Roaring Adventures of Puff: By and For First Nations Children

Final Report

Adapting the Roaring Adventure of Puff (“RAP”) childhood asthma curriculum to be relevant to Canadian First Nations children.

Alberta Asthma Centre, University of Alberta
# Roaring Adventures of Puff: By and For First Nations Children

## Final Report

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Executive Summary

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.
Context

Asthma in First Nations Children

Asthma is a growing concern in First Nations (“FN”) communities. Information on asthma in First Nations communities is limited but recent sources suggest that the prevalence of asthma in aboriginal children and youth ranges from 12-14% (on and off reserve), but lower in the Territories at 5.7%, possibly due to an underestimate because of poor access to health services. Rates of airflow obstruction have been found as high as 25% in Northern Alberta.

Lifestyle, geographic, physical and temporal factors contribute to these statistics and the disproportionately heavy burden of asthma in First Nations populations. For example, high rates of smoking and obesity in First Nations populations contribute to asthma exacerbations. The smoking rate in First Nations is triple the National average; 70% of First Nations youth smoke and obesity is on the rise. Moreover, indoor air quality is poor due to mould, overcrowding and smoke in homes and outdoor air quality is impacted by wood smoke and road dust. These conditions put children with asthma at greater risk of asthma exacerbations. These factors are also put children at greater risk of developing asthma and/or allergies.

Further, unequal access to health care, gaps in social support and a host of cultural and social factors, impact the options First Nations peoples have to address asthma concerns. A recent study showed that Aboriginal people access health care less effectively and find it intimidating. In interviews conducted by Stewart et al., First Nations children and families described numerous barriers to accessing health care and social support including transportation, lack of childcare and loss of work time. Children described feeling isolated. Key support needs for children were listed as: to feel normal, just like their peers; informational support on asthma and asthma management; reducing isolation by building a supportive network; improving support-seeking and other coping skills. Parents reported a need for: support for their children, education for themselves, culturally appropriate support, increased community awareness, child care and additional support or respite care for grandparents.

Part of the Solution: A First Nations Enhanced RAP School-based Asthma Education Program

Recent Pilots/Evaluation of RAP in First Nations Communities:

The asthma related needs of First Nations communities motivated two recent projects which involved pilot testing and/or evaluating RAP in First Nations communities.

1. Shared Voice Projects
ASC has completed two projects relating to the development of culturally appropriate asthma and allergy education resources for First Nations youth and their families called, respectively: “A Shared Vision” and “A Shared Voice”. ASC used questionnaires and webinars to collect feedback about existing resources (including the RAP program and materials) and barriers/concerns relating to receiving asthma education in Aboriginal communities. Relevant recommendations from this process include:

- Focus on the development of culturally appropriate asthma educational materials and resources by modifying existing resources and/or designing new materials based on
identified characteristics (e.g. preferred learning style, format, core elements, desirable content, cultural context, etc.).

- Implement asthma educational activities for children and their extended families as a priority with considerations to be given to adapting existing child-friendly educational programs (e.g. RAP “The Roaring Adventure of Puff”).
- Education should target people with asthma, their caregivers and community in order to create support environments for every community member directly or indirectly affected by asthma.
- Ensure appropriate access to these resources in the communities (e.g. at schools, community centres, health clinics, etc.). Comprehensive dissemination and community uptake strategies should be developed and implemented to ensure the right materials reach the right audiences.
- Engage First Nations and Inuit community members in the development/adaption of new asthma educational materials and community-based programs.

2. **Growing Healthy Children Project** (Ontario Lung Association’s (“OLA”) (2010) National Lung Health Framework-funded project)

In 2010, OLA delivered a condensed version of the RAP program to 78 students in Northern Ontario First Nations communities. OLA reported that RAP demonstrated success in improving: 1) asthma awareness through project reach, 2) asthma self-management through understanding of medication & introduction of an action plan, 3) access to an asthma educator and other related respiratory information and materials, via Keewaytinook Okimakanak Tele Medicine, Ontario (KOTM) and OLA Helpline.

At the close of the project, OLA recommended (in relevant part) to:
1. Mobilize community partnerships;
2. Build capacity for the Community Health Representatives (“CHR”) on lung health;
3. Facilitate lung health screening- lung test and spirometry;
4. Use Primary Care Asthma Program (PCAP) algorithm in asthma management, with video or teleconferencing support;
5. Enable aboriginal people to manage and deliver the services and support each community to deliver the health services that meet the needs of their own people.

In addition to the above projects, and as part of its NLHF funded Phase 1 project entitled, Child-Friendly Asthma Education: Building Capacity in Canadian Communities, AAC began to build relationships and gather information to inform the current project. For example, AAC hosted four meetings of a nationally representative panel of academics, asthma educators and policy/program directors about barriers to asthma care and education in remote settings, including First Nations communities. The group recommended the RAP curriculum, in particular the school-based small group format, as an optimal way to address barriers associated with rural and remote locations, including First Nations communities.

