

Development Process for The Lung Association – Ontario Pediatric Asthma Action Plan (Children 1-15 years)

Background:

A written asthma action plan (AAP) is a tool used by healthcare providers to help the patient/family to understand how and when to use asthma medications, establish self-monitoring, and prevent asthma exacerbations. AAPs have been found to significantly reduce acute asthma exacerbations in children, when compared to care provided without an AAP. (MacGillivray & Flavin, 2014) Despite the evidence in support of such a self-management action plan, delivery by physicians and usage by patients remains low. This may in part be due to variability in available plans leading to confusion among clinicians; a failure to consider visual design and usability factors in the development of existing AAPs, (Gupta, et al., 2012) leading to inefficiencies in preparing AAPs in busy real-world practice; and a failure of previous design processes to include the perspectives of all key stakeholders, in particular patients and primary care providers. Accordingly, The Lung Association – Ontario (TLA) sought to develop an evidence-based and highly usable pediatric asthma action plan (PAAP), through an iterative design process with input from key stakeholders (primary care physicians, asthma educators, respiratory experts, and patients), while considering best evidence for PAAP content and design, and principles of human factors and usability optimization.

Objective:

The objective of this project was to systematically develop an evidence-based pediatric asthma action plan for children ages 1-15 years for a Canadian audience, with input from primary care physicians, asthma educators, respiratory experts, caregivers, and patients, and while considering design and usability factors.

Process:

- 1) We convened an inter-disciplinary steering committee to advise on the development and implementation of the PAAP (June 2015)
 - a. Members of the committee consisted of a convenience sample of professional and patient stakeholders, including content experts identified previously by TLA.
 - b. The committee consisted of: two primary care physicians, two respirologists (one was a general respirologist and the other a pediatric respirologist), three pediatricians, four registered nurses [two Certified Respiratory Educators (CREs) and two Certified Asthma Educators (CAEs)], one pharmacist, two nurse practitioners, and two mothers of children with asthma. The committee's work was supported by members of TLA, including four CREs.
 - c. Chairs of the committee were selected based on their content expertise. Dr. Dhenuka Radhakrishnan, a pediatric respirologist at the Children's Hospital of Eastern Ontario, provided content expertise while also representing the Ontario Thoracic Society (OTS). Dr. Samir Gupta, a respirologist and clinician-scientist at the Li Ka Shing Knowledge Institute of St. Michael's Hospital, brought previous expertise in the form of research-based evidence regarding AAP development, human factors and real-life implementation.
- 2) Next, committee chairs completed a narrative review of the literature informing PAAP development, complemented by relevant references suggested by other committee members. The following key references were identified (June 2015 to October 2015):

- a. Previous formal AAP development processes:
 - i. An Asthma Action Plan Created by Physician, Educator and Patient Online Collaboration with Usability and Visual Design Optimization (Gupta, Wan, Hall, & Straus, 2012)
 - ii. WikiBuild: A New Online Collaboration Process For Multistakeholder Tool Development and Consensus Building (Gupta, et al., 2011)
 - iii. Two for one: A self-management plan coupled with a prescription sheet for children with asthma (Ducharme, et al., 2008)
 - b. Previous AAPs
Developed through systematic processes:
 - i. Ontario Adult AAP (based on Gupta, et al., 2012)
 - ii. Quebec Pediatric AAP (based on Ducharme, et al., 2008)
 - iii. Children’s Hospital of Eastern Ontario (CHEO) and Pediatric Emergency Department Asthma Clinical Pathway (PEDACP) Asthma Action Plan with discharge instructions (based on Ducharme, et al., CRJ 2004 and Tulloch, et al., 2012)Currently in use in Ontario (all ages):
 - iv. The Lung Association – Ontario AAP (based on Primary Care Asthma Program (PCAP) pilot, 2003-2006)
 - c. AAP content:
 - i. Canadian Thoracic Society 2012 guideline update: Diagnosis and management of asthma in preschoolers, children and adults (Lougheed, et al., 2012)
 - ii. Diagnosis and management of asthma in preschoolers: A Canadian Thoracic Society and Canadian Paediatric Society position paper (Ducharme, et al., 2015)
 - iii. Global Strategy for Asthma Management and Prevention (Global Initiative for Asthma, 2017)
 - d. AAP content/format/usability
 - i. Asthma action plans are highly variable and do not conform to best visual design practices (Gupta, et al., 2012)
 - ii. Evaluation, modification and validation of a set of asthma illustrations in children with chronic asthma in the emergency department (Tulloch, Vaillancourt, Irwin, & Pascuet, 2012)
 - iii. Readability, Suitability, and Characteristics of Asthma Action Plans: Examination of Factors that May Impair Understanding (Yin, et al., 2013)
 - iv. Canadian paediatric asthma action plans and their correlation with current consensus guidelines (MacGillivray & Flavin, 2014)
- 3) Committee chairs then prepared a summary of this literature, which was presented to the larger committee for discussion at an in-person meeting on October 1st, 2015. At this meeting, a number of AAPs currently in use were discussed. This overview provided the opportunity to look at the evidence base and decide on the broader goals and objectives of the project. The knowledge gaps identified in the literature review pointed to the need for a standardized, unified asthma action plan for the pediatric population in Ontario that reinforces the principles of asthma management in children. The evidence review further informed the committee’s

