



An evaluation of a pictorial asthma medication plan for Pacific children

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Abstract

Background The burden of asthma falls disproportionately on children from New Zealand's Pacific communities. Guidelines recommend pictorial resources but these have not been evaluated in this population.

Aims Evaluate a *pictorial asthma medication plan* focusing on regular 'everyday' inhaler use and a *signs and symptoms sheet* for Pacific children; the primary outcome measure was continued use of resources after 6 months.

Methods Resources were provided to families with face-to-face education at a general practice or inpatient setting in West Auckland. A questionnaire about the resources was completed after 6 weeks, and an audit regarding use after 6 months.

Results Data from 48 children were analysed (Samoan, n=31); 45 English and 22 first language versions (Samoan, Tongan, Tuvaluan) were used; median time to questionnaire completion was 48 days. The *pictorial asthma medication plan* was acceptable to families, effective at reinforcing the importance of 'everyday' inhalers, and a reminder for regular use; the *signs and symptoms sheets* were informative and improved self-efficacy; 93% of families were using the resources after 6 months. An increase in 'everyday' inhaler use was observed after education.

Conclusion The resources were effective at improving inhaler knowledge and supporting symptom recognition. A 'less-is–more' approach, pictorial format, and first language availability are characteristics that may benefit other ethnicities.

Asthma has a considerable influence on the lives of many New Zealand children and their families. Uncontrolled disease can negatively impact day-to-day activities, such as school attendance and participation in sports, and may lead to acute attacks. These are not only frightening, but can also result in visits to general practice or accident and emergency facilities.¹

The burden of disease falls disproportionately on children from Pacific communities. Pacific children, along with Māori, have a higher asthma prevalence and their acute symptoms are often more severe when compared with other ethnicities.² They are also overrepresented in preventable asthma-related hospital admissions.³ This is a significant health inequity and an ongoing challenge for the health sector.

The exact reason for poor asthma outcomes in Pacific children is unclear. Evidence suggests that Pacific families lack an understanding about asthma medicines use and how to recognise the signs and symptoms of worsening asthma.⁴ These factors are likely to contribute to poor asthma management and symptom control and may be mitigated with appropriate education.³

For all ethnicities, asthma education has traditionally relied upon the use of written asthma action plans, despite there being limited evidence of their effectiveness.⁵ Utilisation rates of such plans may also be decreasing in New Zealand.⁶

Data about the use and utility of asthma education resources in Pacific children is lacking. The only published study that has evaluated asthma self-management plans in Pacific people was in a Tongan community-based programme.⁷ Although older children were enrolled in this study, the overall emphasis was on adults and no specific conclusions were made with respect to the child participants.

The Paediatric Society of New Zealand's childhood asthma guidelines has recommendations around providing asthma education to Pacific families. They stress the importance of educating about 'everyday' asthma inhaler use (e.g. 'preventers', 'controllers'), ensuring language is not a barrier, and suggest that 'action plans with pictures of medicines rather than words may help'.^{8,p41} No such asthma resource has been available to health workers in New Zealand. Furthermore, no studies have been published yet about the use of 'pictorial' asthma action plans in children - of any ethnicity. There is a single study that evaluated a pictorial asthma plan, but this was designed only for use in adults.⁹

Recently, the Pharmaceutical Management Agency (PHARMAC) launched *Space to Breathe*, an initiative that uses a personalised asthma action plan with images of the child's inhalers.¹⁰ However, it has not been formally evaluated, the resources are predominately textual, and are unavailable in the first language for Pacific families. The 'one-size-fits-all' approach of the written asthma action plans that are commonly available in New Zealand could be a potential barrier to effective asthma self-management support in the Pacific community.

We have developed <u>www.pamp.co.nz</u> a web-based tool that health professionals can use to produce personalised pictorial asthma resources in English and three Pacific languages. The focus of the *Pacific Asthma Medication Plan*, or *PAMP*, is on the child's 'everyday' inhalers. Pre-printed information sheets about the signs and symptoms of asthma are also available in the first language. These resources are laminated together with fridge magnets attached for families to take home.

The objective of this study was to evaluate: the utilisation and acceptability of the resources, the effectiveness of the *PAMP* to reinforce the importance of the 'everyday' inhalers and to act as a reminder to use them regularly, changes in 'everyday' inhaler use patterns, and the effectiveness of the *asthma signs and symptoms sheets* to inform and improve self-efficacy. The primary outcome variable was continued use of the resources after 6 months.

Methods

This was a quantitative, prospective study conducted at two sites from June 2009 to May 2010: West Fono Health Trust (a large Pacific Health primary care provider in West Auckland servicing 360 enrolled asthmatic children aged 2-16 years), and the Rangitira Unit, Waitakere Hospital (a 15-bed children's ward). Inclusion criteria were Pacific children aged 2-15 years prescribed 'preventer' or 'controller' asthma medications.

