medication at school (*e.g.*, keeping a spare medication in their school bag). Further, the medication content should include the side effects of asthma medications and the danger of over using them. The medication section should list the various medications with instructions on how to use them corresponding to a diagram or picture beside each medication. People should also be encouraged to contact their Traditional healer with any questions on traditional medications. There should be some mentioning of traditional medicine usage and non-conventional methods for preventing asthma symptoms.
- "Occupational exposures" should be further reviewed to confirm the relevance of presented occupations to First Nations communities from across Canada.

Information on healthy home environments

- More information should be available on indoor air quality with particular attention to air exchange units, air conditioners, venting systems, etc.
- Provide more details on heat and humidity control including more information on how to use a hygrometer. This section should also include easy tips and simple solutions on

what people can do to make their homes healthy without support from community officials.

- There should be a dedicated section discussing the use of household products (*e.g.*, air cleaners, carpet deodorants, *etc.*) which also provides information on cost-effective natural alternatives to chemical cleaners (*e.g.*, how to use vinegar, baking soda, *etc.*).

<u>Emphasis on the topics of highest relevance to community members</u>

- More information should be present on *mould*, with particular attention on "*winter mould"* and how to avoid it. Provided tips on mould remediation should be linked to the websites for further reading and information on how to get rid of it. Further, it is important to mention that water can trap underneath the carpet leading to mould growth. Suggestions should also be given on proper house cleaning.
- Community members would also like to have information about farming and the risk of being exposed to mould.
- An emphasis should be made on *second and third hand smoke* exposure, specifically for caregivers and daycare workers as it is one of the main concerns for the majority of First Nations communities. Specifically, more details should be given about third-hand smoke and how it stays on clothes and the importance of washing hands after a cigarette.
- *"Asthma and exercise"* should be expanded as many community members expressed a greater interest in the information provided. Sports which are "asthma friendly" should also be described (*e.g.,* baseball). Community members would also like to have clear explanations on how to take a rescue puffer before exercising. In general, more information should be provided on healthy lifestyles and how to maintain them.
- There should be information on the importance of receiving the flu-shot as well as a list of healthy lifestyle elements that individuals with asthma should implement into their lifestyle to avoid the flu infections *(e.g.*, stay hydrated, use hand sanitizers when appropriate, *etc.*).

<u>Some terminology requires further clarification</u>

- Information on the "super bug" should be included in the content as it is quite prevalent in the majority of First Nations communities. As well, the terminology related to this phenomenon needs to be clarified.
- To avoid misunderstanding of the information provided, the terminology for the "Traditional Tobacco Use" portion should be changed to "Follow your Traditional Protocols" as each tribe is different in establishing their policies around traditional tobacco use.
- To avoid the usage of specific names for traditional food (e.g., Bannock) and apply general terminology such as traditional breads.

Format

Positive Aspects

- *Use of Subtitles, Pictures and/or Diagrams, and Checklists*

The majority of community members agreed that the format of the material was a huge determinant of whether the booklet would be readily accepted by the community. It was emphasized that the material should be easily readable and concise with the main message getting across at first read. Favorable aspects of the current booklet include good flow, the use of subtitles to separate the main topics, as well as the use of pictures and/or diagrams and checklists. It was felt that the pictures and/or diagrams would serve well to separate the written text and provide visual explanation of the information presented. Further, the use of checklists in the booklet was favoured as it broke up the information provided and helped make the booklet more interactive for the reader.

Suggestions for Improvement

The major negative aspect about the current draft of the Triggers Booklet was that the material was too hard to digest in the current format as too much information was present. In order to make the booklet more interesting to read and easier to follow, it was suggested to make it look less like a document and incorporate the following:

- *Larger Text and more colourful font*

Larger text is necessary for Elders and grandparents who are raising their grandchildren with asthma. It is important for Elders to be able to read and understand the material. As well, font should be colourful to grab reader's attention.

- *Bullet Points and Information Boxes*

The format should include bullets to emphasize the key points in order to grab readers' attention. This will make the material easier to comprehend and follow. Further, the language should be kept short and simple and the main points should be captured within information boxes. This will help reduce the amount of text and emphasize the main messages.

- *Uniform layout*

It was suggested to choose one format either being horizontal or vertical for all the sections. In the draft under review, one section was presented horizontally forcing the reader to turn the pages which could be seen as an inconvenience while using the booklet.

- *Chart Format with Corresponding Pictures or Diagrams*

For the *Medication* section, it was suggested to include colour pictures of each asthma medication next to the written text using a chart format. It was also suggested to include an asthma devices chart portraying aero chamber, nebulizer, oxygen meter, *etc*. In future,

community members would also like to have a resource explaining in detail how to use asthma puffers.

Further, it was recommended to have a small paragraph explaining asthma triggers and irritants with a corresponding picture or diagram of the trigger and/or irritant for better visual presentation.

Layout/Design

Positive Aspects

- *Favoured pictures/diagrams and First Nations references/cultural symbols*

The major finding regarding the design of the draft Asthma Triggers booklet was that project participants greatly enjoyed the pictures and diagrams included in the booklet. They favoured the pictures which featured First Nations individuals and cultural symbols as well as liked the nature aspect of the pictures and suggested the inclusion of more of these images.

- *Favoured the layout/color coded sequence of the booklet*

Participants favoured the layout of the booklet, whereby the green section being asthma triggers, followed by blue colour used for irritants, red - for avoidance, and purple - for medication. Participants enjoyed how the material was separated by subtitles as well as being color-coded as this made the material easier to follow. In order to enhance clarity to the document, it was suggested that each new section or topic should start on a new page and be clearly separated.

Suggestions for Improvement

- *Include a Self-Guide at the beginning of the booklet*

It was suggested to include a "self-guide" at the beginning of the booklet to explain the importance and purpose of the material, how to navigate the booklet, and describe how the booklet is laid out.

- *Material should follow the Holistic Approach (e.g., Medicine Wheel)*

It was suggested that the booklet should follow the Holistic Approach by using elements of the *Medicine Wheel* (mental, emotional, physical, and environmental) when describing asthma to allow the material to be reflective of the unique First Nations culture and traditions. It was recommended that there should be a focus on "healthy living" steps to prevent asthma including exercising and not smoking. Another suggestion to incorporate the *Medicine Wheel* was to start at the top of the wheel with "What is Asthma" and go around to "Asthma Triggers", "Asthma Medication", and "Controlling Your Asthma". Further, information should be presented as an interactive cycle between individual health and the environment (*e.g.*, plants).

- *More First Nations specific diagrams/pictures (Elders) and cultural symbols instead of written text*

Participants felt that the graphic design was only depicting First Nations individuals who reside in the prairies and East Coast and suggested adding more pictures and/or diagrams that reflect all Nations from coast to coast. Pictures should also incorporate more individuals living positively with asthma from all age groups, particularly Elders and children. It was suggested that the images should portray First Nations community members engaging in healthy activities such as riding bikes, walking, playing sports as well as using their asthma medication, and avoiding triggers by taking appropriate avoidance measures. It was also recommended to broaden the use of First Nations symbols to include images of long house, totems, drums, and feathers after confirming their appropriateness with cultural experts.

It was noted that pictures need to be larger, have better resolution, and be more vibrant and contemporary, eye catching, and clear to the reader. Some readers found the background images behind the text were sometimes distracting making it difficult to read the content. The pictures and/or diagrams need to be labeled appropriately so that readers will understand what is being presented.

- *Consolidate information about triggers and avoidance strategies into one location*

The booklet design needs to be simple as well as consistent. A consistent layout will allow the material to follow easier. It was noted that it would be more empowering to change the layout of the "Avoidance Strategies" section and present the information about avoidance methods together with the description of the triggers. For example, information about mould should be placed adjacent to mould reduction strategies. In this case, each asthma trigger category would have information about the trigger itself, and avoidance and prevention strategies consolidated into one area. This will allow the reader to access all the information in one area and potentially reduce confusion. In this scenario, the layout should be separated with tabs to better organize the content.

- *Changing the order of information presented to better suit First Nations needs*

It was noted that there is a need to alter the order of information presented to better match the issues and concerns faced by First Nations community members. For instance, information about *road dust* should be presented first, followed by *smoking* and then *mould*.

- *Booklet Cover Page looks interesting but not relevant*

The booklet cover page picture was not favoured by participants as it does not relate to asthma and/or its triggers. It was suggested to add images related to asthma triggers (*e.g.*, flowers, trees, pollen, grass fields, *etc*.) to make that connection. Further, it was suggested that the cover page include some pictures of adults, children, and Elders of First Nations decent. As well, a First

Nations theme should be incorporated by adding cultural symbols that represent all First Nations (e.g., the Medicine Wheel).

In addition, the title of the booklet "Asthma Triggers" was not favored by participants. It was suggested that the title be more general to incorporate all the information the booklet discusses.

Additional Elements to be considered for inclusion

Recommendations on additional elements to be included in the Asthma Trigger Booklet were consistent amongst the four First Nations communities involved in the initial evaluation. Participants agreed that the described below elements would improve the booklet's appeal to community members as follows:

- *Incorporation of an Asthma Quiz*

An idea of an *Asthma Quiz* about common asthma triggers and irritants with answers to the quiz found within the content of the booklet was preferred by project participants. This will make the booklet more interactive for the reader and will assess the reader's understanding of the main messages regarding asthma.

- *Incorporation of a "My Triggers" and a "My Notes" section*

Inclusion of "My Triggers" and "My Notes" sections was favoured by participants as it will encourage readers to write down important information and numbers in the booklet as they review it. Further, a "My Triggers" section allows readers to apply freshly acquired knowledge of asthma to their own triggers. If taken to a visit with healthcare professionals, the booklet will help nurses gain information about the patient and review the written down triggers.

