



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

**EXECUTIVE SUMMARY**

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**By:**

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

### **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) <sup>i</sup> 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)<sup>ii</sup> program to make it more relevant for First Nations communities.

### **Project Description**

“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 targeted 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 First Nations graphic design company 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 for RAP 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.

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<sup>i</sup> “A Shared Vision: Ensuring quality of life for adults and children with asthma and allergies in First Nations and Inuit communities in Canada”, the Asthma Society of Canada (2009) Available at [http://www.asthma.ca/adults/Shared\\_Vision\\_English.pdf](http://www.asthma.ca/adults/Shared_Vision_English.pdf)

<sup>ii</sup> RAP Program. Available at <http://www.educationforasthma.com/>