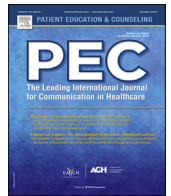




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The Canadian anaphylaxis action plan for kids: development and validation

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ABSTRACT

Objectives: We designed a written Canadian Anaphylaxis Action Plan for Kids (Kids' CAP) which incorporates validated pictograms with written instructions. Using a patient-centered approach, we aimed to validate the Kids' CAP and assess its impact on anaphylaxis recognition and treatment, and to determine its perceived usefulness.

Patient Involvement: Children and their parents were involved in appraising the design and written contents of the Kids' CAP.

Methods: The design process consisted of a development phase and clinical validation phase. First, we assessed the readability and understandability of the Kids' CAP using validated instruments. Then, patients (12–17 years of age) and parents of patients (<12 years of age) were given the Kids' CAP during the first consultation with allergy specialists or an Emergency Department visit for anaphylaxis. Subsequently, we conducted a phone interview 2–3 weeks later to assess their comprehension of anaphylaxis management. We also used the Consumer Information Rating Form to measure the participants' perception of the design quality and usefulness of the Kids' CAP.

Results: Of the 230 participants enrolled, 205 (89%) completed the follow-up interview. The written contents of the Kid's CAP were modified to match grade 7 readability level. The total mean score of the Consumer Information Rating Form for comprehensibility was 23.1 (SD 2.4), and 25.1 (SD 2.3) for design quality. The mean comprehension score was 11.3 (SD 1.8) (reference range 0–12), with no significant difference between participants with and without previous experience with anaphylaxis, or high vs. low literacy level.

Conclusion: Engaging children and parents in the design and contents of written anaphylaxis action plan is an innovative approach to produce a useful document for the end-users.

Practice Implications: The Kids' CAP is a valid tool that can be used in emergency departments and allergy clinics to improve patient's comprehension of anaphylaxis manifestations and treatment.

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1. Introduction

Anaphylaxis is the most severe form of allergy that rapidly affects multiple body systems and can be deadly. [1,2] The lifetime prevalence estimates for anaphylaxis range from 0.3 to 5.1%, and appear to be increasing globally, particularly in young people [3–6]. Importantly, the highest incidence of anaphylaxis occurs in children and adolescents [7,8]. Canadian data indicate that the rate of children visiting Emergency Departments (ED) for anaphylaxis more than

doubled from 2006 to 2014, and 8% of allergy-related ED visits are due to anaphylactic shock [3]. In the United States, over 40% of children with food allergy reported ≥ 1 lifetime allergy related ED visit [9].

Despite its frequency and seriousness, under recognition and treatment of anaphylaxis by patients and caregivers remain a significant gap. [10] To mitigate this issue, both national and international guidelines and professional organizations recommend the use of a written anaphylaxis management plan [11–15]. A systematic review by Nurmatov et al found that anaphylaxis action plan (AAP) has the potential to reduce the frequency and severity of further reactions, improve knowledge of food avoidance techniques, improve the use of epinephrine auto injectors (EAI) and reduce anxiety [16]. However, a recent review of over 40 online AAPs found no plan that included all the

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recommended consensus-based components [17]. Furthermore, the existing plans lack pictorial aids, omit important treatment advice, and include written contents that are too technical and above the readability level of the general population [17–19]. Since these plans are mostly based on a consensus of experts, the World Allergy Organization emphasizes the need for a prospectively validated AAP. [20]

To address these gap using the principles of human-centered design, we designed the Canadian Anaphylaxis Action Plan for Kids (Kids' CAP), a written plan that incorporates pictograms with written instructions. [21] Key counseling pictograms, related to the management of anaphylaxis, were previously identified and validated by our team for comprehension in children and parents/caregivers.²¹ An original infographic action plan tool was then created using these validated images along with basic written instructions for patients. We conducted two steps to validate the original Kids' CAP: development phase and clinical validation phase. The goal of the development phase was to assess the readability and understandability of the action plan. Using a patient-centered approach, the clinical validation phase was aimed to assess the impact of the Kids' CAP on the comprehension of anaphylaxis symptoms and treatment, and to determine its perceived usefulness.

2. Methods

Table 1 provides a summary of the methods, outcomes, and assessment tools used for the development and clinical validation phases.

2.1. Development phase

Three outcome measures were assessed during this phase: readability, understandability, and actionability. First, we conducted readability testing of multiple sections of the original infographic (**Appendix A**) using both the Gunning Fog index (GFI) and the Fry Readability Graph (FRG). [22] Patient information pamphlets are recommended to be at a readability level that is appropriate for the general population which is grade 6–8 [23]. Therefore, statements included in the core sections were assessed and the text was modified until a reading level of grade 7

or lower was attained. Two independent health literacy experts conducted the assessment and discrepancies were discussed when necessary.

Subsequently, three independent parent reviewers were recruited from the Patient and Family Advisory Committee at our institution to assess the understandability and actionability components of the Kids' CAP. The assessors conducted their anonymous review using the Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P). [24,25] A PEMAT score <70% indicate instructions are difficult to understand. [24,26]. Therefore, we targeted a priori score of $\geq 80\%$ before proceeding to clinical validation.

2.2. Clinical validation phase

2.2.1. Participants and setting

A modified version of the Kid's CAP was implemented for clinical validation based on the readability testing. All patients (12–17 years of age) and parents of patients (<12 years of age) were eligible if they presented to the ED with anaphylaxis or consulted an allergy specialist for a first life-time allergic reaction that has the potential risk of anaphylaxis. Children who presented to the ED with anaphylaxis were not excluded if they had previous anaphylaxis. The cut-off age of ≥ 12 years was chosen based on previous data on the expected age of self-carrying and administering EAs. [27] Anaphylaxis was defined as an allergic reaction that matches the World Allergy Organization diagnostic criteria for anaphylaxis [1]. Visits related to drug allergy or drug-induced anaphylaxis were excluded. We also excluded children or parents who were unable to communicate in English or French, or were unable to complete the follow up phone interview 2–3 weeks after recruitment. Participants were enrolled prospectively between June 2016–September 2017 at one tertiary ED (the Children's Hospital of Eastern Ontario) and two community allergy clinics (in Ottawa, Ontario, and Gatineau, Quebec).

2.2.2. Outcome measures

During this phase, two outcomes were assessed:

2.2.2.1. Quality of the written medical information. Three measures of written medical information (WMI) in the Kids' CAP were

Table 1
Summary of the Outcome Measures and Assessment Tools Used for the Development and Validation Phases of the Kids' CAP.

	Outcome measures	Assessment tools	Description	Comment
Development phase	Readability	Gunning Fog index (GFI) Fry Readability Graph (FRG)	Readability testing of the Kids' CAP	Validated tools [22] Conducted by 2 health literacy experts
	Understandability	PEMAT-P [†]	17 statements Focus on important themes (e.g. content, organization, layout, and use of visual aids) [26]	Validated tools developed by the U.S. Department of Health & Human Services Agency for Health Research & Quality [24,25] Completed by 3 independent parents reviewers
	Actionability	PEMAT-P [†]	7 statements Focus on: capacity to give the reader clear actions to execute, provide the reader with a tangible tool (i.e., a checklist), and directly address the user when describing the action	
Clinical validation phase	Health literacy	Newest Vital Sign (NVS)	Health literacy assessment of study participants at the time of enrollment	Validated tool [45,46,47] Validated in parents, teenagers, and Canadian population. [48,49,50]
	Quality of the WMI [‡] (comprehensibility, design quality, and usability)	Consumer Information Rating Form (CIRF)	Completed by participants during follow-up phone interview 2–3 weeks after enrollment	Validated tool [28,29]
	Comprehension	Kids' CAP Comprehension Assessment	Completed by participants during follow-up phone interview 2–3 weeks after enrollment	Original tool Includes 4 clinical vignettes to assess comprehension of anaphylaxis symptoms and management steps

[†] PEMAT-P = Patient Education Materials Assessment Tool for Printable Materials.

[‡] WMI = Written Medical Information.

Table 2
Characteristics of Study Participants.