To generate a *PAMP* using the online tool, details were entered about the child (age, gender), prescribed asthma inhalers (one 'reliever' with variable fields for dose and frequency; up to two 'everyday' inhalers with variable fields for dose and a default frequency of twice a day), health professional (name, location, phone number), and expiry date of the plan. These were printed in colour

in the patient's choice of language/s (English, Samoan, Tongan or Tuvaluan), then laminated with a pre-printed *signs and symptoms sheet* (also in the chosen language/s) on the reverse, and fridge magnets attached (Figure 1).



Figure 1. PAMP (English and Samoan) and asthma signs and symptoms sheet

Participants were given the resources as part of the routine face-to-face asthma education provided during their visit; six weeks later they completed a structured questionnaire about the resources, either in person at West Fono Health Trust, or by phone. For the purposes of follow-up, patients visiting the Rangitira Unit were excluded if they were not enrolled at West Fono Health Trust. The dates of initial visit and follow-up, the family's ethnicity, and language versions of the resources provided were also recorded. Consultations were conducted in English by a registered health professional. The questionnaire answers were collated and statistical analysis carried out using SAS v9.1.3 software for Windows. An additional audit was conducted 6 months after study completion to see if the families were still using the resources.

Adult and child versions of the participant information sheet and consent form were pre-tested for comprehensibility using key informant interviews with six Pacific families; these were available in English only. These documents were tested at a focus group of West Fono Health Trust staff who also assisted with writing the asthma resources in the first language; the choice of languages was aligned with the demographics of the local population. Both groups provided feedback on the layout and design of the asthma resources. The clinical content was compiled by the Quality Use of Medicines Team at Waitemata District Health Board (DHB) and the asthma educators at West Fono Health Trust; this was endorsed by a consultant paediatrician, a paediatric clinical pharmacist, paediatric nursing staff, and Pacific Support Services at Waitakere Hospital.

Changes in 'everyday' inhaler use before and after receiving the asthma resources were investigated using repeated measure analysis to adjust for child to child variability; inhaler use was coded as: 'never' = 0; 'few times a week' = 3-5 (midpoint of 4 was used); 'most days' = 6-7 (midpoint of 6.5 was used).

The study had ethics approval from the Northern X Regional Ethics Committee, Auckland (NTX/08/09/088).

Results

None of the study participants were recruited at the Rangitira Unit during the 11month study period because there were no hospital admissions of West Fono Health Trust enrolled children who met the inclusion criteria. A total of 52 children were recruited, but four children were excluded (two were from non-Pacific families; two had incomplete consent forms); the remaining 48 participants completed the structured questionnaire. Along with parental consent, five older children also gave their assent to participate. The primary visit and follow-up was performed by either of two registered practice nurses who had completed an accredited asthma education course; one nurse enrolled 45 of the participants.

Table 1 describes the patient demographics and utilisation of resources. There were similar numbers of boys and girls, with an average age of 6 years. Samoan made up the largest specific ethnicity (n = 31) in the whole group. The median time to initial follow-up was 48 days. A total of 67 sets of asthma resources were given to 48 families (45 English and 22 first language versions).

Gender of children and age (median;	All participants (n=48)	6 years (2-14)	
range)	Female (n=23)	7 years (3-14)	
	Male (n=25)	6 years (2-13)	
Ethnicity; number of families	Samoan	31 4 4	
	Cook Island Maori		
	Niuean		
	Tongan	3	
	Fijian	2	
	Tuvaluan	2	
	Unspecified [†]	2	
Ethnicity; language version; no. of	Samoan	Samoan + English	16
families who received the resources		English only	13
		Samoan only	2
	Cook Island Maori	English only	4
	Niuean	English only	4
	Tongan	Tongan + English	2
		Tongan only	1
	Fijian	English only	2
	Tuvaluan	Tuvaluan + English	1
		English only	1
	Unspecified [†]	English only	2
No. of English + first language	67 versions to 48 families (English 45; first language 22)		
versions given to families			
Median time between first meeting	48 days (ra	ange 37-119)*	
and follow-up questionnaire			
+ Patients listed as 'Other Pacific'			

Table 1. Patient demographics, distribution and utilisation of resources

† Patients listed as 'Other Pacific'

* Includes five families that took longer than 60 days to follow-up

Table 2 details the questions and responses in the questionnaire. There were minor omissions in nine questionnaires; all available responses were included in the analysis. The questionnaires were completed by the child's parent or caregiver.