### Project Activities

**2010-2011 Fiscal Year**

AAC filed an interim report May 2011.
2011-2012 Fiscal Year

Modification to Submitted Work Plan:
The project activities to be performed by AAC were listed in the work plan (Appendix 2). The project activities and deliverables were modified due to a number of factors (described in the Lessons Learned section) and were agreed upon by AAC and ASC via emails, and in-person and phone meetings.

Accordingly, the following activities were carried out by AAC, consistent with project’s aim to adapt RAP to be relevant to First Nations children, in collaboration with First Nations children and communities, and to evaluate such adaptation:

- Recruit, report to and receive advice of Advisory Group (See Appendix 1 Interim Report for details);
- Host national workshop of asthma educators, RAP Instructors, and representatives of national First Nations organization and community members (See Appendix 1 Interim Report for themes and recommendations);
- Survey RAP Instructors and individuals with experience in First Nations health education programs and health services;
- Review and apply ASC’s survey of First Nations children and families;
- Recruit provincial coordinators and asthma education mentors;
- Establish community of practice for Advisory Group, workshop participants, community-based teams and partners;
- Recruit and support community-based teams;
- Adapt and host Roaring Adventures of Puff On-line Instructor’s Training (“RAP-IT”);
- Organize and host webinars;
- Apply feedback to adapt RAP lesson plans and activities and test adapted materials;
- Collect and apply feedback about the mascot; and
- Recruit artist/graphic Artist for activity book adaptation and apply feedback.

Activities

Survey of RAP Instructors and Individuals with Experience in First Nations Health Education Programs and Health Services (the “Pre-Survey”)

As reported for the 2010-2011 fiscal year, 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.

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

- **Education, Professional Designation, Position and Responsibilities.** 80% indicated that they were registered nurses, 60% were certified asthma educators and 20% were respiratory therapists (Figure 1). 75% (n=12) held positions with responsibility for child asthma education: program delivery (hospital, clinic, primary care or community health centre setting), development and/or implementation. A subset (n=5) of these 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.** 12 of the Respondents had taken RAP Instructor’s training, either in-person or on-line. The remaining 3 Respondents had received information about the curriculum from the Project team. **Appendix 1** contains the RAP Primer that was distributed to Respondents. Respondents who attended the Workshop accessed additional materials including a Powerpoint presentation, RAP Instructor’s manual and sample activities. 10 had taught RAP in schools (Figure 2) and 4 had not. 8 had hosted RAP school sessions that included First Nations children.

- **Expertise and/or Experience with First Nations Health Care and/or Health Education Programs.** 9 of the Respondents worked at First Nations Health Care Centres, 8 worked in First Nations schools, 6 in First Nations community health and 9 conducted group health education (Figure 3). 8 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.

Figure 1:
Figure 2:

Professional Designation (n=15)
(multiple answers permitted)

- Other
- Community Health Representative
- Nurse Practitioner
- Physician
- Certified Asthma Educator
- Registered Nurse
- Registered Respiratory Therapist
- Pharmacist

Figure 3:

Experience with RAP: Number of Sessions Taught (n=14)

- 10 or more times: 3
- 6-10 times: 2
- 2-5 times: 4
- Once: 1
- Zero: 4
2. Feedback about RAP Content and Format
The remaining 29 questions were primarily long answer-type in an attempt to gather unbiased, thorough and thoughtful feedback. Questions were grouped into four sections namely: RAP content, RAP format, RAP Instructor’s Training course and Project Input.

a. Content
Respondents were asked for feedback and suggestions relating to the impact, appeal and relevance of RAP lesson plans, activities, the mascot and Fun Book. They were asked to make recommendations about content and themes to enhance RAP for First Nations children.

In general, Respondents felt that much of the existing content would be engaging and have impact with First Nations children. In fact, one responded:

“Kids are kids.”

Respondents recommended activities be visual, hands-on, active, interactive, creative and employ encouragement/rewards. Existing RAP activities that scored high for impact and fun include:

- Airways activity (n=6);
- Pig lungs;
- Asthma zones (n=5);
- Role playing;
- Jeopardy
- Trigger BINGO (n=2);
- Asthma wishes or stars
- Brave Boy book for storytime or drama
- Inhaler scramble
- Trigger Pictionary
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- Lightning Round Review
- Puppets

Respondents suggested adding online/Smart board activities (n=3), peak flow contest and video games. Respondents suggested incorporating a variety of activities and themes to make the content more relevant to First Nations children. These included:
  - traditional drumming for existing RAP songs;
  - medicine wheel (n=3);
  - traditional healing;
  - storytelling;
  - community involvement;
  - respect for Elders
  - self-respect
  - animals
  - Aboriginal athlete
  - Ashinabe role model;

Respondents felt that the content relating to asthma triggers would be more relevant to First Nations children if it was expanded to add smudge (n=2), tobacco (n=3), sweat lodges, housing (N=3), wood stoves and dusty roads.

Feedback respecting the Fun Book activity book (“Fun Book”) was varied, but consistent with the adaptations suggested for the lesson plans, activities and RAP Instructors training course. In general, responses favoured a decrease in text, more “entertainment”, more workbook-type activities, greater use of colour and more photos/art depicting First Nations communities and children. Specific comments are summarized in Appendix 4.