Item	N = 205 n (%)
Age (years)	
< 6	122 (59.5%)
6–11	52 (25.4%)
≥ 12	31 (15.1%)
Sex	
Male	111 (54.1%)
Female	94 (45.9%)
Recruitment Site	
ED [†]	154 (75.1%)
Community allergy clinics	51 (24.9%)
Level of education of patients (n = 31)	
Elementary school	5 (16.1%)
High school	23 (74.2%)
College	3 (9.7%)
Level of education of parents (n = 171) ^{mv=3†}	
Elementary school	2 (1.2%)
High school	20 (11.7%)
College	40 (23.4%)
University	70 (40.9%)
Higher education	39 (22.8%)
Patients' Health Literacy Level (Newest Vital Sign Score), mean (SD)	5.1 (1.1)
Parents' Health Literacy Level (Newest Vital Sign Score), mean (SD)	5.2 (1)
Co-existing allergic conditions	
Asthma	59 (28.8%)
Allergic rhinitis	24 (11.7%)
Eczema	124 (60.5%)
Past allergic or anaphylactic reactions	148 (72.2%)
Number of previous reactions (n = 147) ^{mv=1†}	
1	30 (20.4%)
2	48 (32.7%)
≥ 3	69 (46.9%)
Number of ED visits for previous reactions (n = 145) ^{mv=4†}	
1	34 (23.4%)
2	20 (13.8%)
≥ 3	69 (47.6%)
Time passed since last reaction (n = 148)	
4 weeks	25 (16.9%)
6 months	57 (38.5%)
1 year	14 (9.5%)
2 years	22 (14.9%)
≥ 3 years	30 (20.3%)
Previous visit to allergy specialist	121 (59.0%)
Previous provision of anaphylaxis emergency action plan	44 (21.5%)
Previous epinephrine auto-injector prescription	129 (62.9%)
Support from family doctor/pediatrician for allergies (n = 149)	
A lot of support	88 (59.1%)
Some or limited support	48 (32.2%)
No support	4 (2.7%)
Don't know	9 (6.0%)
Perceive allergy as "life-threatening"	
Yes	78 (38.0%)
No	90 (43.9%)
Don't know	37 (18.1%)
Anaphylaxis ED visits, (n = 154)	
Severity of reaction[§]	
Severe	33 (21.4%)
Moderate	82 (53.1%)
Mild	39 (25.5%)
Triggers	
Food	110 (71.6%)
Insect stings	11 (7.0%)
Unknown cause	33 (21.4%)
Location of the reaction	
Home	74 (48%)
School or daycare	22 (14.3%)
Restaurant	15 (9.7%)
Outdoor (parks, malls, etc.)	43 (28.0%)
Treatment before arrival to ED	
Self-administered epinephrine	49 (31.8%)
Called 911/an ambulance	56 (36.4%)
Went to doctor's office	8 (5.2%)

Table 2 (Continued)

Item	N = 205 n (%)
Self-administer antihistamine	68 (44.1%)
Other	8 (5.2%)
Nothing	8 (5.2%)
Time of treatment from onset of anaphylaxis	
Within 1 hour	122 (79.1%)
Between 1–2 hours	11 (7.1%)
Between 2–6 hours	5 (3.1%)

[†] MV = Missing value, [‡]ED = emergency department, [§]Based on the severity scoring by Brown et al [51].

assessed: comprehensibility, design quality, and usability. These three elements were measured to assess participants' perception of the overall quality of the WMI in the plan including layout and understanding of the written contents. We used the Consumer Information Rating Form (CIRF) which is a previously validated tool to evaluate these outcome measures [28,29] (**Appendix B–Consumer Information Rating Form**). Participants were also inquired about their perception of the improvement in knowledge and understanding of anaphylaxis management after reading the Kids' CAP.

2.2.2.2. Comprehension. The overall comprehension and knowledge of anaphylaxis management was objectively assessed through four hypothetical scenarios where the participants needed to identify the correct response to the situation and related questions (**Appendix C–Kids' CAP Comprehension Assessment**). Two main elements of comprehension were tested: symptoms associated with an anaphylactic reaction (4 points) and comprehension of management steps (8 points), to make a total testing score of 12. These scenarios encompass core elements of anaphylaxis management previously developed for testing patient knowledge of food allergy, and epinephrine autoinjector administration. [30–32]

2.2.3. Procedure

At recruitment, participants completed two questionnaires: demographic data,

and health literacy test (**Table 1**). The research assistant (RA) then presented the Kids' CAP to the participant and counseled them about anaphylaxis and how to use this plan using a standardized counselling script that we developed for the study (**Appendix D–Kids' CAP Script and Checklist**). For demonstrating the use of the EAI, the RAs followed the "teach-back" technique with a trainer device. [33] At follow up, all participants were contacted to complete the CIRF and the Kids' CAP Comprehension Assessment questionnaires (**Table 1**). See **Appendix E** for further details on study procedure.

2.3. Data analysis

Descriptive statistics were produced for all variables. Central tendency (mean) and dispersion (SD) statistics were produced for continuous variables and frequency distributions for categorical variables. Factors associated with mean knowledge scores were analyzed using Welch two sample t-tests. Two-sided p-values ≤ 0.05 were considered to be statistically significant. All statistical analyses was performed using R statistical software version 3.4.0 (R Core Team, Vienna, Austria). [34] The study protocol was approved by the Research Ethics Board of the Children's Hospital of Eastern Ontario Research Institute.

3. Results

3.1. Readability, understandability, and actionability assessments

Initially, the infographic scored an average GFI of 9 and an FRG score of 5. The infographic underwent several rounds of iteration to reach a GFI of grade 7 or below. Strategies to attain readability of grade 7 or below included reducing the amount of words containing more than three syllables. For example, “severe allergic reaction” was initially described as a “life-threatening allergic reaction”. Furthermore, we added periods at the end of each counselling point and reduced the length of sentences. In addition, on the second page of Kids’ CAP, a list format was used to enumerate allergens to avoid instead of long descriptive sentences in paragraph format. The word “epinephrine” was excluded from the GFI and FRG analysis, because it was deemed essential to the Kids’ CAP despite its complex meaning. The final GFI and FRG results were Grade 7 and Grade 5 respectively. The understandability and actionability of the Kids’ CAP were deemed acceptable in the first review with median scores of 88% (range 84%–92%) and 85% (range 71%–100%), respectively.

3.2. Clinical validation phase

3.2.1. Participants’ characteristics

Of the 230 participants enrolled during this phase, 205 (89%) completed the follow-up interview. The demographic characteristics of those participants are summarized in Table 2. There were no significant differences on demographic characteristics between participants enrolled from the ED versus allergy clinics, or respondents versus non-respondents of the follow-up interview. Parents represented 85% of study participants, the rest were children. Most patients (75.1%) were enrolled from the ED for an anaphylactic reaction that occurred at home (48%), secondary to a food trigger (71.6%) Table 2. Although 121 of 205 patients (59%) have seen an allergy specialist for prior anaphylaxis or allergic reaction, only 44 (21.5%) were given an anaphylaxis emergency action plan.

3.2.2. Quality of the written medical information

The mean and standard deviation for comprehensibility and design quality from the CIRF are shown in Table 3. Generally, parents and children rated the Kids’ CAP as very easy to read, understand, navigate, remember, and keep. The design aspects also scored favorably in all items. Furthermore, 89.7% of the participants also found the Kids’ CAP to be useful. There were no significant differences between patients versus parents on the reported quality of WMI. However, around 7% of the participants reported that the original plan included irrelevant information, and 23.4% commented on missing information Table 3. A thematic summary of the critiques and suggestions from study participants is presented in Table 4. Based on these comments, we updated the plan (Appendix F– Kids’ CAP for Pharmacy) and developed a supplementary teaching video.

3.2.3. Comprehension

Out of a maximum score of 12 for the Comprehension Assessment Questionnaire, the mean knowledge score was 11.3 (SD 1.8). There was no significant difference in the mean knowledge score between parents versus children, participants with versus without previous anaphylaxis experience, or high versus low literacy level (Table 5). However, parental

Table 3

Consumer Information Rating Form and Participant’s Perspective of Anaphylaxis Written Information.