- *Adding a "Glossary of Terms"*

Medical terminology was one of the major issues which prevented readers from fully understanding the content of the booklet. It was suggested to add a *Glossary of Terms* at the back of the booklet as a quick reference to look up any terminology which readers are not sure about. Sample terms include but are not limited to the following: triggers, irritants, chronic, condensation, mould, inflammation, inflammatory, allergic, *etc.*

- *Adding common symbols/logos to flag similar sections*

It was suggested to incorporate symbols/logos into the booklet to identify similar content or sections. For example, a logo will be present next to each *Quick Tips* in the booklet. This will allow the booklet to be organized properly and have sections or topics that are easily identifiable by the reader as they go through the material.

Quantitative Results and Recommendations

During the initial evaluation, quantitative feedback was gathered by asking community members to review the draft booklet and complete an assessment survey. The results and recommendations from the survey are categorized and presented below according to the survey sections. Results in *Section A* contain participants' demographic information and shows how much survey participants know about asthma. *Section B* asks respondents detailed questions about the format and content of the draft Triggers booklet. *Section C* focuses on questions regarding the design and images used in the booklet. *Section D* asks questions on whether the material in the booklet is culturally relevant and appealing to community members. Lastly, *Section E* contains questions on the general impression of the draft booklet to the respondents including information on what they liked the most about the booklet, what they did not like, and what could be improved.

Section A – Demographic Information

A total of 15 people participated in the initial evaluation with the majority of them being female. Most of the respondents live on reserve and of these participants a third live in the village, while nearly 15% live in the city. When asked what level of education they have achieved, the majority responded that they had post-secondary education with over a quarter of participants obtaining high school diploma. For a graphical representation of demographic data please see Appendix 8.

Out of all the project participants, the majority reported having asthma/breathing problems, and/or allergies. From that group, over ninety percent stated they had asthma, over half said they had asthma and allergies, nearly half said they had allergies, and over a quarter had been told that they had breathing problems (Appendix 9). The majority of respondents indicated that they knew their asthma triggers with over a quarter of respondent being unaware of them. The triggers that were most often identified by the respondents are presented in Table 3 below. Dust and dustmites, animal dander, colds and viral infections were named most often by the project participants. For a graphical representation of these results, please refer to Appendix 10.

When asked about additional connections to people affected by asthma, 80% of respondents indicated that they knew someone with asthma/breathing problems and/or allergies. Among this group, over ninety percent stated that they knew someone with asthma, over half indicated they knew someone with allergies or asthma and allergies combined, and forty percent indicated that they knew someone with breathing problems (Appendix 11). Over 50 percent of respondents indicated they had a family member with asthma or breathing problems, followed by forty percent indicating a friend and twenty-five percent a neighbour with breathing problems. For a graphical representation of these data, please refer to Appendix 12.

Nearly three quarters of respondents stated they had been provided with information about asthma triggers. From this group, just under half indicated that they had received this information from a healthcare provider, over a third had received this information from a nurse/nurse

practitioner or an asthma clinic, a quarter received it from a pharmacist and nearly twenty percent from friends and the Internet (Appendix 13).

Table 3: Most common asthma triggers identified by the project participants

Trigger	% of respondents
Dust and Dust mites	**90%**
Animal Dander	**80%**
Colds and Viral Infections	**80%**
Pollen	60%
Outdoor burning and forest fires	50%
Exercise	50%
Traditional Tobacco use	50%
Weather and Smog	50%
Mould	50%
Non-traditional Tobacco use	40%
Food	30%
Stress	30%
Road dust	30%
Occupational Irritants	30%
Indoor air	20%
Medications	20%

Section B – Content and Format

When asked whether the respondents want to change the picture and/or image of the lungs seen at the beginning of the booklet, there was a almost an even split in the response.

The information presented in the "Allergic Triggers" section received a relatively high rating with the majority of respondents giving it a rating of 4 out of 5 and a third of participants giving it the highest rating of 5 (Appendix 14). Most respondents felt that the information provided in the "Allergic Triggers" section was well presented and easy to understand. The respondents also gave positive feedback to the information under each subsection of "Allergic Triggers". The majority rated the amount of information under each allergic trigger as being 'just right' (Table 4). A graphical representation of these results can be seen in Appendix 15.

Additionally, almost half of respondents believed that allergic triggers were presented in the order of importance and relevance to First Nations community members, while over a quarter of respondents did not agree. More than half of respondents also stated that they did not feel that

any particular trigger would need to be addressed further in the booklet. Further, the majority of participants felt that there was no allergic trigger that needs to be added to the booklet due to its particular relevance to First Nations communities.

Table 4: Assessment of the information provided on each allergic trigger, by survey participants

Allergic Triggers	% of respondents		
	Just right	Not enough	Too much
Mould	53.3%	20.0%	13.3%
Dust and Dust mites	60.0%	13.3%	13.3%
Animal dander	60.0%	13.3%	13.3%
Pollen	46.7%	26.7%	13.3%
Food	46.7%	20.0%	13.4%

Project participants felt that the information in the "Irritants" section of the booklet was sufficient with the majority giving it a rating of 4 out of 5 and a quarter giving it a rating of 5 (Appendix 16). As well, most respondents indicated that the information provided about irritants was easy to understand. Overall, project participants indicated that the amount of information on most of the irritants was 'just right' (Table 5). However, participants thought that is was 'too much' information provided on non-traditional and traditional tobacco use. A graphical representation of these results can be seen in Appendix 17.

The majority of respondents believed that the irritants were presented in order of importance and relevance to First Nations community members. Further, most of them did not think that any particular irritant needs to be addressed further. Nearly three quarters of participants also believed that there was no need to add information on any other irritants.

While reviewing the "Avoidance strategies" section, project participants were asked to rate their confidence level in implementing the described strategies with their family, at home, and in the community at large. In general, participants felt quite confident about carrying out the avoidance strategies described in the draft booklet. A third of respondents were fairly confident in carrying out the presented strategies with their children and/or family giving a rating of 3 out of 4. Another third of participants expressed good confidence in implementing these strategies indicting a rating of 4 (Appendix 18). When they were asked about carrying out these strategies at home, nearly half of respondents gave their confidence a rating of 5 with a quarter of participants rating their confidence as 4 out of 5 (Appendix 19). Participants were also confident about carrying out the avoidance strategies in their community with a third of participants giving it a rating of 5 and over a quarter giving it a rating of 4 (Appendix 20).

Table 5 Assessment of the amount of information provided on each of the irritants, survey participants

Irritants	**% of respondents**		
	Just right	Not enough	Too much
Non-traditional and traditional tobacco use	40.0%	6.7%	**53.3%**
Indoor air	60.0%	26.7%	13.3%
Weather and smog	80.0%	0%	20.0%
Cold and viral infections	66.7%	13.3%	20.0%
Medications	66.7%	13.3%	20.0%
Exercise and physical activity	66.7%	13.3%	20.0%
Stress	73.3%	6.7%	20.0%
Occupational irritants	60.0%	20.0%	20.0%
Road dust	66.7%	13.3%	20.0%
Outdoor burning	73.3%	6.7%	20.0%

Participants also thought that information provided in the trigger avoidance strategies section was sufficient. A third of respondents gave it a rating of 5 and almost half gave it a rating of 4 (Appendix 21). Further, a large portion of respondents thought that the information provided in the "Avoidance Strategies" section was well laid out and easy to understand. Participants also thought that the amount of information provided on each of the allergic trigger avoidance strategies was 'just right'. Please refer to Appendix 22 for a graphical representation of these results. The majority of participants thought that no particular allergen avoidance strategy needs to be addressed further as well as no particular allergen avoidance strategy needs to be added to the booklet.

Two thirds of participants gave a rating of 4 to the sufficiency of information provided under irritant avoidance strategies (Appendix 23). As well, a large portion of participants indicated that the information provided in the irritant avoidance strategies section was well represented and easy to understand. Most project participants thought that the information provided on each of the irritant avoidance strategies was 'just right'. A summary of these results can be found in Appendix 24.

Two thirds of project participants thought that the irritant avoidance strategies were presented in order of importance and relevance to First Nations community members. The majority did not

think that there was a particular irritant avoidance strategy that needed to be discussed further in the draft booklet. When asked if there was a particular irritant avoidance strategy that the participants felt needs to be added to the booklet due to its relevancy to First Nations community members, most of participants answered 'no'. When further asked about the format of the "Avoidance strategies" section, the majority of project participants indicated that they liked that the triggers and irritants avoidance strategies were listed in a chart format. A large portion of participants would also like to keep the current format of the section and did not think that it should be formatted differently.

A large majority of respondents indicated that the section on asthma medications was informative and easy to understand. Further, most participants were able to understand what type of asthma medication they were using. The majority of respondents also understood that their maintenance medication needed to be used even when they are not experiencing asthma symptoms. As well, most of them found the Frequently Asked Questions included in the "Asthma medication" section being helpful. "My triggers" section of the booklet also received a positive response with the majority of participants stated they like the fact that they could record their individual triggers in this section. The majority of participants (80.0%) liked that they could write notes throughout the booklet in the "My Notes" section.

Overall, almost half of participants gave the draft booklet a rating of 4, and over a quarter gave it a rating of 5 (Appendix 25). The format of the draft triggers booklet for First Nations communities also received a similar praise. One third of project participants gave it a rating of 3 or higher. (Appendix 26).

Section C – Design and Images

The majority of project participants liked the design of the draft booklet as well as its cover page. However, community members did have a split opinion on whether or not the cover page was culturally relevant to First Nations communities. Almost half of the respondents thought it was culturally relevant with another thinking that it was not. Respondents did not have particular suggestions on the title of the booklet, though of them indicated that the title of the booklet should be changed.

When asked about the pictures and images in the booklet, most of participants indicated that the images of First Nations community members were accurately represented. The majority of respondents also thought that the pictures and images representing each of the allergic triggers were consistent with traditionally used formats.