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. As noted in the Summary of Workshop Themes (Appendix 1) there was a strong consensus to pilot test a wolf mascot.

b. Format
100% of Respondents felt that the school was the ideal setting to deliver the course to First Nations children. When asked about limitations to delivery, they listed:
  - lack of family involvement/connection (n=7);
  - “schools not recommending program”;
  - not enough children with asthma in same school for program;
  - “schools already have so many issues to deal with”;
  - kids go home for lunch;
  - getting Instructors into schools;
  - kids must give up recess time (n=2); and
  - attendance.
Alternative settings and solutions to barriers were suggested and are summarized in Appendix 4.

The survey expressly asked about alternatives to the current delivery model (whereby a trained health care professional acts as the Instructor). Although responses were mixed, 8 Respondents felt that community members, including community/public health workers, school staff, student nurses, referral clerks, Elders, community liaisons, and other “champions” could be trained to facilitate or co-facilitate school sessions. It is significant that 13 felt that mentoring by a Certified Asthma Educator, RAP Instructor or health professional should be a feature of the training and implementation.

c. RAP Instructors Training

Respondents recommended that RAP Instructors training include:
- Device training;
- Working with children (n=3);
- Asthma control/management;
- Anatomy/physiology of lungs and airways (n=2);
- Cultural awareness/sensitivity (n=2);
- Facilitation/presentation skills (n=2);
- “basics of asthma” (n=2);
- RAP curriculum (n=2);
- First Nations-specific triggers;
- Allergies; and
- Useful resources.

d. Project Input

The final section of the survey asked about processes to obtain approvals and engagement from the community, school boards, school(s), and family, respectively. Respondents gave advice about who to approach for assistance, appropriate gifts and time frames. Respondents emphasized that the Project team and processes should respect the culture and community, and some expressed wariness for research.

3. Implementation of Recommendations

Input from the Pre-survey, workshop, collaboration website (explained below) and ASC’s survey of First Nations children and guardians informed the project activities, and adaptation of the RAP children’s curriculum, RAP Instructor’s Training course and Fun book. Implementation of these recommendations is explained under the relevant project activities below.

Survey of First Nations Families and Children by ASC

One of the project activities assumed by ASC was to survey First Nations children and families about the Fun Book. 13 children and guardians were interviewed. Appendices 5 and 6 are ASC’s summary of responses, which was provided to AAC. The majority of children and parents responded very positively to questions about whether they liked and understood the content. Strong themes which emerged were:
- Reduce the amount of text;
- Keep drawing and colouring activities;
- Use colour;
- Ensure activities are fun and exciting;
- “make less busy”; information is “too overwhelming”;
- Add more pictures; and
- Ensure information about medications, device technique, and airways is easy to understand.

As described in the section respecting the Fun Book below, this feedback was considered and applied in the adaptation of the Fun Book.

**Recruitment of Provincial Coordinators and Asthma Education Mentors**

In consultation with ASC, AAC recruited provincial coordinators in Ontario, Manitoba and British Columbia, namely:

- **Ontario**: Ana MacPherson, Ontario Lung Association;
- **Manitoba**: Lesley Stewart, Bev Kulbaba and Jo-Anne St-Vincent, Children’s Asthma Education Centre, Winnipeg Children’s Hospital of Winnipeg;
- **BC**: JoAnna Gillespie.

In Alberta, AAC acted as the 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 be supported by asthma educators, JoAnna, Lesley, Bev, Jo-Anne and Ana agreed to act as “asthma education mentors”. Ambris Ford, a Certified Respiratory Educators from Calgary agreed to act as asthma education mentors for Alberta.

**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.
Usage Statistics of Collaboration Site: Of the 79 members, 60 “logged in” at least once, either by using their username/password to access the site or opening posts through external e-mails. From the launch date, there have been a total of 570 logins - 261 in 2011, 309 in 2012 - excluding logins by Air Exchange administrators or the project team. Air Exchange generates a number of activity reports, which are available upon request.

New members received an e-mail message with their username, password and an explanation of the site’s organization and features. The purpose and content of the project’s collaboration site were described as follows:

We hope that all our partners will actively use this site to:

- follow the progress of the project;
- provide input into project activities and processes;
- share and discuss templates of letters, activities and other documents for community based sites; and
- discuss successes and challenges.

The project team primarily used four features in the collaboration website: the discussion forum, announcements, webinars and resource library.

1. 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:
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.

2. **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.

3. **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.

4. **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.
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. A list of invited and participating communities will be forwarded separately. The following describes the general recruitment process, as well as specifics of its application, by province.

1. Recruitment Process

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 (Appendix 7). 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 (Appendix 8) was attached to the invitation letters, which requested information about the community, team members, budget needs and in-kind contributions.

2. Manitoba

Lesley Stewart, Bev Kulbaba and Jo-Anne St-Vincent from the Children’s Asthma Education Centre acted as provincial coordinators and asthma education mentors. Ms. Stewart received expressions of interest from three First Nations communities but, in consideration of the project budget and CAEC’s available resources, invited two to participate (referred to as “Community A” and “Community B”). The communities’ health centre directors accepted and provided names of their team members.