Item	Participants N=205
Comprehensibility, mean (SD) (Scale: 1=Very Hard – 5=Very Easy)	
Read	4.8 (0.5)
Understand	4.8 (0.5)
Remember	4.4 (0.8)
Locate information	4.7 (0.6)
Keep	4.4 (0.9)
Total (reference range 5 – 25)	23.1 (2.4)
Design Quality, mean (SD) (Scale: 1=Worst – 5=Best)	
Organization	4.6 (0.6)
Attractiveness	4.7 (0.6)
Print size (1=Too small – 5=Too big)	3.0 (0.5)
Tone (1=Alarming – 5=Comforting)	3.8 (1)
Helpfulness	4.6 (0.6)
Spacing	4.4 (0.8)
Total (reference range 6 – 30)	25.1 (2.3)
Usefulness of the Kids’ CAP in managing anaphylaxis, n (%)	
Strongly Disagree	3 (1.5%)
Disagree	0 (0.0%)
Neutral	18 (8.8%)
Agree	51 (25.0%)
Strongly Agree	132 (64.7%)
Perceived improvements after reading the Kids’ CAP, mean (SD) (Scale: 1=Small – 5=Great)	
Improvements in Knowledge	3.5 (1.4)
Improvements in Understanding	3.6 (1.4)
Preferred sources of information about child’s health/allergies, n (%)	
Doctor/nurse	56 (27.3%)
Online	81 (39.5%)
Telephone line	9 (4.4%)
Books/magazines	9 (4.4%)
Other	17 (8.3%)
Preferred method of receiving ED discharge instructions (n=154), n (%)	
Paper handout	73 (47.4%)
Electronic (email, internet website, phone app)	63 (40.9%)
Telephone line	6 (3.9%)
Likelihood of reading information provided by a doctor or at the hospital, n (%)	
Very Unlikely	3 (1.5%)
Somewhat Unlikely	1 (0.5%)
Unsure	11 (5.4%)
Somewhat Likely	30 (14.6%)
Very Likely	160 (78.0%)
Likelihood of using the Kids’ CAP, n (%)	
Very Unlikely	0 (0.0%)
Somewhat Unlikely	2 (1.0%)
Unsure	5 (2.4%)
Somewhat Likely	32 (15.6%)
Very Likely	166 (81.0%)
Likelihood of keeping the Kids’ CAP to use it in the future, n (%)	
Very Unlikely	6 (2.9%)
Somewhat Unlikely	2 (1.0%)
Unsure	11 (5.4%)
Somewhat Likely	36 (17.6%)
Very Likely	150 (73.2%)
Kids’ CAP includes irrelevant information, n (%)	14 (6.8%) [†]
Other information missing from the Kids’ CAP, n (%)	48 (23.4%) [†]
Written information about anaphylaxis is useful, n (%)	200 (97.6%)

[†] See Table 4 for further details.

education level of college or higher was the only factor associated with a statistically different mean knowledge score ($p < 0.001$) (Table 5).

Table 4
Summary of Critiques and Suggestions from Study Participants on the Kids' CAP.

Category	n
Design	
Pictograms	
“Childish cartoons”	2
Treatment pictures: Epi-pen is too high in thigh [†]	1
Too much color [†]	2
Add a pictogram for “keep child in lying position” [‡]	1
Writing	
Decrease amount of writing [†]	3
Increase size of writing to emphasize important information [†]	8
Decrease size of hospital logo [†]	4
Tone	
Alarming [†]	2
Organization/spacing	
Condense contents [†]	6
Move steps for epi-pen administration to front page [§]	6
Have bullet points directly underneath each picture	2
Current written contents	
Treatment	
Clarify symptoms criteria to use epinephrine [†]	15
Clarify when to go to emergency room [†]	2
Clarify when to give second dose of epi [†]	3
How to use autoinjector	
Clarify how many seconds to hold epi-pen [†]	3
Explicitly mention if epi-pen goes through clothes [†]	1
Remove Allerject [™] –no more in the market	7
More practice with a trainer [†]	3
Additional contents	
Clarify the difference between anaphylaxis and allergic reaction [†]	7
Mention that symptoms can be different with each reaction [†]	2
Add “keep-calm”/ “epinephrine won't hurt or harm them” [‡]	3
Clarify when to use antihistamines [†]	5
Add information about delayed reaction	3
Add information on anaphylaxis with asthma [†]	1
Add emergency contact information	2
Add links on how to read food labels	3
Add references for more information and resources [†]	5
Add expiry date for autoinjector	3
Add information about exercise induced anaphylaxis	2
How to dispose epi-pen	2
Add what to do in case of accidental self-injection	1
Other suggestions	
Teaching video would be most useful [†]	4
Create versions for family doctor and paramedics	3
Poster for schools	1
Offer in languages other than English/French	5
Produce in laminated/water-proof copy to keep for long-term	6
Create an online version in case paper is lost	1
Create a separate version for teens	2

[†] Changed in the updated version. [‡] Addressed in the teaching video. [§] Addressed in the school/daycare version.

4. Discussion and conclusion

4.1. Discussion

This study targets one of the critical research priorities identified by the World Allergy Organization and the National Academies of Sciences, which is improving patient education in the recognition and management of allergic reactions. [20,35,36] We followed a patient-centered approach to prospectively validate the Kids' CAP by focusing on what matters most to patients. The readability analytic testing combined with the qualitative assessment of the quality of WMI resulted in multiple modifications of the plan to capture the needs of the target population. More importantly, the clinical validation phase indicates that the implementation of the plan was associated with an improvement in knowledge and adequate comprehension of anaphylaxis management.

Two recent systematic reviews reported best design interventions that are found to be most effective to improve patient comprehension of WMI. [37,38] These strategies involve the inclusion of pictorial aids paired with text, organization (e.g. typographic cues, information chunking, use of color, increased white space, and broken paragraphs), targeting low reading level, information that is easy to navigate, and tools that can be accessed when needed [37,38]. The Kids' CAP conforms to these design features as reported in the CIRF Table 3.

Following the principles of human-centered design [39], much of the design features in the Kids' CAP were enhanced due to critiques from study participants (Table 4). For example, several participants suggested to “move steps for EpiPen administration to front page”. As a result, we generated a separate “school/daycare” version of the Kids' CAP to make it easy to find an essential aspect of anaphylaxis management for school staff, while maintaining consistent typographical cues throughout the plan (Appendix G– Kids' CAP for School/Daycare). Similarly, in response to important suggestions from study participants for further clarifications (Table 4), we updated the Kids' CAP script to create a supplementary knowledge dissemination video (<http://ochsu.ca/en/kidscap>) that teaches the action plan to patients and caregivers.

Although most participants scored high in the comprehension testing at 2–3 weeks after recruitment, the perceived improvement in knowledge and understanding of anaphylaxis recognition and management were moderate. Several characteristics of the study population should be considered in the interpretation of this finding. First, over 70% of study participants had previous anaphylaxis or allergic reactions. In fact, a significant proportion of those participants had two or more previous reactions that required a visit to an ED and counselling by an allergy specialist. These experiences likely influenced participants' knowledge about anaphylaxis. Furthermore, the health literacy level testing of the study participants and the reported parents' education level suggest that most participants had adequate health literacy, which has been shown to influence disease understanding and treatment compliance. [40]

There are no robust data on factors that are associated with knowledge of anaphylaxis management. However, studies from the food allergy literature indicate that parental level of education [31], disease severity metrics [31,41] (e.g. previous anaphylaxis, perception of severe allergy, history of EpiPen use), counselling by an allergy specialist [42], and support/advocacy group membership [31,41] are some of the previously identified factors that seem to impact knowledge about food allergy and treatment compliance. We explored the association of several of these factors with knowledge about anaphylaxis and found that except for parental education level, none of the other factors were significant. It should be noted though that these factors were measured after teaching the participants about anaphylaxis and providing them with the action plan.