Project participants responded positively to the tables and diagrams included in the booklet with the majority of respondents indicating that they liked the tables and the diagrams. As well, the majority of project participants felt that the color tabs on the side of the booklet were helpful in

identifying appropriate booklet sections. A large portion of respondents felt that other pictures and/or images could be added to the booklet to make it more appealing to the audience.

Section D – Cultural Relevance

The majority of project participants felt that the language and terminology used in the booklet was appropriate for them. When asked to rate how well the draft booklet relates to First Nations communities, the equal number of participants gave it a rating of 3 or 4 (Appendix 27). Participants were further asked to rate how well the "Allergic Triggers" section relates to the issues experienced by First Nations community members. Nearly three quarters of respondents gave a rating of 4, and over 10 percent gave a rating of 5 (Appendix 28). A similar trend was observed when participants were asked to rate how well the "Irritants" section relates to the issues experienced by First Nations community members as the majority of participants gave it a rating of 4 (Appendix 29).

The majority of participants felt that the information provided in the booklet could be effective in educating First Nations communities on the asthma triggers. A large number of participants believed that unique issues such as road dust, forest fires, and traditional use of tobacco were effectively addressed in the draft booklet. Survey participants also provided their suggestions on how to make the booklet more relatable to them and their community. These results are graphically presented in Appendix 30. The top two recommendations included having more pictures and/or images related to First Nations culture as well as real life pictures of community members.

Section E – Overall Feedback

When study participants were asked to provide rating for each section of the booklet (A1-A5), the participants gave section A1 (What is Asthma) an average rating of 3.8; section A2 (Asthma Triggers) - an average rating of 3.9; section A3 (Allergic Triggers Avoidance Strategies) - an average rating of 4.0; section A4 (Irritants Avoidance Strategies) - an average rating of 4.1, and section A5 (Asthma Medications) received a rating of 3.7. For a graphical representation of these results, please refer to Appendices 31, 32, 33, 34, and 35, respectively.

Participants provided a variety of responses when asked what they liked about the draft booklet (Appendix 31). The most favourable feature named was content/information followed by imaging/design and "My notes" section (Table 6).

Participants also provided opinions on what they like the least about the draft booklet (Table 7). The booklet design was listed as the least likable feature of the draft booklet.

Table 6: What participants like the most about the draft booklet

Features	% of respondents
Imaging/Design	**33.3%**
Content/Information	**73.3%**
Real life images	20.0%
Organization/Format	20.0%
Personal Stories	13.3%
Section on ‘My Triggers’	20.0%
Section in the booklet for 'Notes on Asthma' to write my personal information	**26.7%**

Table 7: What participants like the least about the draft booklet

Features	% of respondents
Imaging/Design	**40.0%**
Content/Information	33.3%
Real life images	0%
Organization/Format	13.3%
Personal Stories	33.3%
Section on ‘My Triggers’	6.7%
Section in the booklet for 'Notes on Asthma' to write my personal information	20.0%

All of the survey participants thought that the booklet was informative and could help them learn about asthma triggers and irritants. As well, all of the survey participants felt that the booklet could help them better manage their asthma by managing their environment.

The majority of respondents indicated that there was nothing they did not like about the booklet. Additionally, the majority of respondents felt that both members of their community who do not suffer from asthma or who are affected by asthma would find this booklet informative and easy to follow.

The majority of participants also thought that the information in the booklet was written in a language and presented in the format that could be easily understood. An idea of including personal stories in the booklet received a positive response with two thirds of participants indicating that real life stories should be included.

When survey participants were asked about how members of their community would respond to the information provided in the booklet, they felt that the youth would be keener to use the

booklet. Participants gave the response by youth an average rating of **3.6**; the response by grandparents- an average rating of **3.5**, and the response by Elders- **3.4**. A detailed graphical representation of these results can be found in Appendices 37, 38, and 39, respectively.

Finally, survey participants were asked about changes that need to be made to improve the usefulness of the booklet. A summary of their responses is presented in Table 8 below. Participants would like to see more images and real life stories being incorporated into the booklet.

Table 8: Recommended changes for booklet improvement, survey participants

Recommended changes	**% of respondents**
Have more written information/explanations	20.0%
Have more pictures and/or images that relate to my culture	**60.0%**
Have more characters (real-life) that relate to my culture	**60.0%**
Have more personal stories	40.0%
Have more space in the section on 'My Triggers'	13.3%
Have more space in the section 'Notes on Asthma' to write my personal information	13.3%
I would not change anything	6.7%

In summary, participants gave positive feedback about the content and format of the booklet. Most respondents felt that the information provided on allergic triggers, irritants and avoidance strategies was well presented and easy to understand. Participants also indicated that this information was presented in order of importance and relevance to First Nations communities. The majority of participants believed that no trigger needs to be addressed further and be added to the booklet. They also felt confident in carrying out the avoidance strategies described in the booklet with their families, at home and in community at large.

The overall content of the booklet received an average rating of **4.1** and the format of the booklet received an average rating of **3.8**. Two thirds of the survey participants liked the design of the booklet. The images of First Nations community members received positive feedback because participants felt they were accurately represented. A large number of participants also liked the tables and diagrams. However, participants felt that still more images could be included in the booklet.

When it came to cultural relevance, respondents felt that the booklet was written appropriately for them. The majority of survey participants wanted more picture/images and more characters,

but felt that all the unique issues (i.e. road dust and forest fires) were addressed appropriately. In addition, participants think that personal stories should be included in the booklet and that it should have more real-life characters that relate to their culture, as well as more pictures/images, and more personal stories.

Final Revisions of the Asthma Triggers Booklet

To view booklet please see Appendix 39

Changes made to the draft booklet after the initial evaluation

Based on the feedback and key recommendations received during the initial evaluation of the booklet, the ASC has incorporated the following changes in the draft booklet:

- *Incorporated more pictures instead of written text*

The major collective feedback was about the need for more pictures instead of written text when explaining main concepts. The ASC performed 3 sets of revisions/versions working closely with the First Nations graphic designer in order to ensure that more pictures were added into the content. This addition of images and/or diagrams will allow the information to be more easily digested and understood by First Nations community members. Further, a visual aid will allow the material to be more appealing for learning when compare to reading a text. Additionally, more First Nations relevant pictures will be incorporated during the next iteration of the booklet.

- *Incorporated simple wording when explaining main concepts*

The language of the material content was changed to be at a Grade 6-7 literacy level in order to be more understandable and readable by the First Nations community members. The ASC has incorporated simple wording that is concise, right to the point and not lengthy. The written text was also complimented by the use of pictures.

- *Changed the format by using bullet points and reducing the amount of information provided*

The ASC performed 3 sets of revisions/versions of the booklet core content in order to ensure the proper Grade 6-7 literacy level was achieved and the material was presented in the format that is easy to follow. According to the comments received during the initial evaluation, several booklet subsections were also reviewed and reduced in their content (*e.g.*, information on non-traditional tobacco use).

- *Gathered personal success stories of First Nations individuals living with asthma to be included in the future iteration of the booklet*

The ASC worked closely with Elders, community leaders, and members to collect and record personal stories (Appendix 32). These stories will be condensed as necessary and included in the next booklet revision before pilot distribution of the booklet in First Nations communities.

- *Incorporated "Quick Tips" for reduction/avoidance strategies underneath each asthma trigger*

Quick Tips has been added to the draft booklet to provide First Nations community members with quick ideas on how to avoid their asthma triggers as well as control their environment. The ASC will create a special icon for the "Quick Tips" section to make this information easily identifiable while reading the booklet.

- *Incorporated a list on "Healthy Lifestyle Elements" into the content*

Simple recommendations on how to maintain a healthy lifestyle have been added to the first section of the booklet (What is Asthma).

- *Incorporated "My Notes" and "My Triggers" sections*

Both sections have been added to the booklet and will undergo further revisions as required.

Changes to be made to the draft booklet for pilot distribution to First Nations communities

Due to the project timelines, the ASC did not have an opportunity to address all the recommendations provided during the initial evaluation. The ASC provided the following changes before the pilot distribution of the Asthma Triggers booklet:

Content Changes

- Adapt the introduction of the booklet (What is Asthma) to a "story-like" format in order to incorporate the holistic approach and add the image of the Medicine Wheel
- Provide more clear explanations about the difference between "allergic" and "non-allergic" triggers
- Expand information on healthy home environments and provide easy tips on what people can do themselves in order to improve their homes
- Add personal stories into the booklet and inquired whether the individuals who shared their stories would like to include their pictures into the booklet
- Discussed changes on questionable items with First Nations cultural experts, members of the development team, and the AFN
- Clarified further some terminology

- Reviewed the subsection on occupational exposure to ensure its relevance to the majority of First Nations communities across Canada

Design and Format Changes

- Continued to include pictures and diagrams which are diverse in age representation and were culturally appropriate to First Nations communities from coast to coast through consultation with First Nations cultural experts, the AFN and the development team. Adopt existing medication charts to include images of asthma puffers and devices
- Added symbols and information boxes into the booklet to highlight important points
- Finalized the design of the cover page as well as the title of the booklet

Evaluation of the draft Asthma Triggers booklet during the pilot distribution

After completing the modification of the booklet based on feedback garnered in the initial pilot distribution and provided by the development team we proceeded with preparations for a second pilot distribution in First Nations communities to solicit their impressions on the modified booklet and gather additional feedback. We prepared two questionnaires – one longer format and one shorter format in order to allow respondents to rate content and design based on a standard scale as well as make comments in their own words.

The Report Card - Eight simply worded questions

- Two short introductory paragraphs outlining the Asthma Society of Canada's interest in helping adults with asthma and associated allergies in First Nations communities with the intent of empowering youth, adults and Elders affected by asthma and allergies to achieve a symptom-free life.
- Questions relating to the usefulness in identifying triggers and whether there were triggers that community members experienced that we had not addressed.
- Did respondents find the material had been useful, comprehensible and culturally relevant?
- Feedback on the design and layout (i.e. images and artwork)
- Was there anything missing?
- Suggestions on how to use the booklet and make people aware of it.