Both Manitoba teams enrolled their members in RAP-IT and had certain team members who participated in the course, including the Sharing Circle, case studies, teleconferences, webinars and videoconferences. See the Evaluation section below for detailed quantitative and qualitative analysis of participation. The provincial coordinators and project team stayed in contact with both sites to discuss their progress and any barriers.

In the case of Community A, the primary contact and designated RAP Instructor, a public health nurse, repeatedly contacted the school board, providing information and requesting consent to offer the course. To assist, the project team drafted a letter which the nurse sent to the Education Director, Chief, Band Council, School Board Health Portfolio Lead, Health Director, Principal, and Vice-Principal to attempt to obtain consent. To date, she has not obtained consent to offer RAP in the school. The project
team asked whether any additional funds would assist her team, but the nurse advised that the issue was not funding-related. Lesley Stewart has agreed to attend at the school to assist with the school sessions.

In Community B, two of the team members participated in RAP-IT. As explained in a letter from this community’s designated RAP instructor and in the Evaluation section, these members remain interested in delivering RAP in their community’s school. However, they have numerous competing demands, including other chronic health education programs – especially in the spring. The designated RAP Instructor advised that she intends to complete the course and has the school’s consent to offer RAP in the fall.

3. Alberta

Recruitment in Alberta was led by the project team. Ambris Ford, Certified Respiratory Educator agreed to act as asthma education mentor for Alberta communities.

The project team met with Dr. Christopher Sarin, Public Health and Preventive Medicine, First Nation and Inuit Health, Alberta, to introduce the project, define site criteria and discuss potential sites, timelines and engagement procedures. Two communities were invited based on proximity to the asthma education mentor and site criteria. Community C was invited through a physician, who had advised that asthma education would address a critical need. Health centre staff said they faced staff shortages and too many competing demands to commit to the project.

Community D was invited through the health centre director, who committed that centre employees would form a community-based team. He arranged for a meeting between the project team and staff which was attended by the medical director, administrator and community health nurse. This meeting was also attended by Dr. Sarin, Ambris Ford and Dr. Mary Noseworthy, a Pediatric Respirologist and Director of the asthma program at the Alberta Children’s Hospital, who had agreed to support the project.

Pilot site activities at Community D are ongoing. To date, the project team has attended a health fair to promote the project, communicated with area schools and enrolled the community health nurse in RAP-IT. The schools have expressed interest in the program and are in the process of deciding which staff will also act on the community-based team. The community health nurse has provided input into the Asthma Journey activity book.

As explained in further detail under Recommendations, the project timeframe was insufficient to be properly introduced to communities and their leaders, build relationships and trust, obtain approval from all entities, train community teams and pilot test the adapted curriculum. With this insight, and a desire to ensure sufficient testing of the adapted curriculum, the project team agreed to assist the Social Support Research Team (University of Alberta) with an Allergy, Asthma and Eczema camp for First Nations children and youth. On October 28-30, the SSRN hosted 19 children from an Alberta community (Community E) for a weekend retreat. In partnership with Sharon Anderson, Roxanne Blood, Elders and peer mentors, AAC supported 13 activities from the original and adapted RAP curriculum, including:

1. What Bugs Me About My Asthma
2. Making and Squishing Bugs
3. Edible Airway Craft  
4. Airway (Clay) Sculpting  
5. Asthma Collages  
6. Asthma Doodle  
7. (Elder-guided) Visioning Exercise  
8. Guided Art activity of asthma feelings, fears and living a healthy life  
9. Trigger Pictionary  
10. Trigger Charades  
11. Know your Meds  
12. Medication De-Scramble  
13. Asthma Zones

Appendix 9 is a report about the Asthma, Allergy and Eczema camp. Appendix 10 is a poster presented at the Canadian National Asthma Conference (2011) shortly after the camp.

4. Ontario

Ana MacPherson, of the Ontario Lung Association, acted as provincial coordinator for Ontario. In 2010, through a National Lung Health Framework Program project, Ms. MacPherson had introduced RAP to eight Ontario First Nations communities. Many of these were remote sites and had expressed concerns about sustainability. Fittingly, Ms. MacPherson invited a number of these sites to participate in the current project. Teams from three communities (Communities F, G and H, respectively) agreed to act as community-based teams and registered team members for RAP-IT. Despite continued and creative efforts, these sites have not remained engaged. Some have not logged on to RAP-IT, despite sending personal information which was expressly requested to enrol them. Some have attended teleconferences and webinars but have not accessed RAP-IT.