To our knowledge, this is the first anaphylaxis action plan in the literature that has gone through a multifaceted prospective validation process that included all the infographic and written contents and followed evidence-based strategies in designing the written information. The written contents in the Kids' CAP overcome many of the deficiencies identified on previous plans. [17] Furthermore, the innovative approach of engaging children and their parents/caregivers in the study expanded the practical usefulness of this document. Nevertheless, our study has several limitations. The research was conducted on a population of mostly educated parents who by and large showed adequate health literacy. Although the readability and infographic design of the Kids' CAP target a low literacy population, we cannot make an inference about this application without formal testing.

Table 5
Difference in The Knowledge Score Between Study Participants.

Factor	Mean knowledge score ($\pm$ SD)	Mean Difference	95% CI	p-value
Respondent				
Parents, n= 174	11.3 ($\pm$ 1.7)	0.3	–0.4, 0.9	0.4
Children, n= 31	11.0 ($\pm$ 1.9)			
Parent education				
College or above, n= 149	11.4 ($\pm$ 1.7)	1	0.5, 1.6	<0.001
Lower, n= 22	10.4 ($\pm$ 1.2)			
Literacy level				
Newest Vital Sign score $\geq$ 4, n= 169	11.3 ($\pm$ 1.7)	0.4	–0.2, 0.9	0.2
Newest Vital Sign score <4, n= 36	10.9 ($\pm$ 1.7)			
History of eczema				
Yes, n= 124	11.3 ($\pm$ 1.7)	0.2	–0.30, 0.6	0.4
No, n= 77	11.1 ($\pm$ 1.8)			
History of epinephrine autoinjector use				
Yes, n= 65	11.1 ($\pm$ 1.7)	–0.2	–0.7, 0.3	0.3
No, n= 140	11.3 ($\pm$ 1.7)			
Perceive allergy as life-threatening				
Yes, n= 78	11.2 ($\pm$ 1.7)	–0.04	–0.5, 0.5	0.8
No, n= 90	11.2 ($\pm$ 1.7)			
History of anaphylaxis				
Yes, n= 147	11.2 ($\pm$ 1.7)	–0.3	–1, 0.5	0.4
No, n= 58	11.5 ($\pm$ 1.9)			
Seen an allergy specialist				
Yes, n= 121	11.2 ($\pm$ 1.7)	–0.1	–0.6, 0.3	0.5
No, n= 82	11.3 ($\pm$ 1.7)			

The study is also limited by the small proportion of youth and adolescents in the validation population. Finally, the Kids' CAP teaching strategies that we followed in the study may have impacted the knowledge of the study participants. All participants received personalized and consistent teaching on the Kids' CAP for 15–20 minutes with “teach-back” technique for demonstrating the use of EpiPen. These effective teaching styles may have influenced the knowledge outcome. [33,37,43] We suspect that the positive impact on knowledge was due to the combined effects of the design features of the Kids' CAP in addition to the teaching techniques.

4.2. Conclusion

In conclusion, engaging children and parents in the design and contents of written anaphylaxis action plan is an innovative approach to produce a useful document for the end-users. Future research needs to explore the impact of this patient-centered plan on three critical outcomes: the long-term retention and recall of knowledge, the behavior of patients and caregivers toward treatment of anaphylaxis and adherence to self-care recommendations, and quality of life. Further data are also required to assess the impact of the Kids' CAP on low literacy population.

4.3. Practice implications

The provision of an anaphylaxis action plan is one of the key quality metrics for acute and long-term management of anaphylaxis. [44] The Kids' CAP is a valid tool that can be used in ED and allergy clinics to improve children's and caregiver's comprehension of anaphylaxis manifestations and treatment. It covers core aspects of post anaphylaxis care proposed in a recent systematic review [44], including the proper steps of management, the use of EALs, and prevention strategies. We also designed it to serve as a standard pre-filled prescription form for EALs, and a reminder for allergy specialist referral. As such, it is a useful clinical tool for professionals in acute care settings where most patients with anaphylaxis are diagnosed.

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Declaration of Competing Interest

The authors declare no competing financial interest.

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Supplementary data

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.pec.2019.07.028>.

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Appendix A

CHEO

Emergency Department

ANAPHYLAXIS ACTION PLAN & PRESCRIPTION

ADDRESSOGRAPH: _____

Weight: _____ kg

These are the signs and symptoms of an allergic reaction to _____ (allergen):

--	--	--	--

If you develop any symptoms:

1
1st

→

2

 5 min

→

4
2nd

- Give epinephrine at the first sign of an anaphylactic reaction.
- Call 9-1-1 or local emergency medical services. Tell them the child is having a life-threatening allergic reaction.
- If the reaction continues or worsens, give a second dose of epinephrine in 5 to 15 minutes.
- Keep the child sitting or lying position and avoid quick change in position (even if the child is not light-headed).

Medications:

Epinephrine 0.15 mg autoinjector for between 15 and 30 kg:
 Brand: ☐ EpiPen ☐ Allerject ☐ Other: _____

Epinephrine 0.3 mg autoinjector if 30 kg or greater:
 Brand: ☐ EpiPen ☐ Allerject ☐ Other: _____

Refer to an allergist

Physician: _____ (print name) Co-Menter: _____ Signature: _____ Date: _____ (dd/mm/yyyy)

How to use Auto-Injectors:

EpiPen®:

- Hold firmly with orange tip pointing downward.
- Remove blue safety cap by pulling straight up. Do not bend or twist.
- Swing and push orange tip firmly into mid-outer thigh until you hear a "click."
- Hold on thigh for several seconds.

Allerject™:

- Pull Allerject™ from the outer case. Do not go to step 2 until you are ready to use Allerject™. If you are not ready to use, put it back in the outer case.
- Pull off red safety guard. Do not touch the black base of the auto-injector. This is where the needle comes out and you might stick yourself by accident. If you do stick yourself with the needle, get medical help right away. **Note:** The safety guard is meant to be tight. Pull firmly to remove.
- Place black end against the middle of the outer thigh (upper leg). Only inject into the middle of the outer thigh (upper leg). Do not inject into any other location. **Note:** Allerject™ makes a distinct sound (click and hiss) when you press it against your leg. This is normal and indicates Allerject™ is working correctly.
- Seek medical or hospital care right away. Replace the outer case. Take your used Allerject™ with you to your pharmacist or doctor. They will dispose of it properly and will give you a new one.

Avoiding Allergens:

Food: Avoid relevant allergen containing foods. Read food labels. Bring new food to school. Do not share food, plates, placemats or utensils.

Insects: Cover up as much as possible. Wear closed-toe shoes when outdoors. Avoid scents. Tie back long hair. Stay away from pigeons and bats.

Medication: Let doctors, pharmacists, dentists and nurses know of any medication allergies.

Controlling your Anaphylaxis

- Avoid relevant allergens.
- Know how and when to use your auto-injector.
- Make sure the auto-injector is always close at hand.
- Make sure your auto-injector is not expired. Do not store in very hot or very cold place.
- If you are a long distance from a hospital, have a backup auto-injector.
- Wear a medical identification bracelet that is what you are allergic to.

Note: Children with asthma are at higher risk for severe anaphylaxis.

Appendix B- Patient’s Perspective of Comprehensibility, Design Quality, and Usefulness of the Kids’ CAP

SECTION 1: Consumer Information Rating Form for the Kids’ CAP

For each question, please circle the number that most closely reflects your opinion on the “Anaphylaxis Action Plan”.

1. Overall, how easy or hard would you say it is to:

	Very hard	Pretty hard	In between	Pretty easy	Very easy
Read the Anaphylaxis Action Plan	1	2	3	4	5
Understand the information	1	2	3	4	5
Remember the information	1	2	3	4	5
Find the information	1	2	3	4	5
Keep the information to use later or in the future	1	2	3	4	5

Please tell us more about how we could make the Anaphylaxis Action Plan easier to understand:

2. Where do you normally look for information about your/your child’s health or allergies?

Patient's Perspective of Comprehensibility, Design Quality, and Usefulness of the Kids' CAP

3. If you receive written information from your doctor or at the hospital, how likely is it that you would:

	Very unlikely	Somewhat unlikely	Unsure	Somewhat likely	Very likely
Read the information?	1	2	3	4	5
Use this action plan and the information?	1	2	3	4	5
Keep this action plan and the information to use it in the future?	1	2	3	4	5

Please tell us how you would prefer to receive more information or discharge instructions after your recent visit to the Emergency Department?