Table 2. Questions and responses from structured questionnaire

Questions†	Choices	No. of responses	% of responses
Q1. Are you still using the asthma	Yes, we are still using the plan	45/45#	100
medication plan?	No, we are not using the plan	0	0
Q2. Where did you keep the asthma medication plan that we gave you?	Fridge	45/47	96
	Bedroom	1/47	2
	Drawer	1/47	2
Q3. Have you ever been given another type of asthma medication plan, or asthma action plan before?	No, this is the first time (go to Q5)	39/45	87
	Yes, we have been given one before	6/45	13
Q4. How does the asthma medication plan we gave you compare to ones you've used	Better* (from Q3)	6/6	100
	Same*	0	0
before?	Worse*	0	0
Q5. About the number of words used on the	About right	46/47	98
asthma medication plan, which of the	Not enough words	1/47	2
following do you agree with?	Too many words	0	0
Q6. About the number of pictures used on	About right	46/47	98
the asthma medication plan, which of the	Too many pictures	1/47	2
following do you agree with?	Not enough pictures	0	0
Q7. After we gave you the asthma	Most days	32/47	68
medication plan, how often have you been	Few times a week	9/47	19
using your everyday asthma inhalers, e.g. the brown Beclazone inhaler?	Never	6/47	13
Q8. Before we gave you the asthma	Few times a week	23/47	49
medication plan, how often did you use your	Most days	15/47	32
everyday asthma inhalers, e.g. the brown Beclazone inhaler?	Never	9/47	19
Q9. Which of the following options best fits with this statement? "The pictures of the everyday inhalers in the asthma medication	Agree	47/48	98
	Disagree	1/48	2
plan were a reminder to use these inhalers."	Don't agree, don't disagree	0	0
Q10. Was the asthma medication plan used by other people, like family members, teachers, and other caregivers who help to care for you/your child?	No, the asthma medication plan wasn't used by other people	28/46	61
	Yes, some other people used the asthma medication plan	18/46	39
Q11. Which of the following options best	Agree	48/48	100
fits with this statement? "The information	Disagree	0	0
about the asthma warning signs informed us about what to watch out for."	Don't agree, don't disagree	0	0
Q12. Which of the following options best	Agree	48/48	100
fits with this statement? "The asthma medication plan informed us about how important it is to use the regular inhalers everyday."	Disagree	0	0
	Don't agree, don't disagree	0	0
Q13. Which of the following options best fits with this statement? "The written information we were given has made us feel more confident about how to look after the asthma."	Agree	48/48	100
	Disagree	0	0
	Don't agree, don't disagree	0	0
Q14. Which of the following statements do you agree with?	We like the asthma medication plan*	45/47	96

	We thought the asthma medication plan was OK*	2/47	4
	We didn't like the asthma medication plan*	0	0
Q15. Will you keep using the asthma medication plan?	Yes, we will keep using it	47/47	100
	No, we won't keep using it	0	0
Q16. Why won't you keep using the asthma medication plan?	n/a – no negative responses in Q15		

† The table contains all 16 questions used in the questionnaire

Responses were missing for some questions; total is less than number of participants in some instances

* Responses were associated with a modified Likert-type scale using pictorial faces

Questionnaire responses indicated that all complete respondents were still using the *PAMP* (45/45) at the 6-week follow-up, with the majority kept on the fridge (45/47), and that for most it was the first plan they had used (39/45). All six who had previously had an action plan reported that the *PAMP* was better. Further positive responses indicated from most respondents that the number of words and pictures in the *PAMP* were 'about right'.

Participants agreed that the *PAMP* reinforced the importance of using the regular inhalers everyday (48/48), the inhaler images in the *PAMP* acted as a reminder (47/48), the *asthma signs and symptoms sheets* were informative (48/48), and the resources helped to improve confidence (48/48). None of the families reported that they didn't like the *PAMP*, all intended to continue using it, and some (18/46) had shared it with other people, e.g. the extended family (Table 2).

Questions 7 and 8 asked families about how often they used the 'everyday' inhalers; 47 of the 48 families responded. A statistically significant difference (p=0.014) in the trend of inhaler use was observed, between before and after receiving the asthma resources, after adjusting for the subject effect. There was an increase in the proportion of children receiving these inhalers 'most days', from 15/47 (32%) at recruitment to 32/47 (68%) after they received the education and resources; a proportional increase of 36% (Table 2). Of the 47 children, 12 children used their 'everyday' inhalers 'most days' at the beginning and continued to do so.

For the remaining 35 children, their use can be described as follows: *unchanged*: never \rightarrow never (1), few times a week \rightarrow few times a week (5); *decreased*: few times a week \rightarrow never (2), most days \rightarrow never (3); *increased*: few times a week \rightarrow most days (16); never \rightarrow most days (4), never \rightarrow few times a week (4). Therefore, 24 of the 35 children (69%) increased the frequency of their 'everyday' inhaler use.