Ana MacPherson and the project team e-mailed team members directly (in addition to Air Exchange announcements and discussion posts) to attempt to increase participation. Also, a number of novel approaches were taken (and features were added to RAP-IT and Air Exchange) to:

- Ensure community-based teams did not experience technical issues. In addition to the University of Alberta’s moodle “tip sheet”, the initial RAP-IT e-mail linked participants to a narrated screencast showing site navigation and features. The project team held two teleconferences coinciding with the launch of the website to address technical difficulties, offered one-on-one assistance and referred newly enrolled participants to colleagues/team members who had already accessed the site. Finally, the project team reminded participants about the availability of provincial coordinators and asthma education mentors.
- Optimize colourful, interactive, non-text features. Numerous vokis (animated narration) and case scenarios were added.
- Add content about and relevant to First Nations community members and children including photos, teleconferences about asthma from FN perspective; and links to SSRP series of telehealth series related to asthma and allergies including housing, advocacy, etc.
- Increase live (or similar) content including full day video conference and videos of demonstrations of activities with RAP instructor and kids.
- Expand partnerships to ON Knet.
- Offer toolkits of puppet and activity supplies.
In February, Ana MacPherson proposed to organize an in-person session in one of the participating communities, with transportation and accommodation provided for the three Ontario community-based teams. Unfortunately, project funds were limited, so this was not possible. Instead, Ana and Lesley Stewart organized a one-day videoconference to demonstrate each lesson plan and associated activities. Unfortunately, despite advance publicity and significant effort to organize videoconferencing sites, only one participant (from Manitoba Community A) attended.

Contemporaneously with this project, K.C. Rautiainen, Asthma Coordinator, Sudbury & District Health Unit, Ontario delivered RAP, as part of the Creating Asthma Friendly School program, in two Ontario First Nations communities (Communities I and J, respectively). In contrast with the proposed model in other sites, Ms. Rautiainen travelled to the communities to deliver school sessions. Ms. Rautiainen has had extensive experience with the RAP program, delivering it since 2002, developing RAP-IT content, and acting as primary facilitator.

Ms. Rautiainen provided ongoing input into current project processes, RAP-IT curriculum, lesson plans, activities and the FunBook and contributed new activities (details under specific activities) from her experience in these two communities. Evaluation of these sites activities is described in Evaluation below.

5. **British Columbia**

JoAnna Gillespie agreed to act as BC provincial coordinator and asthma education mentor. She recruited three nursing students from Victoria to assist in community recruitment. In contrast to the model in other provinces, the nursing students agreed to act as RAP Instructors and accordingly, were enrolled in RAP-IT.

One of the students proposed to recruit a school with predominantly First Nations students, which she had worked with in a previous nursing course. Unfortunately, this student moved away and the successor student did not have a relationship with community members. She contacted and made a presentation to the community’s public health nurse (Community K), who then took the idea to the band. The band expressed interest in the project however wanted it to be initiated by nursing students from a local institution. Also, the public health nurse for the reserve was retiring soon and did not want to initiate a new project, but proposed to wait and work with the nurse taking her place. JoAnna Gillespie and the project team assisted recruitment efforts, by offering letters and phone meetings with local health and band contacts.

**RAP-IT Course**

Until 2009, RAP-IT was delivered to small groups in an in-person format. In 2009, to optimize flexibility and access for remotely located health care professionals, RAP-IT was launched as an on-line course. A summary of RAP-IT’s history and studies of its impact are found in Appendix 1. The on-line course contained 10 required and two elective courses, namely:

1. Introduction to RAP
2. Lived Perspective
3. Asthma 101
4. Changing Behaviours
5. Supporting Parents
6. Asthma Friendly Schools
7. Social Support and Peer Mentoring
8. Teaching Skills
9. Small Groups
10. RAP Up
11. Diversity in Health Care
12. Puppetry

Features included discussion forums, self-assessment tools, on-line expert facilitators and extensive resources. Participants had the flexibility to complete the course at their own pace – within a 10 week timeframe.

Applying feedback from the pre-survey, workshop and Air Exchange discussion forum, RAP-IT was adapted for community-based teams, including "lay" learners (who were not health care professionals). Modifications included:

- Adding photos of First Nations communities and people.
- Adding content about First Nations context: 7 Sacred Teachings, protocol for community engagement, asthma in First Nations, RAP education in First Nations, First Nations families’ perspective, housing issues, advocacy with health care professionals etc.
- Condensing 12 modules into the following 5 chapters, with additional materials provided as suggested, but not mandatory, readings:
  1. Overview of RAP: introduction to the Roaring Adventures of Puff (RAP) course and history of the RAP program. Participants were asked to discuss how to maximize use of RAP in First Nations (FN) communities in the Sharing Circle section.
  2. Asthma 101: introduction to the basics of asthma diagnosis, symptoms and management. Participants were asked to complete an asthma management knowledge self-assessment and to discuss how they would respond to five case studies of poor asthma control in the Sharing Circle;
  3. Gathering Stories – From Children, Families and Community: collection of anecdotes from people affected by asthma, as well as more information on asthma management with an emphasis on community and family level management strategies. The Sharing Circle questions asked about identifying children’s and parents’ asthma needs;
  4. RAP Program: information about teaching skills, the RAP curriculum, games and role play exercises instructors could use to prepare themselves for RAP. The Sharing Circle questions asked participants to assess their performance in the role play exercises;
  5. wRAP up: participants were asked to complete a course satisfaction survey and final quiz.