4. Below is a list of words describing the design, layout and tone of the Anaphylaxis Action Plan. Please circle the number which best describes your opinion:

Poorly organised	1	2	3	4	5	Well organised
Unattractive	1	2	3	4	5	Attractive
Writing is too small	1	2	3	4	5	Writing is too big
Alarming in tone	1	2	3	4	5	Comforting in tone
Not helpful	1	2	3	4	5	Very helpful
Poor spacing between lines	1	2	3	4	5	Excellent spacing between lines

Do you have any other comments about the design, layout and tone of this Anaphylaxis Action Plan?

Patient's Perspective of Comprehensibility, Design Quality, and Usefulness of the Kids' CAP

5. After reading this Action Plan, circle the number that most reflect the improvements on your knowledge and understanding of anaphylaxis:

Small improvement in knowledge	1	2	3	4	5	Great improvement in knowledge
Small improvement in understanding	1	2	3	4	5	Great improvement in understanding

6. Do you feel some of the information is not relevant?

☐ Y ☐ N

If yes, please tell us more about this:

7. Is there any other information regarding allergies that should be included on this action plan?

☐ Y ☐ N

If yes, please tell us more about this:

8. Please add other comment or feedback about the Anaphylaxis Action Plan:

9. Do you find written information about anaphylaxis useful?

☐ Y ☐ N

SECTION 2: Perception of the Usefulness of the Kids' Cap in Managing Anaphylaxis

10. The Anaphylaxis Action Plan was useful in managing the Anaphylaxis?

Strongly Disagree	1	2	3	4	5	Strongly agree
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11. If you have any additional comments regarding this Anaphylaxis Action Plan or would like to make suggestion to improve this tool, please write them down.

Thank you for completing the survey!

Appendix C- Kids' CAP Comprehension Assessment - Patient Clinical Scenarios and Testing Rubric

For this section, please read carefully the scenarios and answer the questions associated with each scenario

Scenario #1

You/your child were recently diagnosed with an allergy to peanuts and the doctors have explained symptoms and signs of an allergic reaction.

You/ your child have just been in a birthday party and ingested a food that contains peanuts. What symptoms and signs could you expect to follow?

				
Symptoms and signs	☐ Hives ☐ Swelling ☐ Itching ☐ Warmth ☐ Redness	☐ Coughing ☐ Wheezing ☐ Shortness of breath ☐ Chest pain/tightness ☐ Throat tightness ☐ hoarse voice ☐ trouble swallowing	☐ Pale/blue colour ☐ Weak pulse ☐ Dizzy/ lightheaded ☐ Loss of consciousness	☐ Nausea ☐ Pain/cramps ☐ Vomiting ☐ Diarrhea
Scoring	0 = 0 / 1 ≥1 = 1 / 1	0 = 0 / 1 ≥1 = 1 / 1	0 = 0 / 1 ≥1 = 1 / 1	0 = 0 / 1 ≥1 = 1 / 1
Score				
Total score (out of 4)	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4			

Scenario #2

RA to present the individualized scenario to the patient (*You were stung by a bee or your child was stung by a bee, then you quickly find yourself out of breath and gasping for air! You then start to feel lightheaded and dizzy!*). Based on your Anaphylaxis Action Plan, please describe in as much details as possible what you would do in this situation?

	Action	Score
Step 1	☐ Administer epinephrine/use EpiPen	0 = 0 / 1 1 = 1 / 1
Step 2	☐ Call 9-1-1/call for help ☐ Specify that child is having a sever/LIFE-THREATENING allergic reaction	0 = 0 / 1 ≥1 = 1 / 1
Step 3	☐ If symptoms continue or worsen, give a second dose of epinephrine in 5-10 minutes ☐ Give a second dose of epinephrine if not better after 5-10 minutes of first dose	0 = 0 / 1 1 = 1 / 1

Step 4	☐ Keep child on lying position unless precluded by difficulty breathing ☐ Avoid quick change in position	0 = 0 / 1 $\geq 1 = 1 / 1$
Total score (out of 4)	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4	

Scenario #3

RA to present the individualized scenario to the patient/parent (*You have been feeling ill for a few days now and have developed runny nose and cough. You have also developed a rash on your arms and torso! You have taken some medication to help you feel better but are still “feeling under the weather”.*) Based on the Anaphylaxis Action Plan, what would you do in that situation?

		Score
Correct conclusion/actions	☐ This is NOT anaphylaxis ☐ Call/see my doctor ☐ Call health information line ☐ Do nothing	$\geq 1 = 2 / 2$
Wrong conclusion/actions*	☐ This is anaphylaxis ☐ Administer epinephrine/use EpiPen ☐ Call 911	0 = 0 / 2
Total score (out of 2)	☐ 0 ☐ 2	

If the participant chooses a wrong action, mark the score then add the following comment:

“Although some symptoms may resemble an anaphylactic reaction, this is NOT an anaphylactic reaction. your child is likely suffering from the common cold! Did you recognize that this was not anaphylaxis?”

Scenario #4

You/your child is having an anaphylactic reaction. Please list the correct steps for using an EpiPen auto-injector?

	Steps	Score
Correct answer	☐ Hold firmly with orange tip pointing downward ☐ Remove blue safety cap ☐ Place the orange tip firmly into MID/OUTER thigh until you hear a "click" ☐ Hold on thigh for several seconds	☐ 0.5 ☐ 0.5 ☐ 0.5 ☐ 0.5
Total score (out of 2)	☐ 0 ☐ 0.5 ☐ 1 ☐ 1.5 ☐ 2	

Thank you for completing the comprehension survey!

Appendix D- Kids' CAP Script and Checklist

The purpose of this action plan is to:

1- Explain the features or symptoms of an allergic reaction.

Understanding these symptoms will make it easy for you and those around you (such as your parents and teacher) to recognize that you are experiencing an allergic reaction or anaphylaxis. Remember: anaphylaxis occur very quickly and can be very serious.

2- Explain the correct actions to take when you experience an allergic reaction.

Once you know you are experiencing an allergic reaction, the next step is to know what to do about it. This is the second goal of this plan.

3- Explain how to use your epi-pen.

Every person with potentially severe food or insect allergy should carry an epinephrine injection device (such as epi-pen).

Epinephrine is the only life-saving therapy for anaphylaxis.

Therefore, it is very important to know how to use your epi-pen correctly.

4- Explain how to prevent anaphylaxis.

The best treatment for anaphylaxis is to prevent it by avoiding the food that you are allergic to. This written plan explains the important steps that you can easily do to prevent anaphylaxis

Now, let me go over this plan with you in more details:

STEP #1: EXPLAIN THE SIGNS AND SYMPTOMS OF ANAPHYLAXIS

You are allergic to....(ex:peanut), which means that your body will show any of the following symptoms when you eat or get exposed to something that you are allergic to such as..(peanut butter or chocolate bar that has peanuts). The easy way to remember this is to think of your body from top (face) to down (stomach).

Skin and face	Breathing	Heart	Stomach
Diffuse Hives Diffuse Redness Swelling of the face Swelling of the lips Swelling of the tongue Swelling around the eyes	Difficulty breathing Wheezing Cough Throat swelling/tightness Chest pain/tightness Hoarse voice Blue discoloration of face Drooling with saliva Trouble swallowing	Feeling dizzy or lightheaded Pale Floppy (these signs indicate a drop in the blood pressure)	Vomiting Constant tommy pain Sudden behavioral changes in babies (excessive crying/fussiness)

STEP #2: EXPLAIN ACTIONS TO TAKE WHEN EXPERIENCING ANAPHYLAXIS

1- Give epinephrine **at the first sign** of an anaphylactic reaction. Epinephrine is the only life-saving therapy for anaphylaxis. **Do not** delay epinephrine injection to give Benadryl or other antihistamines.