The Long Questionnaire

The longer format questionnaire began with a detailed "Introductory Letter" which included information about the purpose and aim of the project and the importance of participant's feedback. There was no need for a consent form since we gathered the information anonymously. This questionnaire was divided into five sections.

Section A- Personal Information - participant's demographic information, including their sex, where they reside and their relationship to asthma i.e. whether they had asthma or breathing problems or knew someone who did, whether they were aware of their triggers and which ones applied to them, and if they had ever received information on asthma triggers.

Section B – Content and Format of the Draft Triggers Booklet - Did respondents consider *An Asthma Story* to be relevant to First Nations? Did they find the lined pages provided for them to make notes and list their triggers to be useful? Here we also asked participants to rate the overall content and layout of the booklet.

Section C – Design and Images - Requested feedback on the overall design of the booklet including the cover page, title, pictures and images of First Nations community members, pictures and images of allergic triggers and irritants as well as tables and diagrams used in the booklet.

Section D – Cultural Relevancy - Addressed the language and terminology used in the booklet and then asked participants to use a scale of one to five to rate how well the booklet related to First Nations communities overall and in particular with regard to allergic triggers and irritants such as road dust, forest fires and traditional use of tobacco smoke. We also asked participants how effective they thought the information provided in the booklet would be as an educational tool for First Nations communities and how they thought it would be best used.

Section E – Personal Feedback - Respondents were given the opportunity to share ideas or suggestions and make additional comments. Copies of the modified booklet and questionnaires accompanied by a cover letter were distributed to nine First Nations communities in 6 provinces representing First Nations people living on reserve, in urban centres and in geographically diverse areas.

103 surveys were returned of which only four were incomplete. These results are especially remarkable when considering the research fatigue in First Nations communities. Community contacts that provided their assistance in identifying community members to participate remarked on the high level of interest in asthma education and the need for such materials. Please see the table 9 below for details on the number of surveys completed by location.

Summary of Data Analysis

While the overall feedback received was very positive many respondents commented that the booklet contained a lot of information, more than typically contained in a booklet or pamphlet. As a result we decided to call this tool a workbook, which is also more in keeping with the interactive elements that were added as a result of community feedback i.e. quiz questions, lined pages for notes, triggers etc.

Table 9 details on the number of surveys completed by location

Anaham, British Columbia	13
Goodfish, Alberta	11
Red Deer, Alberta	18
Winnipeg, Manitoba	6
Toronto, Ontario	17
London, Ontario	20
Montreal, Quebec	1
Wendake, Quebec	8
Conne River, Newfoundland	9
Total Questionnaires	**103**

Summary of Short Survey (Report Card) Results

Only very few respondents said that the booklet did not identify triggers they had previously been unaware of. Most respondents stated they had learned of at least one or two triggers that were new to them. Most commonly stated were:

Dust mites	Road dust	Cold weather
Pollen after thunderstorms	Food allergies	Cleaning products
Stress	Animal dander	

The overwhelming majority of survey participants stated that the booklet had helped them or loved ones find better ways to manage their asthma or allergies and said that the booklet was easy to understand.

Summary of Ratings - Longer Questionnaire

Most respondents rated the booklet's contents, layout and cultural relevancy to be excellent or good. The lowest rating that the booklet received was poor with regards to layout by only two participants. This we believe was due to the fact that they were reviewing a draft, which was printed, in house and not in the final tabbed format with coil binding.

Development team members also received copies of the draft booklet parallel to the second pilot among the above communities. They were very pleased with the modifications and incorporation of feedback from the first round community review.

"The material is easy to understand and presented in a way that is culturally relevant to First Nations – you should be very proud." An Elder affiliated with the Assembly of First Nations

"It is a wonderful booklet and they are kind people to think of us that have respiratory illnesses, now we can learn what we can do to help ourselves. … They did a wonderful job and I know lots of Elders I would like to give threat to when they have it in print. …. Good people let them know

I will help them out any way I can if they need me in the future, I felt so important knowing they wanted my advice." – An Alberta Elder and also a member of the development team.

Future Implications for the Use of the Booklet at the Community Level

During the evaluation process, participants provided their own suggestions on how the booklet could be distributed and/or used by the communities. The suggestions are presented below as follows:

- Health care professionals could provide an individual or group presentation to community members about the content of the booklet
- The booklet should be available at local health stations and/or centres for distribution to people who have asthma
- The booklet should be provided to families through mail delivery. One booklet should be distributed per household as a reference on asthma.
- The booklet should be available at Hospitals and Clinics (*e.g.*, waiting rooms)
- The booklet should be available at Schools
- The booklet should be disseminated through public health units
- Group discussions with Elders could be organized to discuss the booklet

One of the major suggestions was to have the booklet explained through a discussion with health care providers during individual or group consultations. This will ensure that community members fully understand the content of the booklet by being able to go through the main messages. *To view final booklet please see Appendix 39*

IV. Project Objectives, Core Activities and Results - Component 2"Adaptation and Development of the Roaring Adventures of Puff" (RAP)

Objectives for Component 2

- Ensure the RAP curriculum addresses the needs identified by First Nations children and their families during the "A Shared Voice" project (2010) conducted by the Asthma Society of Canada (ASC).
- Ensure that the RAP lesson plans, activities, and resources are culturally appropriate and relevant for children and their families from First Nations communities (*e.g.*, including personal stories).
- Engage First Nations community members in the modification and/or development of the RAP program throughout all phases of the project.

- Gather input from and confirm relevance and appropriateness of the modified and/or newly developed activities and resources for the RAP program with First Nations community members and stakeholders who were involved in the "A Shared Voice" project (2010).
- Utilize expertise and resources of Certified Asthma/Respiratory Educators (CAE/CREs) who have and/or are using the RAP program in First Nations communities.
- Build further on the existing RAP program and resources to include specific First Nations tools and activities to be piloted in these communities.

Core Activities and results for Component 2

For full description of the project and results see Appendix 38, Roaring Adventures of Puff: By and For First Nations Children, Final Report

As part of Asthma Society of Canada's ("ASC") implementation of recommendations from its "A Shared Voice" project, AAC was contracted to adapt the Roaring Adventure of Puff ("RAP") childhood asthma curriculum to be relevant to Canadian First Nations children. Continuation of this process resulted in an additional agreement as par to of "Asthma Education on Triggers, Environmental Control, and Asthma Management: Two Tools Designed for and by First Nations Communities" (Signed agreement in Appendix 33). To ensure project activities were informed and community-based, AAC proposed a process that included an Advisory Group, a national workshop, on-line survey, collaboration website and community-based training and delivery.

This section describes activities undertaken, additional funds acquired and products developed including the new Legend of Tahnee, the Wolf: My Asthma Journey activity book ("Asthma Journey book")

Brief description of RAP

1. In 1993, Alberta Asthma Centre (AAC) developed the Roaring Adventures of Puff ("RAP") childhood asthma education program to address the lack of asthma self-management education for children and related training for health care professionals. The program consists of two curricula:
2. For 6-12 year olds: Six activity-and game-filled sessions are to be delivered in schools by trained health professionals, in a small group setting. The program is designed to enable child to self-manage her asthma and includes scripts for facilitators, "Puff the Asthmasaurus" puppet, games, assembly plans, templates and lists of resources. This curriculum is found at www.educationforasthma.com.

For Healthcare Professionals: The interactive, on-line training course (at www.raponline.ca) includes strategies and templates to plan, prepare, implement and evaluate RAP.

RAP's effectiveness was evaluated in a randomized controlled trial involving 256 students in 26 suburban Toronto elementary schools. By every measurement except two, the students who had completed the RAP program reported significant gains: improved asthma quality of life, better self-efficacy, fewer absences, fewer days of interrupted activity and fewer urgent health-care visits. Similar results have been recorded in other studies. Well controlled asthma positively impacts quality of life, physical activity school performance[16], overall health and thereby reduces the likelihood of other chronic diseases.

Shared direction and implementation of the project between the ASC and AAC

An initial teleconference was held on January 10, 2011 between the AAC (Shawna McGhan, Director of Health Innovations, and Maureen Douglas, Project Coordinator) and the ASC (Oxana Latycheva and Rupinder Chera, Project Coordinator) to discuss a potential partnership to adapt the Roaring Adventures of Puff ("RAP") childhood asthma education program for First Nations communities. Once the partnership was formed, additional meetings and correspondence were held from January 25 to March 31 to discuss and define project activities, budget, timelines and partners. Additional correspondence between the AAC and the ASC project staff was conducted as needed or requested by either party.

AAC, in partnership with the Alberta Lung Association, launched a group on a collaboration website (called "Air Exchange") for the project. The Advisory Group, Workshop participants, Provincial coordinators, community-based teams (including potential teams) and other partners including FNIH, Alberta Region, and researchers were enrolled in the site. To June 15, 2012, there were 79 enrolled members.

Advisory Group Recruitment and Meetings

In consultation with the ASC, the AAC recruited members for the project's Advisory Group by holding in-person consultations and exchanging emails with potential members. The final list of **Advisory Group** members is presented as Appendix 34.

The ASC and the AAC met with main stakeholders and a portion of the Advisory Group members in person and via teleconference. (See Appendix 35 & 36). In addition the AAC project staff met one-on-one with those Advisory Group members who could not attend February 7th or March 24th meetings. The AAC provided a report to the Advisory Group about work shop activities and recommendations and distributed the on-line survey to the Advisory Group to gather their feedback about adapting the content and format of the RAP program and plans for the next phase of the project.

Adaption of the "Roaring Adventures of Puff" (RAP) program

Adaption of the RAP program was made possible through feedback gathered from RAP instructors working in First Nations communities and First Nations children and their families through on-line surveys, discussion boards, and phone interviews. Feedback gathered was also used for the development of additional content and/or activities for the RAP program.