- Reviewing the grade level of all text and, wherever possible, making grade level in grade 6-9 range.
- Increasing non-text, interactive features including website links, cartoon narration, screen casts, Powerpoint presentations, teleconferences, videoconferences and webinars.
- Increasing content about general health, in general including physical, emotional and spiritual;
- Enrolled provincial coordinators and asthma education mentors to be participants in the course and Sharing Circle discussion forum.
• Adding tip sheets, screen casts, e-mails, teleconferences and other assistance to address technological issues.
• Adding 10 videos showing RAP Instructors leading children in RAP activities and a further video showing Dené artist leading children in artistic activity about emotional aspect of asthma.

Evaluation of RAP-IT by the community-based teams is included in the Evaluation section below.

**Adaptation of RAP Lesson Plans and Activities**

As noted elsewhere, input into the adaptation of RAP lesson plans and activities was gathered through a national workshop (March 20, 2011), the Pre-survey, Advisory committee, Air Exchange discussion forum and webinar discussions, Asthma, Allergy and Eczema camp and meetings with RAP Instructors and Siksika team. These revisions were also informed by ASC’s survey of kids and parents about the FinBook.

**Appendix 12** is a list of 35 activities reviewed, modified, created and contributed in the course of this project. It includes a brief description of each activity and its fit with the RAP curriculum. The final column (entitled “Strengths”) shows the application of the feedback and the rationale for including the activity. The linked documents, photos and video demonstrations of the games are available upon request.

Evaluation of the activities is included in the Evaluation section.

**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 (**Appendix 16**).

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. **Appendix 13** is the Legend of Tahnee, the Wolf: My Asthma Journey book which will be sent to print later this month. Highlights include:

• “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 the mascot and Asthma Journey book are included in the Evaluation section.

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.
- Community D 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

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.
1. **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, for example:

“I think you have done a great job! Graphics and content look great! I think all the key issues have been covered well. . . I like the idea of the paw prints images where children will plan how they will work towards achieving their wishes (goals) . . .”

“First off, FANTASTIC WORK. It looks great. . . I got excited about using this new resource.”

“I love the new look of the Fun Book” . . . Great job on the content and graphics”

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. A copy of comments from Air Exchange is available upon request.

2. **Evaluation of Activities by Children**

   a) **Asthma, Allergy and Eczema Camp Evaluation**

**Methods:** As explained in greater detail above, and in Appendix 9, 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:** Appendix 14 shows the results of the “bulls-eye” survey. 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. This interview is summarized in Appendix 9.
b) Ontario Communities

As noted in the Activities section, 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:

- 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 her original plan was to attend five times to host the RAP sessions, Ms. Rautiainen 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, Ms. Rautiainen found that these groups responded to short sessions that were largely active and outdoors (like the playground). Consequently, she modified lesson plans and activities to be applied to these settings and situations.
- Ms. Rautiainen discussed the format and length of sessions with the kids. This helped build the relationship and specifically addressed that the kids were missing recess to attend RAP. 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.

3. Health Fair Survey

In May 2012, AAC was invited to participate in an annual health fair in Community D. 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.

A table showing the results is Appendix 15. 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.

### 1. 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.

Team members were recruited to build asthma care capacity. Several different recruitment processes were used in recognition of the multiple paths to working with First Nations communities and the desire to empower the provincial coordinators to determine the recruitment strategy most appropriate for each community. As a result, participants varied in their expectations for the course, past experience with asthma and in their previous understanding of the RAP program. Not all team members intended to teach or implement the RAP program. This high degree of heterogeneity, combined with the small number of participants, meant that most data was best suited for qualitative, rather than quantitative 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.

2. 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 (n=8) worked in a community health care centre. Other reported locations of work were an outpatient/primary care clinic (n=2), a nursing station (n=1) and home care facilities (n=2), with some respondents reporting multiple locations of work. All respondents had at least a high school diploma (n=11), with most respondents also having a university or college degree or diploma (n=8). Slightly more than half of respondents reported having worked in their community for three years or more (n=6/10).

"How many years have you worked in your current community?" (n=10)

- 1 person worked less than 1 year
- 1 person worked 1-2 years
- 3 people worked 3-5 years
- 3 people worked 6-9 years
- 2 people worked 10 or more years
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 (n=5); home and community care (n=3); clinical care (n=3); school health (3) and public health (n=3), as was expected, but others stated that they were responsible for programs less related to RAP, such as secretarial/reception work (n=2) and post-partum care (n=1).

<table>
<thead>
<tr>
<th>Responsibility</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>health prevention/promotion/education</td>
<td>5</td>
</tr>
<tr>
<td>home/community care</td>
<td>3</td>
</tr>
<tr>
<td>clinical work</td>
<td>3</td>
</tr>
<tr>
<td>public health</td>
<td>3</td>
</tr>
<tr>
<td>secretarial/reception</td>
<td>2</td>
</tr>
<tr>
<td>school programming/health</td>
<td>2</td>
</tr>
<tr>
<td>emergency response</td>
<td>1</td>
</tr>
<tr>
<td>Head Start</td>
<td>1</td>
</tr>
<tr>
<td>Infection control/communicable disease</td>
<td>1</td>
</tr>
<tr>
<td>asthma</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
</tr>
<tr>
<td>CVD</td>
<td>1</td>
</tr>
<tr>
<td>Medication</td>
<td>1</td>
</tr>
<tr>
<td>preschool immunization</td>
<td>1</td>
</tr>
<tr>
<td>post-partum</td>
<td>1</td>
</tr>
<tr>
<td>NADAP assessments</td>
<td>1</td>
</tr>
</tbody>
</table>