2- Call 911 and tell them that you/your child is having a life-threatening allergic reaction

3- If the reaction continues or worsens, give a second dose of epinephrine in 5-15 min

4- Keep the child in a lying position unless he/she is vomiting or short of breath

STEP #3: EXPLAIN HOW TO USE EPI-PEN

EpiPen is the only epinephrine injection device that is currently available in Canada; we will now focus on learning how to actually use it. We will demonstrate the use of the EpiPen using a trainer device with no needle or medication.

 1 Blue to the sky. - Hold firmly with orange tip pointing downward. - Do not hold your thumb over the end - Remove blue safety cap by pulling straight up - Do not bend or twist - For young children, make sure to hold the child's leg steady before injecting	 2 Orange to the thigh. - Push orange tip firmly into mid-outer thigh until you hear a 'click'. - Hold on thigh for three seconds. - After injection, the orange cover automatically extends to ensure the needle is never exposed.
---	--

➤ **Now, I want you to show me how to use it by repeating those steps to me.**

Couple of things to remember about the epi-pen:

- Know how and when to use it. There is a mobile app (My EpiPen) that can also help you learn more about it
- Epinephrine is the only life-saving therapy for anaphylaxis. Make sure it always close at hand

Anaphylaxis Action Plan Script and Checklist

- Make sure your epi-pen is not expired
- Do not store your epi-pen in very hot or very cold place
- If you are a long distance from a hospital, have a back up epi-pen
- Please make sure you have an epi-pen with you before you go home today

STEP #4: EXPLAIN HOW TO PREVENT ANAPHYLAXIS

Use the section that is relevant to the patient. For example, If the patient has food allergy only, use the listed instructions under “Food”. Here is an example:

“You know that you are allergic to peanuts, here is what you need to avoid an allergic reaction to peanuts:

- Read food labels
- Avoid food that you are allergic to
- Bring your own food to school
- Don’t share food, plates, utensils, or placemats

CHECKLIST

Please initial all the check points that you have covered in teaching the action plan:

- ____ I explained the signs and symptoms of anaphylaxis
- ____ I emphasised that epinephrine is indicated after exposure to a known allergen especially if the symptoms involve any respiratory or cardiac symptoms/signs.
- ____ I explained the four treatment actions to do after an anaphylactic episode
- ____ I demonstrated the use of EpiPen as detailed in the script
- ____ I use a trainer device to demonstrate the use of EpiPen
- ____ I emphasised that epinephrine is the only life-saving therapy for anaphylaxis and should always be close at hand
- ____ I explained steps of allergen avoidance as detailed in the action plan
- ____ Patient is discharged with a script for an epinephrine autoinjector
- ____ For ED, patient is referred to an allergy specialist

SIGNATURE

PRINT NAME

DATE & TIME

Appendix E- Procedure of the clinical validation phase:

Potentially eligible participants were identified and approached by a trained research team for consent and assent when appropriate. Once they signed consent, the research assistant (RA) then proceeded to complete two questionnaires. First, the demographic data questionnaire, which included questions about past allergic reaction/s, co-morbid allergic conditions, and for patient enrolled from the ED, detailed information about the presenting anaphylaxis. Second, the health literacy test using the Newest Vital Sign (NVS) tool (**Table 1**). Based on the number of correct answers, the respondents were categorized as having an adequate health literacy (score 4–6) or a low health literacy (score <4).

The RA then presented the Kids' CAP to the participant and counseled them about anaphylaxis and how to use this plan. In order to maintain consistent teaching at all study sites, the RA followed a standardized counselling script that we developed for the study. The script was followed with a checklist that the RAs completed for every enrolled participant in order to ensure that all parts of the action plan were covered before discharge (**Appendix D**– Kids' CAP Script and Checklist). For demonstrating the use of EpiPen, the RAs followed the “teach-back” technique with a trainer device.³⁹ Finally, all participants were contacted by phone 2-3 weeks after enrollment to complete the CIRF and the Kids' CAP Comprehension Assessment questionnaires. For participants who did not answer the first phone follow-up, two subsequent contacts were attempted, one week apart.

Appendix B- Patient’s Perspective of Comprehensibility, Design Quality, and Usefulness of the Kids’ CAP

SECTION 1: Consumer Information Rating Form for the Kids’ CAP

For each question, please circle the number that most closely reflects your opinion on the “Anaphylaxis Action Plan”.

1. Overall, how easy or hard would you say it is to:

	Very hard	Pretty hard	In between	Pretty easy	Very easy
Read the Anaphylaxis Action Plan	1	2	3	4	5
Understand the information	1	2	3	4	5
Remember the information	1	2	3	4	5
Find the information	1	2	3	4	5
Keep the information to use later or in the future	1	2	3	4	5

Please tell us more about how we could make the Anaphylaxis Action Plan easier to understand:

2. Where do you normally look for information about your/your child’s health or allergies?

Patient's Perspective of Comprehensibility, Design Quality, and Usefulness of the Kids' CAP

3. If you receive written information from your doctor or at the hospital, how likely is it that you would:

	Very unlikely	Somewhat unlikely	Unsure	Somewhat likely	Very likely
Read the information?	1	2	3	4	5
Use this action plan and the information?	1	2	3	4	5
Keep this action plan and the information to use it in the future?	1	2	3	4	5

Please tell us how you would prefer to receive more information or discharge instructions after your recent visit to the Emergency Department?

4. Below is a list of words describing the design, layout and tone of the Anaphylaxis Action Plan. Please circle the number which best describes your opinion:

Poorly organised	1	2	3	4	5	Well organised
Unattractive	1	2	3	4	5	Attractive
Writing is too small	1	2	3	4	5	Writing is too big
Alarming in tone	1	2	3	4	5	Comforting in tone
Not helpful	1	2	3	4	5	Very helpful
Poor spacing between lines	1	2	3	4	5	Excellent spacing between lines

Do you have any other comments about the design, layout and tone of this Anaphylaxis Action Plan?

Patient's Perspective of Comprehensibility, Design Quality, and Usefulness of the Kids' CAP

5. After reading this Action Plan, circle the number that most reflect the improvements on your knowledge and understanding of anaphylaxis:

Small improvement in knowledge	1	2	3	4	5	Great improvement in knowledge
Small improvement in understanding	1	2	3	4	5	Great improvement in understanding

6. Do you feel some of the information is not relevant?

☐ Y ☐ N

If yes, please tell us more about this:

7. Is there any other information regarding allergies that should be included on this action plan?

☐ Y ☐ N

If yes, please tell us more about this:

8. Please add other comment or feedback about the Anaphylaxis Action Plan:

9. Do you find written information about anaphylaxis useful?

☐ Y ☐ N

SECTION 2: Perception of the Usefulness of the Kids' Cap in Managing Anaphylaxis

10. The Anaphylaxis Action Plan was useful in managing the Anaphylaxis?

Strongly Disagree	1	2	3	4	5	Strongly agree
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11. If you have any additional comments regarding this Anaphylaxis Action Plan or would like to make suggestion to improve this tool, please write them down.

Thank you for completing the survey!

Appendix C- Kids' CAP Comprehension Assessment - Patient Clinical Scenarios and Testing Rubric

For this section, please read carefully the scenarios and answer the questions associated with each scenario

Scenario #1

You/your child were recently diagnosed with an allergy to peanuts and the doctors have explained symptoms and signs of an allergic reaction.

You/ your child have just been in a birthday party and ingested a food that contains peanuts. What symptoms and signs could you expect to follow?