Survey of RAP Educators and others with Relevant Experience and Expertise working in First Nations communities (*To view the full summary and results of the survey please see the Roaring Adventures of Puff, Final Report, Appendix 38)*

AAC drafted and sent out an electronic survey to RAP Instructors to elicit input on the project and in particular, recommendations to make RAP relevant and engaging for First Nations children. In April and May 2011, the target audience was expanded to include health professionals, community representatives and academics with expertise in health education program development/delivery in First Nations communities. Some of these individuals were chosen because of their involvement in other RAP-related projects involving First Nations communities. Some were referred by survey participants, the Advisory Group and other partners. Between March and May 2011 the survey link was sent to 60 individuals inviting them to complete the survey if they had experience with First Nations health issues or RAP in First Nations communities. 15 completed the survey.

Respondents' Demographics
The survey contained 42 questions. The first 13 questions asked for contextual information including:

- **Education, Professional Designation, Position and Responsibilities**. Responses included registered nurses, certified asthma educators and respiratory therapists. The majority of respondents held positions with responsibility for child asthma education: program delivery (hospital, clinic, primary care or community health centre setting), development and/or implementation. Some were also responsible for care or programs relating to other respiratory and/or chronic diseases. Three respondents held positions that fall outside these categories, namely: an Executive Director of an Aboriginal Health Access Centre, a researcher/clinician specializing in asthma and asthma education, and an Elder who educates the social service community about First Nations health concerns.
- **Experience relating to RAP: Instructor's Training and Facilitation of School Sessions**. Most of the Respondents had taken RAP Instructor's training, either in-person or on-line with the remaining respondents indicating they had received information about the curriculum from the Project team. Respondents who attended the Workshop accessed additional materials including a PowerPoint presentation, RAP Instructor's manual and sample activities. Many had taught RAP in schools and had hosted RAP school sessions that included First Nations children.

- **Expertise and/or Experience with First Nations Health Care and/or Health Education Programs**. Many respondents worked at First Nations Health Care Centres, worked in First Nations schools, in First Nations community health and had conducted group health education. Over half indicated that they had experience with First Nations health education program development, implementation and delivery. The following response illustrates the type and breadth of Respondents' experience with health education programs:

  > More implementation and delivery; though did initiate a chronic-kids program in one community. Programs: prenatal, well woman, chronic kids, some chronic disease, school program, school and infant immunization. Did teach community based classes for a northern college (anatomy + physiology and medical terminology) for pre-LPN course students. Settings and target audiences; varied ages, sizes, settings.

Asked questions relating to the RAP course content and format, respondents:

- In general felt that much of the existing content would be engaging and have impact with First Nations children
- Recommended activities be visual, hands-on, active, interactive, creative and employ encouragement/rewards
- Suggested that the content be made culturally relevant (as opposed to culturally specific)
- Felt that the content relating to asthma triggers would be more relevant to First Nations children if it was expanded to add smudge, sweat lodges, housing, wood stoves and smoke

Respondents were asked about children's responses to "Puff, the Asthmasaurus mascot". Of the nine who responded, three reported positive interaction between the kids and puppet, although educators noted each group of kids varied in their use of and enthusiasm for Puff. The remainder felt that a more appropriate mascot could be chosen – perhaps in consultation with First Nations children. Suggested animals included turtle, bear, wolf, deer, beaver, snipe, fish, goose, gopher, eagle and "Ashinabe role models". Respondents commented that perhaps no single animal would have significance to First Nations from different regions. There was a strong consensus to pilot test a wolf mascot.

The survey also solicited input about who from First Nations communities should receive RAP training. The original RAP program is facilitated by health care professionals who have completed RAP on-line or in-person training. However, many involved in this and earlier First Nations projects felt that the RAP program would be more sustainable if training was offered to other community members including Elders, high school students, teachers (and retired teachers), Community Health Representatives, referral clerks and Community Outreach workers. Survey participants agreed that training should include mentoring by Elders and CAEs and be extended to community members and suggested content (including reading level) and format.

Finally, the survey canvassed how to integrate the community into the program from the inception. Respondents gave advice about proper protocol and how to describe the project to community members (*e.g.*, as an educational component of health care as opposed to a research project) to facilitate collaboration and community engagement in the program.

RAP Fun Book Survey

The ASC took a lead in developing the Fun Book survey in consultation with the AAC and Advisory Group members. The survey was distributed to First Nations communities in Ontario (Oneida Nations of the Thames), British Columbia (Hazelton First Nations), and Alberta (Whitefish Lake First Nations). In total, **20** surveys were given to community members for completion along with a copy of the RAP Fun Book. The AAC prepared a version of the RAP Primer **(**Appendix 37**)** to be distributed with the survey to First Nations families. The survey results were analyzed and incorporated into Phase II of the project.

Recruitment of Provincial Coordinators and Asthma Education Mentors

In consultation with ASC, AAC recruited provincial coordinators in Ontario, Manitoba and British Columbia, with the AAC acting as the Alberta Provincial coordinator. These coordinators assisted the project team with planning community-based activities, recruiting and inviting community based teams, determining appropriate approval processes, drafting templates, provided input into adapting RAP-IT, RAP curriculum for children and the Fun Book, contributing to the collaboration website and RAP-IT. Provincial coordinators were paid an honorarium of $200 but otherwise provided these services in kind.

The Project Team and provincial coordinators communicated through the collaboration site, webinars, e-mail, teleconferences, the Workshop and in-person meetings (where these could coincide with conference attendance).

In addition, in response to feedback that community teams, "asthma educators" and "asthma mentors" were recruited to provide advice and support.

Collaboration Website

AAC, in partnership with the Alberta Lung Association, launched a group on a collaboration website (called "Air Exchange") for the project. The Advisory Group, Workshop participants, Provincial coordinators, community-based teams (including potential teams) and other partners including FNIH, Alberta Region, and researchers were enrolled in the site. To June 15, 2012, there were 79 enrolled members. The project team primarily used four features in the collaboration website:

Discussion Forum

Eleven discussion topics were launched during the project and were introduced as follows:

1. **Project Overview and Progress Reports** for general discussion of project activities and processes including timelines, updates, work shop and survey results.
2. **Draft Letters for Band Council/School Board/Principal** for community based teams to use (or cut and paste) to contact band councils, school boards, principals and others in the community.
3. **Your Feedback about Key Themes and Activities** which contains a brief summary of recommendations from the workshop, meetings and online survey relating to activity development.
4. **The Asthma-zing Race, Asthma Idol . . . Check Out the New Activities!** Six new RAP activities - incorporating humour, storytelling, family, tactile learning, performance arts, pictures/video, Smartboard/computer applications, physical play, music, nature etc.
5. **Enhanced Jeopardy: Smartboard-ready, new clues and cartoons** - activities which we propose to modify from the traditional RAP curriculum.
6. **Evaluation Component and opportunity for additional funding –** a discussion forum about the evaluation component of this project. Keeping the above in mind, we propose to use the following methods:
7. **Training: Invitation to Enrol and Proposed Curriculum** contains an outline of RAP-IT curriculum, features and timelines.
8. **First Nations RAP Activity Booklet** draft of new version of the Fun Book for discussion.
9. **Wishlist for Community Team's Toolkits** contains a proposed list of supplies to be distributed to community-based teams and a request for input.
10. **RAP Lesson Plans and Activities** shows a complete list of proposed revisions and new curriculum with rationale.
11. **Legend of Tahnee, the Wolf: My Asthma Journey** contains the next-to-final version of the FunBook.

Announcements

Air Exchange's announcement feature was the primary method used to communicate to project partners, as a group. In particular, the announcements were used to publicize all webinar/teleconference/videoconferences, newly posted resources, RAP-IT chapters and gather Fun Book input. In many cases, these announcements were followed up with personalized e-mails. Announcements and discussion forum posts were also digested weekly and sent to all group members – unless they changed their preference settings.

Webinars

The webinar feature of Air Exchange was used for communication, collaboration and as an integral part of the RAP-IT course. To foster community team building and access to asthma education mentors, and in response to formal (and informal) feedback that the course be less

text-based, more interactive and include "live" learning opportunities, the Project team and Provincial coordinators organized two webinars through Air Exchange and one videoconference (through provincial/FNIHB telehealth systems). Participants were polled (via the discussion forum) about preferred topics. The sessions offered were:

1. **"Asthma in First Nations Communities: Three Perspectives"** presented by Ana MacPherson, Jo-Anna Gillespie and Oxana Latycheva. Guests talk about asthma needs and challenges with projects, programs and health delivery in BC and Ontario for First Nations communities.

2. **"Asthma and Allergies in First Nations Children: Challenges Described by First Nations Children and Their Families"** presented by Sharon Anderson and Roxanne Blood. The interview summaries and findings from the University of Alberta Social Support Research Program, led by Dr. Miriam Stewart, are relevant to this project (for example, community support and awareness, gaps in educational resources and social supports, environmental vulnerability, inadequacies/inequities in health care etc.) but also provide context for anyone working with First Nations communities.

3. **RAP Curriculum** presented by RAP Instructors and asthma education mentors, Ana MacPherson and Lesley Stewart. Ana and Lesley introduced each of the six RAP lesson plans, demonstrated activities, gave teaching tips and answered questions. The AAC introduced the newly developed activities and an outline of the new FunBook.

The first two webinars were 90-120 minutes in length, and were comprised of presentation and questions-and-answer sections. The third was a full day session.

Resource Library

33 documents were posted by AAC for partners and community-based teams to review and, where applicable, use as templates for project activities. Documents included template invitation letters (for band, school board and schools), a proposed timeline for community-based activities, publicity posters, a RAP primer, the training site curriculum, activity instructions, and enrolment forms.

Pilot Site Recruitment and Progress of Community-Based Activities

From May 2011 to the present, the project team and provincial coordinators made continuous and considerable efforts to recruit and retain communities to participate in community-based activities. In order to attempt to secure five sites (the number referred to in the Work plan), 10 communities were contacted. During the project term, 8 communities agreed, verbally or in writing, to participate.