decision to focus the new PAAP for the ambulatory/office setting in children 1-15 years of age. We agreed upon a methodological approach that would evaluate the current evidence-based action plans, to establish a foundation upon which our PAAP could be built. As a result, the committee agreed to participate in a survey that compared four existing AAPs, as outlined above. (October 2015)

- 4) Next, committee chairs and TLA administrators prepared a survey. The survey asked committee members to indicate strengths and weaknesses of the four plans reviewed. Questions focused on format, layout, and content. The results of the survey identified some clear design preferences and concerns around volume of text versus the availability of “white space”. Broadly, it was agreed that too much text would decrease usability for families/patients. Respondents also indicated that the appropriate amount of “white space” balanced with a guided prescription approach would facilitate use among clinicians. (Spring 2016)
- 5) Subsequent to this, all development was led by committee chairs, with iterative feedback from other committee members. Based on findings of the literature search and the in-person meeting, chairs serially developed content for review and discussion by other members. Feedback was acquired electronically (over email), by telephone, and/or in-person, as per convenience. Development took place in the following order:
 - a. Green, yellow, and red zone titles
 - b. Green, yellow, and red zone symptom descriptors and control criteria
 - c. Green, yellow, and red zone management instructions
 - d. Header/footer region content
 - e. PAAP format/usability features (e.g. colours, fonts, layout, diagrams)
 - f. PAAP back page content

Where possible, committee chairs sought consensus among committee members. In unusual situations where consensus could not be resolved, decisions were made by majority vote. (Summer 2016 – Fall 2017)

- 6) There were a number of opportunities for external reviewers to provide feedback. A draft of the PAAP was presented to approximately 70 Emergency Department Registered Nurses from the Hospital for Sick Children in Toronto. Overall, their feedback was positive. The Hospital for Sick Children Asthma Clinic also provided feedback from three patients/family members, one Physician, and two Respiratory Therapists. Reviewer feedback, on both occasions, gave us the opportunity to ensure that symptom descriptors in each zone were clearly stated, easily understood, and were in line with current guidelines. It also allowed us to improve overall presentation and readability. At the request of the committee co-chairs, the draft PAAP was also reviewed by an allergist. The allergist’s feedback was specific to the allergies’ and triggers’ sections on the back page. It provided further evidence-based detail around the optimal wording needed to describe each allergy and trigger. The PAAP was serially edited to reflect each group’s feedback, with approval of committee members. (September 2017)
- 7) The Pediatric Asthma Action Plan Steering Committee reported to The Lung Association’s Asthma Advisory Committee. On-going support for the project and feedback was also sought from other Asthma Program committees including the Provider Education Program Steering Committee and the Primary Care Asthma Program Advisory Committee. Each of these groups provided further feedback, which was discussed at length, and where possible, incorporated into the PAAP. On June 8, 2018, the new PAAP was presented to the Ontario Thoracic Society (OTS) Executive. Based on feedback received at this meeting, the PAAP was further improved and then endorsed by the OTS.

- 8) The PAAP was officially launched on World Asthma Day, May 1, 2018. The Lung Association produced a press release highlighting the introduction of the new, evidence-based Pediatric Asthma Action Plan for children 1-15 years of age. Current asthma educational programming will be updated to include the new PAAP and development of a French translation is in the planning stages. Implementation of this PAAP will be supported through on-line and in-person workshop learning opportunities.

For further support or if you have questions about how to use this action plan please contact info@lungontario.ca or call our Lung Health Information Line at 1-888-344-LUNG (5864) to speak with a Certified Respiratory Educator.

References

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