				
Symptoms and signs	☐ Hives ☐ Swelling ☐ Itching ☐ Warmth ☐ Redness	☐ Coughing ☐ Wheezing ☐ Shortness of breath ☐ Chest pain/tightness ☐ Throat tightness ☐ hoarse voice ☐ trouble swallowing	☐ Pale/blue colour ☐ Weak pulse ☐ Dizzy/ lightheaded ☐ Loss of consciousness	☐ Nausea ☐ Pain/cramps ☐ Vomiting ☐ Diarrhea
Scoring	0 = 0 / 1 ≥1 = 1 / 1	0 = 0 / 1 ≥1 = 1 / 1	0 = 0 / 1 ≥1 = 1 / 1	0 = 0 / 1 ≥1 = 1 / 1
Score				
Total score (out of 4)	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4			

Scenario #2

RA to present the individualized scenario to the patient (*You were stung by a bee or your child was stung by a bee, then you quickly find yourself out of breath and gasping for air! You then start to feel lightheaded and dizzy!*). Based on your Anaphylaxis Action Plan, please describe in as much details as possible what you would do in this situation?

	Action	Score
Step 1	☐ Administer epinephrine/use EpiPen	0 = 0 / 1 1 = 1 / 1
Step 2	☐ Call 9-1-1/call for help ☐ Specify that child is having a sever/LIFE-THREATENING allergic reaction	0 = 0 / 1 ≥1 = 1 / 1
Step 3	☐ If symptoms continue or worsen, give a second dose of epinephrine in 5-10 minutes ☐ Give a second dose of epinephrine if not better after 5-10 minutes of first dose	0 = 0 / 1 1 = 1 / 1

Step 4	☐ Keep child on lying position unless precluded by difficulty breathing ☐ Avoid quick change in position	0 = 0 / 1 ≥1 = 1 / 1
Total score (out of 4)	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4	

Scenario #3

RA to present the individualized scenario to the patient/parent (*You have been feeling ill for a few days now and have developed runny nose and cough. You have also developed a rash on your arms and torso! You have taken some medication to help you feel better but are still “feeling under the weather”.*) Based on the Anaphylaxis Action Plan, what would you do in that situation?

		Score
Correct conclusion/actions	☐ This is NOT anaphylaxis ☐ Call/see my doctor ☐ Call health information line ☐ Do nothing	≥1 = 2 / 2
Wrong conclusion/actions*	☐ This is anaphylaxis ☐ Administer epinephrine/use EpiPen ☐ Call 911	0 = 0 / 2
Total score (out of 2)	☐ 0 ☐ 2	

If the participant chooses a wrong action, mark the score then add the following comment:

“Although some symptoms may resemble an anaphylactic reaction, this is NOT an anaphylactic reaction. your child is likely suffering from the common cold! Did you recognize that this was not anaphylaxis?”

Scenario #4

You/your child is having an anaphylactic reaction. Please list the correct steps for using an EpiPen auto-injector?

	Steps	Score
Correct answer	☐ Hold firmly with orange tip pointing downward ☐ Remove blue safety cap ☐ Place the orange tip firmly into MID/OUTER thigh until you hear a "click" ☐ Hold on thigh for several seconds	☐ 0.5 ☐ 0.5 ☐ 0.5 ☐ 0.5
Total score (out of 2)	☐ 0 ☐ 0.5 ☐ 1 ☐ 1.5 ☐ 2	

Thank you for completing the comprehension survey!

Appendix D- Kids' CAP Script and Checklist

The purpose of this action plan is to:

1- Explain the features or symptoms of an allergic reaction.

Understanding these symptoms will make it easy for you and those around you (such as your parents and teacher) to recognize that you are experiencing an allergic reaction or anaphylaxis. Remember: anaphylaxis occur very quickly and can be very serious.

2- Explain the correct actions to take when you experience an allergic reaction.

Once you know you are experiencing an allergic reaction, the next step is to know what to do about it. This is the second goal of this plan.

3- Explain how to use your epi-pen.

Every person with potentially severe food or insect allergy should carry an epinephrine injection device (such as epi-pen).

Epinephrine is the only life-saving therapy for anaphylaxis.

Therefore, it is very important to know how to use your epi-pen correctly.

4- Explain how to prevent anaphylaxis.

The best treatment for anaphylaxis is to prevent it by avoiding the food that you are allergic to. This written plan explains the important steps that you can easily do to prevent anaphylaxis

Now, let me go over this plan with you in more details:

STEP #1: EXPLAIN THE SIGNS AND SYMPTOMS OF ANAPHYLAXIS

You are allergic to....(ex:peanut), which means that your body will show any of the following symptoms when you eat or get exposed to something that you are allergic to such as..(peanut butter or chocolate bar that has peanuts). The easy way to remember this is to think of your body from top (face) to down (stomach).

Skin and face	Breathing	Heart	Stomach
Diffuse Hives Diffuse Redness Swelling of the face Swelling of the lips Swelling of the tongue Swelling around the eyes	Difficulty breathing Wheezing Cough Throat swelling/tightness Chest pain/tightness Hoarse voice Blue discoloration of face Drooling with saliva Trouble swallowing	Feeling dizzy or lightheaded Pale Floppy (these signs indicate a drop in the blood pressure)	Vomiting Constant tommy pain Sudden behavioral changes in babies (excessive crying/fussiness)

STEP #2: EXPLAIN ACTIONS TO TAKE WHEN EXPERIENCING ANAPHYLAXIS

1- Give epinephrine **at the first sign** of an anaphylactic reaction. Epinephrine is the only life-saving therapy for anaphylaxis. **Do not** delay epinephrine injection to give Benadryl or other antihistamines.

2- Call 911 and tell them that you/your child is having a life-threatening allergic reaction

3- If the reaction continues or worsens, give a second dose of epinephrine in 5-15 min

4- Keep the child in a lying position unless he/she is vomiting or short of breath

STEP #3: EXPLAIN HOW TO USE EPI-PEN

EpiPen is the only epinephrine injection device that is currently available in Canada; we will now focus on learning how to actually use it. We will demonstrate the use of the EpiPen using a trainer device with no needle or medication.

 1 Blue to the sky. - Hold firmly with orange tip pointing downward. - Do not hold your thumb over the end - Remove blue safety cap by pulling straight up - Do not bend or twist - For young children, make sure to hold the child's leg steady before injecting	 2 Orange to the thigh. - Push orange tip firmly into mid-outer thigh until you hear a 'click'. - Hold on thigh for three seconds. - After injection, the orange cover automatically extends to ensure the needle is never exposed.
---	--

➤ **Now, I want you to show me how to use it by repeating those steps to me.**

Couple of things to remember about the epi-pen:

- Know how and when to use it. There is a mobile app (My EpiPen) that can also help you learn more about it
- Epinephrine is the only life-saving therapy for anaphylaxis. Make sure it always close at hand

Anaphylaxis Action Plan Script and Checklist

- Make sure your epi-pen is not expired
- Do not store your epi-pen in very hot or very cold place
- If you are a long distance from a hospital, have a back up epi-pen
- Please make sure you have an epi-pen with you before you go home today

STEP #4: EXPLAIN HOW TO PREVENT ANAPHYLAXIS

Use the section that is relevant to the patient. For example, If the patient has food allergy only, use the listed instructions under “Food”. Here is an example:

“You know that you are allergic to peanuts, here is what you need to avoid an allergic reaction to peanuts:

- Read food labels
- Avoid food that you are allergic to
- Bring your own food to school
- Don’t share food, plates, utensils, or placemats

CHECKLIST

Please initial all the check points that you have covered in teaching the action plan:

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Weight: ____ kg

CANADIAN ANAPHYLAXIS ACTION PLAN FOR KIDS

These are the signs and symptoms of an allergic reaction to: _____
(allergen)



Skin: Widespread hives, swelling, itching, warmth, redness



Breathing: Coughing, wheezing, shortness of breath, chest pain/tightness, throat tightness, hoarse voice, trouble swallowing