The project team and provincial coordinators applied feedback about community-based processes and activities received from the Advisory Group, Workshop participants, pre-survey participants and partners. The project team drafted template letters to the band, health centre,

school boards and school principals, which were circulated by the provincial coordinators. These letters introduced communities to the project, provided background information, proposed activities and a draft timeline. Communities were asked to recruit a team – preferably large and diverse – to:

- Participate in RAP-IT training;
- Provide input into adaptation of existing RAP curriculum (including FunBook) and suggest new curriculum (including FunBook);
- Pilot test the adapted curriculum in the communities' school(s).

A pilot site information form was attached to the invitation letters, which requested information about the community, team members, budget needs and in-kind contributions. (*To view the comprehensive details please see the Roaring Adventures of Puff, Final Report, Appendix 38)*

The Legend of Tahnee, the Wolf: My Asthma Journey (Funbook) and Mascot

Under the work plan, the Fun Book adaptation was the role of ASC. ASC completed the survey of children and guardians however, in September 2011, requested that AAC retain an artist and complete the Fun Book modification. Given the Fun Book adaptation was not in AAC's budget, AAC drafted a proposal to AllerGen NCE Inc. which was approved.

AAC researched and sought references for local Aboriginal artists and graphic artists. After short-listing based on suitability (colourful, child-friendly, focus on nature/animals etc), experience, price and arranging a meeting to assess her ability to work with a team, AAC hired Carla Gilday.

Prior to meeting with Ms. Gilday, AAC staff reviewed all input and recommendations respecting the FunBook, gaps in asthma content and outdated material. AAC staff and Ms. Gilday met monthly to review progress and brainstorm content and format. Throughout this period, updated versions and proposed amendments were posted on Air Exchange for feedback.

- "Tahnee, the Wolf"", is introduced as Puff's buddy mascot. Although the wolf's symbolism varies by community, region and group, research indicated positive themes of leadership, teaching, community and wisdom. Use of the wolf was endorsed by community members and children (See "Evaluation" for greater detail).
- The new art, content and legend incorporate story-telling, colour, Elders, nature, animals, support of family/friends, humour, circle, self-management, lung health and general health/wellness themes.
- The new version is designed to be used as stand alone or with RAP curriculum
- Glossary of terms in short, colourful text boxes, with pictures.
- "Your Stories" feature for children, families and communities to submit anecdotes, photos and artistic expressions.

- Minimal text; use illustrations to "teach". For example, to simplify information about lungs, asthma and illustrate differences between medications, created cartoon characters to depict healthy ("The Relax-i-nator", "Agent Invisible", "Mr. Smooth") and unhealthy airways ("Spazzzm", "The Booger Man" and "Puff Daddy"). Also, used pictures of facial features/body language to illustrate symptoms and emotions.
- Incorporates triggers relevant to First Nations children in "Find the Triggers" exercise including pets, forest fire, campfire, gravel dust, virus, overcrowding, household chemicals, mould, cigarette smoke.
- Includes asthma action plan in response to "A Shared Voice" recommendations (97% of respondents indicated would use an asthma action plan).
- Links to websites with vokis (animated cartoon characters with asthma stories), games, information, parent information.

Evaluation of Roaring Adventures of Puff: By and For First Nations Children

To reflect modifications to project activities, AAC proposed and ASC agreed to amend the evaluation component. AAC carried out evaluation of the adapted activities, new mascot, **Legend of Tahnee, My Asthma Journey**, RAP-IT and collaboration website via the following methods:

- Feedback via Air Exchange, e-mails and meetings from RAP Instructors, community-based team members and other partners.
- Asthma, Allergy and Eczema Camp 2011.
- Siksika health fair activity demonstration and questionnaires; and
- On-line survey and phone interview of **community-based team members** (May and June 2012) about RAP-IT and collaboration website.

Evaluation of Child Asthma Curriculum, Activities and Fun Book

To view the comprehensive details please see the Roaring Adventures of Puff, Final Report, Appendix 38

There were four evaluation methods used during the project to evaluate the RAP curriculum. First, the Pre-survey was conducted to obtain input into specific content and activities as well as cultural themes. The results of the Pre-survey and application of feedback is described above. Secondly, drafts of the adapted curriculum (including activities and Fun Book) were circulated for review by asthma educators and community teams through Air Exchange and at meetings. Thirdly, original, modified and new activities were pilot tested with children from three communities. Finally, a survey respecting the mascot was conducted at a First Nations health fair.

Air Exchange Feedback about Child Asthma Curriculum, Activities and Fun Book
Six of the discussion topics posted on Air Exchange related to the curriculum, activities and Fun Book. These topics were relatively the most active, although some community members and partners chose to provide feedback through e-mail, meetings and phone calls. In general, this feedback was very positive.

Otherwise, suggestions related to specific content for example the order and emphasis of content, peak flow meter, mascot's name, mascot's gender, new activities, triggers, typographical errors and were reviewed and applied by the project team.

Evaluation of Activities by Children

a) Asthma, Allergy and Eczema Camp Evaluation

Methods: 19 children from an Alberta First Nations community attended this event. The project team, two certified asthma educators, SSRP, Elders, community champions and peer mentors facilitated 13 activities from the original and adapted RAP curriculum. The activities were drawn from all parts of the curriculum including: Child's Perspective, Airways, Triggers, Symptoms, Medicines, Asthma Zones and the Action Plan. 3-4 activities ran simultaneously with small groups of approximately 4-6 children and their assigned peer mentor rotating through the activities.

After each round of activities, the children were asked to evaluate the "fun factor" and "impact" of each activity. Children were given a sheet showing two "bulls-eye" targets. On one target they were asked to show the "fun factor" and on the second they were asked whether the game "will help my asthma and allergies". They were told that for each sheet completed, they would be entered into a draw for a Wii console, which was provided by SSRP.

Results: In general, the children responded very favourably to the activities – whether from the original RAP curriculum or new content. 45 of 48 responses rated the "fun factor" as 1 or 2 (out of 5). 39 of 43 responses rated the impact as 1 or 2 (out of 5).

SSRP interviewed the children and their guardians about the camp. These interviews have not yet been tabulated and reported by SSRP, but AAC interviewed Sharon Anderson about these interviews, her observations and recommendations from the camp.

b) Ontario Communities

K.C. Rautiainen hosted RAP in two Ontario First Nations communities from September 2011 to June 2012. The school and Ms. Rautiainen agreed that the evaluation method would be for Ms. Rautiainen to interview the school principal after the program had concluded. Although the interview has not yet occurred, Ms. Rautiainen has reported the following observations, results and recommendations to AAC:

In general, Ms. Rautiainen noted a general wariness of communities to participate in research. Ms. Rautiainen's evaluation component will be limited to interview of school principal. Health Centre director and school principals advised that the Creating Asthma Friendly Schools Program was health intervention (as opposed to research), and consequently approval of local

government was not required;

With respect to the school sessions flexibility is required in timeline and delivery. Although the original plan was to attend five times to host the RAP sessions, it was found that 10 sessions were required to properly deliver the content, taking into account necessary relationship building and the children's learning needs and preferences. For example, groups responded to short sessions that were largely active and outdoors (like the playground). Consequently, lesson plans were modified and activities to be applied to these settings and situations.

The children were actively engaged in the discussion around the format and length of sessions This helped build the relationship and specifically addressed that the kids were missing recess to attend RAP and built strong relationships with the children in the group. The large age range (6-12 years) in these groups had to be taken into account when choosing appropriate learning activities.

- Ms. Rautiainen found that the children enjoyed artistic activities, including drawing and murals.
  Ms. Rautiainen used the wolf puppet in her sessions and wolf-related merchandise (including t-shirts) to reinforce the mascot, themes and encourage good behaviour and participation.
  With respect to specific activities: Ms. Rautiainen created the airways activity and contributed it to the Legend of Tahnee, My Asthma Journey. The children were asked to draw a tree with trunk and branches, then turn it upside down to see how it looks like lungs. The activity was accompanied by a discussion about the role healthy trees play and prompted the children to appreciate healthy living, health airways and the connection between nature and health.
- Ms. Rautiainen built strong relationships with the children in the group. They felt affection for her – which made them enthusiastically anticipate her visits and the sessions.

All 3 schools in the 2 communities have invited Ms. Rautiainen back for the 2012-2013 school year. Activities will include asthma assemblies for the entire school population and a community initiative to raise asthma awareness within their communities.

Health Fair Survey

In May 2012, AAC was invited to participate in an annual health fair at an Alberta First Nations community. AAC's display included curriculum materials, Fun Book excerpts and activity demonstrations. AAC staff requested passers-by complete a six question survey about the mascot and Fun Book cover. Those who completed the survey were entered in a draw for a chance to win a wolf puppet, craft supplies or Tim bits card ($2). Entrants had a 1 in 5 chance to win.

Organizers reported that over 700 members of the community and outlying areas attended the health fair – including school groups and teachers. Of those that stopped at AAC's display, 20 filled out the survey. 2 were younger than 7, 0 were 7-11, 8 were 12-17 and 10 were greater than 18. Six of 20 reported having asthma but many reported relatives who had asthma. 90% gave a

“thumbs up” to the wolf as mascot for the program; 17 of 20 gave a thumbs up to the Fun Book cover.

RAP-It Course Evaluation
Two methods were used to evaluate RAP-IT namely:

1. Usage and completion statistics from RAP-IT (including Air Exchange features used in RAP-IT); and
2. Results from a survey of community based team members.

RAP-IT Course Usage and Completion Evaluation

a. Methods and Limitations

As described above, community based teams were recruited in Ontario, Manitoba and Alberta. Teams were composed of participants with diverse expertise and roles in their communities. The AB group was excluded from analysis due to late enrolment. Between the remaining communities, there were 18 members of the community based teams. Over the course of the project, two team members dropped out. They were not including in the course usage analysis.