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 (n=7) was “I wanted to know more about asthma.” Other popular motivations were wanting to “help implement the RAP program” in their community (n=6), wanting to “know more about RAP” (n=5), wanting “to teach RAP” (n=5), and a personal experience with asthma (n=5). 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 (n=9) 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 (n=10) 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” (4.8/5.0); “Work time is provided for me to take the course” (4.8/5.0); and “I can access online resources, like links and videos” (4.8/5.0). More disagreement occurred with the statement “The class is conducted in person,” (3.7/5.0) and the statement “I have deadlines to keep me motivated” (3.6/5.0).

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Overall Rating</th>
<th>Response Count (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability do the course at times that are most convenient for me</td>
<td>4.80</td>
<td>10</td>
</tr>
<tr>
<td>I can complete units as fast or as slow as I like</td>
<td>4.73</td>
<td>11</td>
</tr>
<tr>
<td>Work time is provided for me to take the course</td>
<td>4.82</td>
<td>11</td>
</tr>
<tr>
<td>I can access online resources, like links and videos</td>
<td>4.82</td>
<td>11</td>
</tr>
<tr>
<td>I can learn from people that don't live in my community</td>
<td>4.40</td>
<td>10</td>
</tr>
<tr>
<td>I can take the course with other people in my community</td>
<td>4.45</td>
<td>11</td>
</tr>
<tr>
<td>I can communicate with the asthma education mentor, as needed</td>
<td>4.55</td>
<td>11</td>
</tr>
<tr>
<td>I can discuss the course with my classmates</td>
<td>4.36</td>
<td>11</td>
</tr>
</tbody>
</table>
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 (n=14), chiefly a lack of work time reserved for taking the course (n=4), the need to replace other staff in addition to completing one’s own work (n=3) and an inability to justify spending time on RAP-IT due to it not being part of the respondent’s job description (n=3). Other barriers to engagement included technical issues (n=7), dislike of course format (n=5), inappropriate timing (n=3), personal demands (n=2) and generally being too busy (n=10).

<table>
<thead>
<tr>
<th>Category</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work environment (14)</td>
<td>Insufficient time given by employer (4)</td>
</tr>
<tr>
<td></td>
<td>Lack of partner at work (1)</td>
</tr>
<tr>
<td></td>
<td>Insufficient notification given - 2-3 months ideal (1)</td>
</tr>
<tr>
<td></td>
<td>Had to replace other staff (3)</td>
</tr>
<tr>
<td></td>
<td>Frequent interruptions (1)</td>
</tr>
<tr>
<td></td>
<td>Not part of job description (3)</td>
</tr>
<tr>
<td></td>
<td>Conflicted with work (not doing on employer request) (1)</td>
</tr>
<tr>
<td>Personal demands (2)</td>
<td>In school (2)</td>
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<tr>
<td>Offered at an inappropriate time (3)</td>
<td>Health workers should be trained in September; program offered in November (2)</td>
</tr>
<tr>
<td></td>
<td>Winter is better than summer (1)</td>
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<tr>
<td>Course format (5)</td>
<td>Paper would be better/could supplement (1)</td>
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<td></td>
<td>CD-ROM could make up for technical issues (1)</td>
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<td>AirExchange - &quot;only for the white people&quot; (1)</td>
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<td>Units not all uploaded at beginning of course (1)</td>
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<td></td>
<td>In-person makes it easier to learn (1)</td>
</tr>
<tr>
<td>Technical issues (7)</td>
<td>Lack of webcam (2)</td>
</tr>
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</table>
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% (n=9) agreeing that RAP “would help kids in my community” and 70% (n=7) 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].”

○ 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.

○ 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 (n=1), more information about asthma (n=1) and teaching (n=1), shorter/more uniform length chapters (n=2) and dedicated work time to complete the course (n=1). 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 Networks** 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.

Challenges and Lessons Learned

Importance of Proper Introductions and Relationship Building Prior to Community-Based Activities

Communities were more readily identified and recruited in regions where provincial coordinators had previous links or relationships with First Nations communities. For example, in Ontario, eight communities had experienced RAP school sessions through OLA’s NLHF (2010) project and had expressed a desire for the program. In contrast, in BC, the provincial coordinator and team were impeded by the lack of ties to First Nations communities and perceived lack of general asthma awareness. In Alberta, introductions to First Nations communities were made through other University of Alberta researchers and FNHB, Alberta region, which greatly facilitated recruitment. However, a 14-month timeframe, with an 8-10 month recruitment window is insufficient for proper introductions, relationship building, recruitment and approval processes which must precede site activities.

Importance of Proper Protocol, Communication and Transparency

Related to the above, it is critical that provincial coordinators and the community based team have the time to become informed about appropriate local protocol and to obtain approvals. As stated by one Pre-survey respondent:

I think the material covered is terrific; but the time commitment is not conducive to delivery or reception . . . If you are planning on delivering this program in FN communities, be ever respectful of the people, culture and protocol. . . always be mindful of their needs and not what your focus is for the project, this should not be another research project, you need community engagement . . .