The majority of the *PAMPs* utilised Salamol[®] (a brand of salbutamol) and Flixotide[®] (fluticasone) and all were valid for a period of 6 months. The average reported time for staff to create each set of laminated resources was 10 minutes. An audit by West Fono Health Trust staff revealed that 6 months after the 6-week follow-up, 40/43 (93%) of families had the original asthma resources in their possession and were still referring to them.

Discussion

Our evaluation demonstrated that the two asthma resources were fit for purpose. The majority of families found the design and layout acceptable, and agreed that the resources reinforced the importance of 'everyday' inhaler use and helped to improve self-efficacy around symptom recognition. The resources were well utilised by families, both at the 6-week follow-up and 6-month audit. Although subjective, 45 out of 47 families said they 'liked the plan' – an important measure nonetheless.

The *Pacific Asthma Medication Plan*, or *PAMP*, appears to have been an effective reminder for families to use the 'everyday' inhalers on a regular basis. We observed a statistically significant change in inhaler use (p=0.014); the proportion of children using their inhalers 'most days' increased from 32% at baseline to 68% after they received the education and resources. However, the extent to which the *PAMP* contributed to these improvements, versus the effects from face-to-face education (and other factors) is unknown. This also applies to the absence of asthma-related hospital admissions observed in the children during the study, although fewer inpatient stays was the initial rationale for developing the *PAMP*. Of concern were the five families that reported reduced regular inhaler use; the reasons for this were not recorded and would require further qualitative investigation.

For the purposes of this study, we developed and evaluated a new asthma resource, which departs from the traditional step-wise, symptom or peak flow-based format. The intention was to use a 'less-is-more' approach, mindful that about 50% of New Zealand adults have low literacy levels,¹¹ and that patients generally prefer, simple, visual plans.¹²

We found there was demand for each of the first language versions; 67 plans in four languages (45 English and 22 in the first language) were given to 48 families. Just over a third shared their plans with the extended family; the availability of 'translated' versions may have facilitated this. Additionally, three families chose the first language version only, which we suggest is evidence that current asthma resources may not be meeting the needs of patients with adequate first language skills, but low English literacy. Finally, only 13% of study families reported having been given an asthma action plan previously, which is low relative to earlier reports.⁶

To our knowledge this is the first evaluation of a pictorial asthma plan designed especially for children - of any ethnicity. Roberts *et al*, a group of British researchers, have published a report detailing the development and comprehensibility of an electronic pictorial asthma action plan, but this was only evaluated in Somali and Malaysian adults.⁹ This group used 'guessability testing' to show the pictograms were understood, and 'translucency testing' to reveal agreement with the intended meaning of the images. In our study, the pictorial elements were images rather than pictograms and we used a less sophisticated, but more pragmatic study methodology.

The <u>www.pamp.co.nz</u> website is not the first 'electronic' asthma plan to be devised. The pictorial plan developed by Roberts *et al* required manual download of the programme onto practice computers;¹³ others have based their formats on Microsoft Access[®].¹⁴ In our case, we chose to construct a web-based tool (using Microsoft .NET[®] framework) so it could be easily accessed and shared with health professionals across New Zealand. There are a number of limitations regarding this study; the questionnaire was subjective in nature, the results were self-reported and subject to social desirability bias, and the study was confined to a single general practice. The 6-week follow-up period between visits may be perceived as too short, but we believe this was sufficient time for families to familiarise themselves with the resources. The strength of this research comes from the inclusive study methodology, focus on a targeted population, and the high level of consultation and engagement with the participant community and health workers. Despite the resources being tested solely in Pacific children, we believe the results are generalisable to other ethnicities; especially children or caregivers who may benefit from their simple and pictorial nature.

In our study we have described a successful nurse-led initiative in a single primary care practice. Further research could focus on the use and utility of the resources within other primary care settings (and secondary care), or by other professional groups. Roberts *et al* conducted a follow-up study to examine the applicability of their pictorial asthma tool in British general practices; they encountered barriers arising from time pressures, staff apathy and change avoidance.¹³ Even though the *PAMP* is simple and quick to personalise, print and laminate, similar issues could be expected here. Other priority research areas could focus on evaluating these resources specifically in tamariki Māori.

The study findings are significant in the context of Pacific Health because they describe and validate the useful textual and pictorial characteristics of asthma resources that may assist with providing asthma education to this population. This could be a step towards reducing the significant asthma-related health inequalities observed in Pacific children. However, asthmatic children from other ethnicities may also benefit from this educational approach. In fact, the *PAMP* website has already been re-branded as a paediatric *Pictorial Asthma Medication Plan* for use by all ethnicities, and is currently being promoted as such to New Zealand health professionals.

Competing interests: None known.

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