The collaboration website (Air Exchange) was used to facilitate webinar participation, post announcements, seek feedback and share documents and archived webinars. Many of these features trigger automatic daily or weekly emails to subscribers. The site monitors read emails and counts them as external logins. Participants can unsubscribe from emails without resigning membership in the site. Emails deliver current daily or weekly content only, so if a participant wishes to access archival content, they must log on to the site proper.

The online learning portal, Moodle, contained the online course chapters, in addition to general tips for course navigation and instructions on what was necessary for course completion. Although completion of the course was expected if a participant intended to teach RAP, given the emphasis on capacity building over instructor training it was not expected that all participants would aim for course completion. Instead, it was expected that participants would use the self-assessment tools to tailor their involvement with the course to fit their knowledge needs.

In the course syllabus, the criteria for course completion were listed as:

- *complete all 5 on-line chapters*
- *in each chapter, posts (at least) one response to the Online Sharing Circle question (to be clear, this means a total of 5 responses - one for each chapter)*
- *in each chapter, posts (at least) 2 responses to other participants' posts;*
- *completes online course satisfaction survey (in "wRAP Up" chapter);*
- *completes childhood asthma education quiz (in "wRAP Up" chapter);*
- *completes case scenarios in Online Sharing Circle (Discussion Forum) in "wRAP Up" Chapter*

Participation in the collaboration website, webinars and teleconferences was thus considered useful for capacity building but not necessary for course completion. However, in recognition of potential confusion with the course criteria and unexpected difficulties with the course format, it

was decided to use a standard of "substantial completion" for evaluative purposes. Substantial completion was defined as completing all or part of the requirements for a particular chapter. As no one had completed all five units at time of analysis, completion was evaluated by chapter, rather than on the course as a whole.

The analysis of course usage was done by accessing usage data from the two main platforms used to deliver the course – the collaboration website, Air Exchange, and the online learning portal, Moodle. Course usage statistics accessed from Air Exchange included number of logins, nature of logins (on site or by email), time spent logged in, dates of logins and number of page views. Course usage statistics accessed from Moodle included dates of logins, total number of page views and specific pages viewed. Both sites allowed usage statistics to be linked to individual participants. The data were therefore analyzed as summary statistics and individual usage statistics. Data were collected from May 23 to June 8, 2012. There was no activity in either platform from the community-based teams during this period.

Additionally, attendance records from the webinars were accessed to determine participation in that element. It was not possible to determine who had viewed the archived webinars or how many times they had been viewed.

b. Results

Of the 16 participants, two used only the collaboration website, one used only Moodle and three used both Air Exchange and Moodle. Therefore, a total of six participants logged in to either or both platforms.

Two teleconferences were held to introduce participants to the course. The first teleconference was held on November 25th; the second on December 2nd. The two teleconferences were identical in format and together drew an audience of three community-based team members.

In total, four community team members attended at least one webinar. No community team members joined the first webinar. Four joined the second webinar and one joined the third webinar. It is possible that some participants viewed the archived webinars, but data on this could not be obtained.

Use of the online learning portal, Moodle, was quite varied. Three participants appeared to take a methodical approach, as an examination of their course usage showed that they had viewed most or all of the resources in one chapter before proceeding to the next, while the other participant viewed items of interest non-sequentially. The highest level of chapter completion was four chapters. However, only one participant attained this level of completion.

RAP-IT Survey Evaluation

The RAP-IT Survey solicited information from community based team members on topics such as demographics, motivation for course participation, extent of course participation, learning preferences, satisfaction with the course in general and with specific elements and attitudes regarding asthma and school-based asthma education.

An invitation to community based team members to participate in the survey was posted on the collaboration website. Invitees were given the option to complete the survey online or by telephone. A reminder email was sent to the team members (n=18), followed by phone call invitations.

a. Methods of Survey Creation and Analysis

Survey question formats were multiple choice, open-ended response, Likert-style response and ratings from 1-5. The survey was designed to have mostly multiple choice, Likert-style and rating questions with the intention of simplifying data analysis and shortening survey length to entice more participants to complete the survey. Survey topics, as described above, were chosen to solicit information pertaining to the objectives of the evaluation. Specific questions, particularly multiple choice questions, were developed with an eye to feedback received during the project to date and through use of the Ottawa Model of Research Use.

The multiple choice, Likert-style and ratings questions were then analyzed quantitatively by noting the frequency with which each response was chosen. Due to a small number of participants, the two highest and two lowest Likert-style options were collapsed for analysis ("strongly agree" and "agree", and "strongly disagree" and "disagree"respectively). The individual ratings for each rating question were averaged to produce a collective measure of agreement for each question.

Qualitative data was obtained through the open-ended response questions and by noting down comments made by participants over the course of phone surveys. The qualitative data was grouped by theme expressed and then analyzed for the frequency with which each theme was expressed. Themes included barriers to participation, suggested modifications to the course, motivations for participation, intent or lack thereof of continued participation, effects of participation and personal anecdotes.

b. Results:

Of the 18 invited participants, 11 completed all or part of the survey. One of the 11 participants in the survey completed it online; the remaining ten completed the survey by phone. Not all participants completed all survey questions. Participants who elected to complete the survey by telephone and who indicated that they had not logged into the course were not asked questions about specific course features or their impressions of the course but were instead asked to complete just those questions regarding their motivation for taking the course, demographic information, learning preferences and attitudes towards asthma and school-based asthma education. Results were as follows:

i. Demographics:

Of those who responded to the survey, there were four community health representatives (CHR), three registered nurses (RN), two health care aides and one each of a licensed practical nurse (LPN) and nurse practitioner. The majority of respondents worked in a community health care centre. Other reported locations of work were an outpatient/primary care clinic, a nursing station and home care facilities, with some respondents reporting multiple locations of work. All respondents had at least a high school diploma, with most respondents also having a university or

college degree or diploma. Slightly more than half of respondents reported having worked in their community for three years or more.

When asked to describe their responsibilities in their current position, participants gave varied answers. Some of the most frequent responses were preventative health care, health promotion and education; home and community care; clinical care; school health and public health, as was expected, but others stated that they were responsible for programs less related to RAP, such as secretarial/reception work and post-partum care.

ii. Motivation and Attitudes:

Respondents were given a number of options to choose from to describe their motivation for participating in the course, as well as the option to list a motivation not on the list. They were asked to list all relevant motivations. The most frequently cited motivation was "I wanted to know more about asthma." Other popular motivations included wanting to "help implement the RAP program" in their community, wanting to "know more about RAP", wanting "to teach RAP", and a personal experience with asthma. Four respondents stated that they had been asked to participate in the program by their employer.

Ten of the respondents were asked three Likert-style questions to gauge their attitudes towards the importance of asthma education. When asked, most respondents agreed or strongly agreed with the statement "Childhood asthma is a problem in my community" and with the statement "There is a need for asthma education in my community."All respondents agreed or strongly agreed with the statement "I think in-school asthma education would help the kids in my community."

iii. Learning Preferences:

Respondents were asked to rank the importance of a number of attributes of the course on a scale of 1 to 5 with 1 being "not at all important" and 5 being "very much important." Respondents ratings were then averaged to provide an overall rating of the importance of each attribute (scored out of 5). Sample items included "I can complete units as fast or as slow as I like" and "I get a lot of feedback on my learning." Participants generally agreed with all statements. The three attributes ranked as most important were:

- "Ability to do the course at times that are most convenient to me
- "Work time is provided for me to take the course"
- "I can access online resources, like links and videos"

More disagreement occurred with the statement "The class is conducted in person," and the statement "I have deadlines to keep me motivated".

When asked if, in general, they like online learning "as much as, less than or about the same as" other forms of learning, five stated that they felt about the same about online learning as other forms of learning, while three felt that they liked it less than other forms of learning. No respondents ranked online learning as being preferable to other forms of learning. However, when asked what the best format for future courses would be, seven respondents selected online learning or online learning supplemented by in-person learning while only two picked exclusively in-person options.

iv. Barriers to Engagement

Barriers to engagement were assessed through multiple choice questions as well as open-ended questions and comments provided by participants over the course of the survey. Some participants cited more than one barrier to engagement. The most frequently cited barriers to engagement were difficulties related to the work environment, chiefly a lack of work time reserved for taking the course, the need to replace other staff in addition to completing one's own work and an inability to justify spending time on RAP-IT due to it not being part of the respondent's job description. Other barriers to engagement included technical issues, dislike of course format, inappropriate timing, personal demands and generally being too busy.

v. Overall Impressions, Anecdotes and Feedback about Specific Course Elements

Overall, respondents appeared enthusiastic about RAP and agreed that it would be of value to their community, with 90% agreeing that RAP "would help kids in my community" and 70% agreeing that they would "recommend RAP-IT to other First Nations communities." Ten of the eleven participants expressed interest in repeat or continued participation in the course. Participants also expressed their appreciation for the project in their open-ended questions and comments about the course. For example, one community health nurse mentioned that she did not often go out into the schools to deliver programs but "for that [RAP] I would have made myself available" while also noting that school staff in her community had "seen a need for it [RAP]."

o Effects of Participation

While a number of respondents commented that they had not participated in enough of RAP to feel the effects of participation, others stated that even though their involvement with the course had not been extensive, they had gained skills and knowledge and/or made changes to their practice due to participation in the project. One participant, who had been involved in the asthma camp but not heavily involved with the online course, explained that involvement in RAP-IT had helped her connect to a Certified Respiratory Educator and that she had benefited from this connection. She explained that she was now more aware of triggers and referral services available and that in her work in the community she was helping raise awareness of appropriate medication use. Her use of RAP-IT was non-standard, due to her involvement with the camp, but her experience indicates the potential benefits of retaining the asthma mentor system. Two other participants reported raising awareness of proper medication use, despite not having completed the program.

o Need for the Program

Other participants shared anecdotes demonstrating the need for the program. One participant detailed a situation in which her nephew had an asthma attack and she had to drive him into the nearest hospital because he was not able to store his inhaler in the school office. Another respondent relayed a story that one of her patients had told her about a child who had an asthma attack while his teacher stood there without knowing what to do. Both expressed the belief that a program like RAP could help raise awareness and prevent such situations in schools. When asked how important an in-school asthma program was to the community, one of participants simply replied "we just need it."