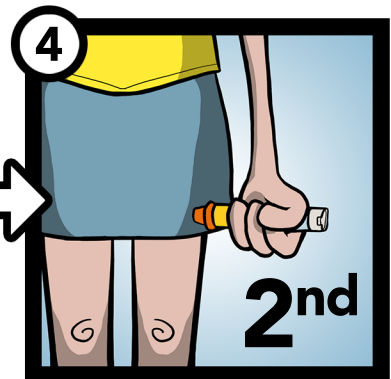
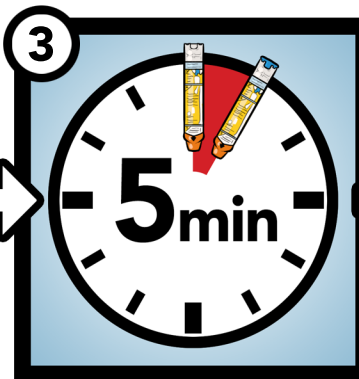
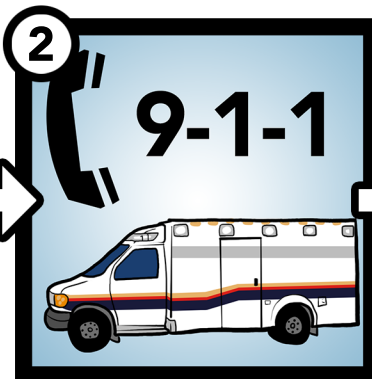
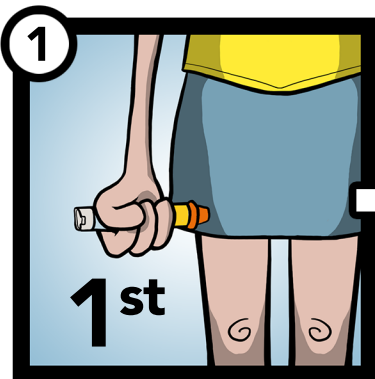


Heart: Pale or blue colour, weak pulse, dizzy or lightheaded



Stomach: Nausea, pain, cramps, vomiting

If you develop any symptoms:



- Give epinephrine at the **first** sign of an anaphylactic reaction.
- Call 9-1-1 or local emergency medical services. Tell them the child is having a severe allergic reaction.
- If the reaction continues or worsens, give a second dose of epinephrine in 5 to 10 minutes.
- Keep the child in a lying position unless the child is vomiting or short of breath.

[] Prescription for Medications:

Epinephrine **0.15 mg** autoinjector if between 15 and 30 kg:

Brand: [] Epipen [] Other: _____ Refill X ____

Epinephrine **0.3 mg** autoinjector if 30 kg or greater:

Brand: [] Epipen [] Other: _____ Refill X ____

[] Refer to an allergist:

Dr. _____

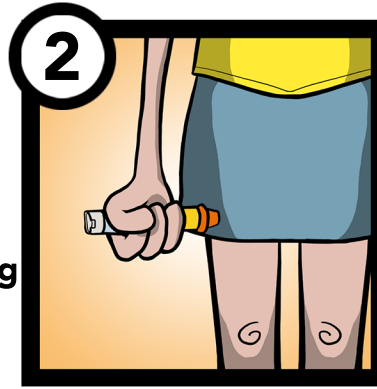
Physician: _____ (print name) License #: _____ Signature: _____ Date: _____ (dd/mm/yyyy)

How to use Auto-Injectors:



Blue to the Sky

- Hold firmly with orange tip pointing downward.
- Remove blue safety cap by pulling straight up. Do not bend or twist.



Orange to the Thigh

- Push the orange tip firmly into mid-outer thigh until you hear a "click."
- Hold on thigh for three seconds.

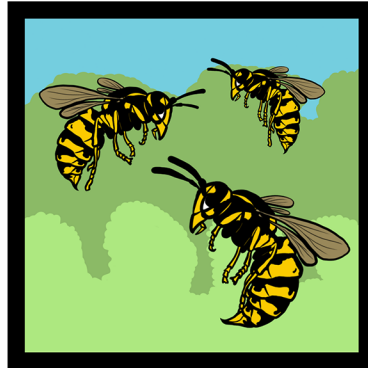
Note: If injecting in a young child, hold the child's leg and keep the leg steady while you inject

Avoiding Allergens:



Food:

- Read food labels
- Avoid foods you're allergic to
- Bring your own food to school
- Don't share food, plates, utensils or placemats



Insects:

- Wear long sleeves & pants
- Wear closed toe shoes
- Avoid drinking from straws, cans, or bottles outdoors
- Tie back long hair
- Stay away from garbage cans



Medication:

Tell your doctor, pharmacist, dentist and nurse about any medication allergies.

Preventing and Controlling Anaphylaxis

1. Avoid relevant allergens.
2. Know how and when to use your auto-injector.
3. Make sure the auto-injector is **always** close at hand.
4. Make sure your auto-injector is not expired. Do not store in very hot or very cold place.
5. If you are a long distance from a hospital, have a backup auto-injector.
6. Wear a medical identification bracelet that lists what you are allergic to.
7. For more information and support with food allergy, visit Food Allergy Canada website (<http://foodallergycanada.ca>)

Note: Children with uncontrolled asthma are at higher risk for severe anaphylaxis



CANADIAN ANAPHYLAXIS ACTION PLAN FOR KIDS

These are the signs and symptoms of an allergic reaction to: _____ (allergen)



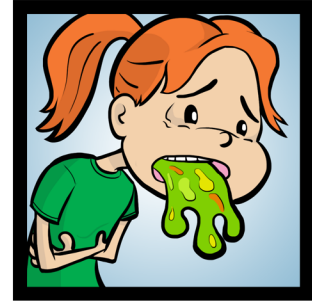
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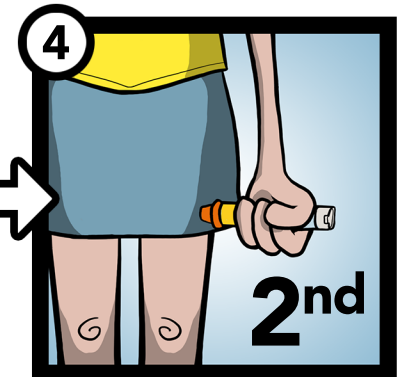
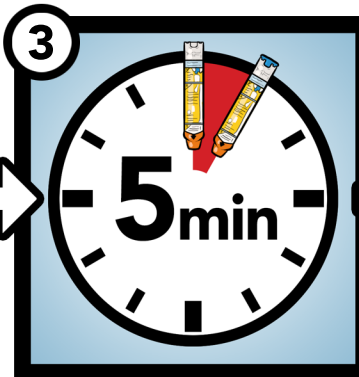
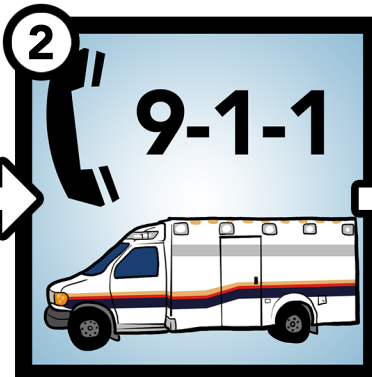
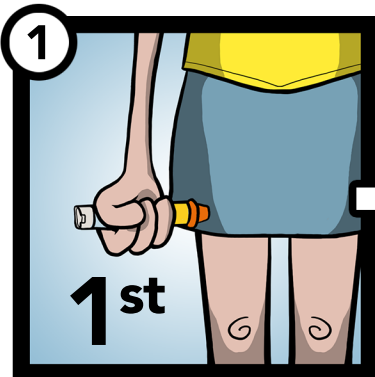


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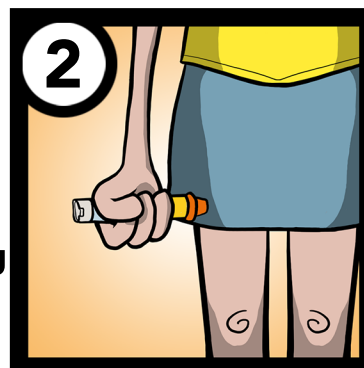
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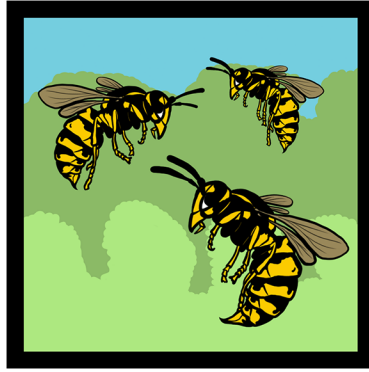
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