In certain communities, coordinators were advised that RAP, as a discreet school-based program, did not require the approval of local government. In other communities, notwithstanding that the health centre had agreed to facilitate the program, band approval was required. In others, it is unclear whether band approval would have facilitated recruitment and engagement of the school board, school and parents. However, a fully participatory approach would contribute to the general purpose of RAP – building awareness, capacity and champions – and is consistent with the general principles in Chapter 9 of the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans and AFN’s First Nations Environmental Health Innovations Network Protocols and Guidelines.

Importance of Assessing Capacity and “Readiness” of Community

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 and RAP, there were significant rates of attrition. The project team and provincial coordinators had underestimated the amount of technical support and continued personal contact required to maintain engagement. Despite numerous and creative attempts to the engage the teams – including introducing the Clean Air Champions’ athlete speaker program, assembling a toolkit (including puppet, activity supplies and prizes), organizing webinars and videoconferences, and offering asthma mentor support – some sites did not stay engaged.

At various times throughout the project, AAC and provincial coordinators offered the $2,000 budgetted to community based teams. None of the teams claimed this amount and, when it was re-offered later, advised that "money was not the issue".

**Lessons relating to RAP-IT**

Course usage was generally low, with 37.5% (n=6) of retained participants (n=16) engaging in some part of the course. Specific barriers (in addition to above) included:

- Lack of technological capacity and support at the community level – Although, these were not frequently reported during the duration of the project and many communities reported access to technological resources, some team members expressed technological issues.
- Lack of designated work time and support to complete RAP-IT. Also, three survey respondents reported that they would have had more time available for RAP-IT in fall/winter. All well,
- Need for in-person training – Although the screen casts, teleconferences and webinars may have helped, some component of face-to-face time may be essential to retain interest and increase confidence.
- Personal demands were cited twice – so a factor, but not a very significant one

However, course usage is not conclusive of capacity building. Participants were permitted to assess their knowledge and skills and thereby customize their participation. Variances in asthma knowledge, teaching skills and goals for the course complicated the assessment of capacity building. The key question to assess this aspect was “On a scale of 1-5, how much has the course so far changed the way you work with asthma in your community?” followed by the prompt “Please tell us which changes you’ve made or plan to make.” Engagement with the course was low and completion lower but it was noted that a few (n=3) participants were acting to raise awareness of proper medication use in their community and that one participant in particular used many of the resources available to her without completing much of the RAP-IT curriculum. More research is needed to assess the capacity building potential of RAP-IT.

**Lessons respecting RAP School Sessions**

Lessons learned about the RAP curriculum, activities, and mascot arising from the Asthma, Allergy and Eczema camp and community based activities are:

- Involve community members in the RAP sessions, including Elders and artists, to build capacity and support systems for the children, showcase talent, engage children and optimize relevance.
As an illustration, one of the community members who attended the camp subsequently enrolled in RAP-IT to increase her asthma knowledge and skills. She has emerged as an asthma resource in her community and for surrounding communities. Also, through the camp, she was introduced to an asthma educator from her region, whom she has accessed for further information and services.

- Use a mascot in the RAP sessions, whether it is Puff or the wolf, or both! These children (the boys, in particular) clearly bonded with the puppet, making him and nametag and giving him a spot at the table. Children responded favourably to wolf as proposed mascot.
- High ratio of adults to children assists in delivering curriculum and responding to individual children’s needs. For example, some children need to break off from the group activity when they lose focus. Also, diversity in adults – peer mentors, asthma educators, community members – increases opportunities for meaningful engagement and relationship building.
- Deliver curriculum content through play. Children’s attention span for lecture-style and group demonstration was short (especially as the weekend progressed). Games that were team-based, fast-paced and interactive were very well received. Games that had brief instructions or followed a well known format (ie. Trigger Pictionary) were well received. Asthma educators were skilled at injecting lessons during course of games.
- Use various tactile media (charcoal, markers, pencil crayons, clay, food-based crafts), to illustrate content, address different learning styles and give the children something to manipulate and make into models.
- To respond to a variety of learning needs and attentions spans, have a variety of approaches and activities ready to deliver.
- There are benefits to having older and younger children working together. Older children help explain and reinforce the content and activities and act as mentors.
- Peer mentors play a very valuable role to make the camp comfortable and fun, offer support, and co-lead activities. Peer mentors should receive appropriate training about asthma content so that they are not giving incorrect information.
- Adapt the curriculum to the children’s needs and preferences. The content may have to be delivered over a greater number of visits.

Recommendations

General

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; and
• 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 may 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.
References


8. Postl BD, Cook CL, Moffatt M. Aboriginal child health and the social determinants: why are these children so disadvantaged? Healthc Q 2010; 14 Spec No:42-51.


Appendixes

Appendixes are available upon request via e-mail to MaureenDouglas@med.ualberta.ca or ShawnaMcGhan@med.ualberta.ca.