- **Feedback about Specific Elements**

One of the intentions of the evaluation was to explore satisfaction with specific course enhancements, such as the animated cartoon characters (called "Vokis") and narrated powerpoint. However, given the small number of respondents accessing these elements, impressions of the course, as disclosed in open-ended response questions and general comments, were used in lieu of ratings for or questions about specific elements.

Those who had systematically accessed the course discussed deadlines, feedback, course topics, the asthma mentors and cultural suitability. All of these respondents stated that deadlines would have helped them complete more material or complete the material faster, although one participant incongruously also noted that he "need to have [his] foot on the gas pedal" to control his pace through the course. Other comments from this group included requesting more feedback on progress through the course, more information about asthma and teaching, shorter/more uniform length chapters and dedicated work time to complete the course.

Three of the six participants that had accessed Moodle, Air Exchange, webinars, and/or teleconferences reported a strong relationship with an asthma mentor. One participant noted that she felt that much had been done to make the course culturally appropriate. One participant who had not accessed the course expressed that she felt that the research team had made appropriate efforts to solicit her engagement and support her in the course but that the factor limiting her involvement was beyond the control of the research team.

Project Reach: Dissemination, Capacity Building, Networking and In-Kind Contributions

The project activities had reach beyond that contemplated by the original work plan, including:

- **Dissemination of Interim Results to Researchers and Health Care Professionals in Respiratory/Allergic Disease and Health Education** – This project was presented to the Canadian Network of Asthma Care (Gatineau, 2011), Alberta Respiratory Disease Symposium (Edmonton, 2012) and AllerGen NCE (Toronto, 2012).

- **Contributing to Further Research Activities - Appendix 16** is a summary of AAC's application summary to AllerGen NCE for funds to expand and sustain the current project activities including adapting RAP-IT, developing a toolkit (including the Fun Book) for community teams and launch an artistic submission contest in communities. A proposal evaluating the Funbook was submitted and declined to the Lung Association of Alberta and NWT. Stakeholders have suggested future research activities.

- **Fostering New** N**etworks** with nursing students (BC provincial coordinators), University of Waterloo researchers (evaluation and contest development), FNIHB, Alberta Region (Dr. Chris Sarin, health promoters, aboriginal nurses, etc.), and asthma education mentor teams.

- **Building Capacity** of community champions – who were not otherwise involved in the project. For example, one parent/community champion who attended the Allergy, Asthma and Eczema Camp enrolled in RAP-IT and became an asthma resource for her

community and other communities in the region. She was also introduced to a Certified Respiratory Education in her region to provide ongoing support.

- **Supporting and Linking to other Asthma Education Projects** including the work of University of Alberta's Social Support Research program, The Lung Association of Ontario and Children's Asthma Education Centre.

- **Partners Contribution of In-Kind Support** – the provincial coordinators provided significant in kind contributions to recruit, train and communicate with community teams. At the project level, University of Alberta hosted RAP-IT and provided extensive technological support.

V. Challenges and lessons Learned

This project's biggest challenge has been to create a tool that resonates with as many First Nations communities and individuals as possible. We attempted to achieve this by including as much diversity as possible and practical in terms of design and information as well as relying on pan-Indigenous symbols and concepts as much as possible.

When developing materials, the language used should be simple, with explanations being incorporated into the content where necessary. As well, some terminology may need to be confirmed with Elders and knowledge keepers to ensure their understanding of the subject under description.

Participants from this project felt that personal stories, pictures and, if possible, real life characters that relate to their culture should be included in materials for their communities.

Materials, such as the triggers booklet, should be distributed and explained through discussion with health care providers during individual or group consultations. This ensures that community members fully understand the content of the booklet.

It is important to have proper introduction and a full relationship building process in place prior to implementing community-based activities. Communities were more readily identified and recruited in regions where provincial coordinators had previous links or relationships with First Nations communities.

Proper protocol, communication and transparency is key to achieving buy-in and success in community-based settings.

Successful participation of communities and community groups is reliant not only on financial capacity, but often human resources and knowledge. Numerous communities and individual team members advised that they were impeded by staff shortages, high staff turnover, competing demands and priorities. Although many confirmed that asthma and lung health were significant

issues in their community, and initially expressed enthusiasm about the project, there were significant rates of attrition.

It is important to involve the leaders and key decision makers in the community at all levels of project and program planning (development, implementation and evaluation) to ensure the maximum success and future "buy–in".

VI. Recommended next steps

First Nations communities are interested in receiving an asthma poster or card with key information about asthma triggers. Other format suggestions include a pamphlet style to serve as a quick reference for asthma education when needed (*e.g.,* carry-on item).

A key feature of this project has been the engagement of leaders, stakeholders and communities and the resulting collaboration and ownership. All of these groups, including the provincial coordination teams, have expressed interest and plans for extending this project and its outputs. Alberta Asthma Centre has received several requests to expand and continue to utilize and promote some or all of the project. For example, it is exploring offering the training program RAP-IT, utilizing the Funbook with their RAP sessions and teaching mentoring the enhanced RAP in the FN communities.

To maximize impact from this initial investment, the AAC feels that the RAP program and the project outputs, including the adapted RAP program, RAP-IT training course and the Asthma Activity Fun booklet now need:

1. plans to continue to build on momentum, capacity and training opportunities;
2. expanded reach by creating and implementing a dissemination plan;
3. to expand the online community of practice to facilitate ongoing review and inclusion of community input into the program;
4. to establish a systematic way of facilitating linkages to asthma education mentors and clinical teams with the program and for the community;
5. structure, staffing and supports (i.e. technological) to better enable communities to implement RAP;
6. evaluate utility and health and society impact in other aboriginal communities.

Specific recommendations include:

1. **Build on the Strengths of this Project, namely:**
    - Evidence of needs and gaps in First Nations health and asthma care;
    - Network of highly committed and knowledgeable asthma and RAP Instructors;
    - Emerging capacity of community teams, community members and provincial teams;
    - Emerging networks of community teams and asthma education mentors;
    - Relationships between project team, provincial coordinators, asthma education mentors and participating communities;

- Evidence-based children's curriculum, training curriculum and activity book adapted to reflect communities' preferences and containing First Nations art, subjects and themes; and
- Evidence of community based teams learning preferences;

2. Sustain and Expand RAP Asthma Education for First Nations Children by:

- Promoting and facilitating health professionals and/or community health representatives in First Nations communities to receive RAP-IT training and deliver RAP in the community's school(s);
- Resourcing asthma education mentors' services, including RAP-IT training facilitation, teaching and support and travel time (for 1 t- 2 sessions);
- Promoting the continuing implementation and evaluation of RAP and RAP-IT to First Nations communities;
- Engaging a coordination team such as the AAC to facilitate communication, incorporate community input, activities and stories, provide annual sessions of RAP-IT and sustain the children's art contest features in The Asthma Journey book;
- Advising and consulting with communities and coordination teams about complementary FNIHB, Health Canada initiatives, funding opportunities and positions which can support RAP for example, including RAP in job responsibilities and training for First Nations health promoters.

3. **Publicize and Promote Widespread Dissemination of *Legend of Tahnee, the Wolf: My Asthma Journey***

The Asthma Journey has been developed for use within the RAP curriculum and as an independent resource. As a result, it can be used to:

- increase general awareness about asthma;
- introduce the program and its potential to communities;
- provide information and skills where RAP is not currently available; and
- strengthen learning in RAP delivery.

The AllerGen proposal includes a limited budget for printing of The Asthma Journey. In light of what has been invested for development to date, additional funds for printing and dissemination would be warranted and well spent. Further evaluation of this new resource is needed.

4. Promote RAP as an Integrated, Efficient Model to Capture, Refer and Support Children with Asthma

This model uniquely captures children through their school. These children may not otherwise access services, or many access only emergency services. RAP increases their awareness, provides information to family members and provides **links to asthma education mentors, certified respiratory educators, primary care and specialists.** As well, the format of six weekly sessions, in contrast to one emergency visit or one education session, provides multiple opportunities to re-inforce the need to obtain a proper diagnosis and ensure proper medication use.

VII. Leveraged impact of the project and deliverables

In addition to achieving the program deliverables, "Asthma Education on Triggers, Environmental Control, and Asthma Management: Two Tools Designed for and by First Nations Communities" provided an opportunity for community residents from First Nations communities to be involved in the development and further distribution of asthma education resources and materials

Requests and offers to share the project process and outputs more broadly among aboriginal communities have been extended through the AAC's networks and collaborations. Plans are being developed to share the project at various meetings with leaders, administrators, nurses and health promoters working in aboriginal communities and they have been invited to announce project resources on national websites. The AAC also plan to present the project at respiratory and aboriginal related conference, workshops and health fairs.

A greater sense of awareness of asthma and respiratory health at the community level, discussion about ways to integrate asthma and the RAP program into their long term structure has begun. This has including asthma in their chronic disease funding plan, examining staff to support the program and continuing to build relationships with outside clinical experts.

Funds provided by FNIHB made it possible to access matching dollars from AllerGen to help expand the project and be responsive to feedback. These funds and the resulting progress will help to leverage additional funds and resources from other sources with the partners that have been formed.

- For example an Alberta based grant (Alberta innovates Health Solutions) is being drafted for a large collaborative research grant that responds to needs and recommendations stimulated from this project.
- Discussions have begun about at CIHR grant and additional KT funds.

VIII. References

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IX. Appendices (Separate document)