# An education intervention for childhood asthma by Aboriginal and Torres Strait Islander health workers: a randomised controlled trial

Patricia C Valery, Ian B Masters, Brett Taylor, Yancy Laifoo, Peter K O'Rourke and Anne B Chang

inority groups in developed countries, including Indigenous Australians,<sup>1-3</sup> have poorer asthma outcomes than the general population, with higher rates of emergency department visits and asthma-related deaths.1 Asthma education for patients, including information on medications and written plans for responding to changes in asthma symptoms, is essential for improving asthma outcomes.4-6 Child-specific asthma education can increase management skills, reduce symptoms, and improve school performance.<sup>7,8</sup> Specific education programs (eg, homebased, or culture-specific) are likely to be more effective then generic ones.9

While it is accepted worldwide that Indigenous health care workers (IHCWs) play an important role in educating Indigenous people about illnesses,<sup>9,10</sup> no controlled studies have examined the effect on health outcomes of interventions conducted by IHCWs. We have reported previously that children with asthma in the Torres Strait region of northern Australia have more severe disease than children in urban areas.<sup>11</sup> Building on our previous work in this community,<sup>11,12</sup> we conducted a randomised controlled trial of an education intervention by IHCWs for children with asthma.

## **METHODS**

Our study was conducted in conjunction with an Indigenous Paediatric Respiratory Outreach Program providing the only specialist paediatric respiratory care (specialist clinics) for children in the Torres Strait region. During 2005-2008, we trained 67 IHCWs, conducting seven 3-day asthma education workshops on Thursday Island. IHCWs also attended the specialist clinics where their asthma management knowledge and skills were reinforced by providing education to children and carers. We adapted existing paediatric asthma and respiratory education resources to the Torres Strait culture, introducing child-friendly and agespecific booklets.

#### Participants

Children (<18 years) were referred to the specialist clinics in a primary health care

## ABSTRACT

**Objective:** To assess the outcomes of an education intervention for childhood asthma conducted by Australian Indigenous health care workers (IHCWs).

**Design and setting:** Randomised controlled trial in a primary health care setting on Thursday Island and Horn Island, and in Bamaga, Torres Strait region of northern Australia, April 2005 to March 2007.

**Participants:** 88 children, aged 1–17 years, with asthma diagnosed by a respiratory physician (intervention group, 35; control group, 53; 98% Indigenous children).

**Interventions:** Children were randomly allocated to: (i) three additional asthma education sessions with a trained IHCW, or (ii) no additional asthma education. Both groups were re-assessed at 12 months.

**Main outcome measures:** Primary endpoint: number of unscheduled visits to hospital or a doctor caused by asthma exacerbation. Secondary outcomes: measures of quality of life (QoL) and functional severity index; asthma knowledge and understanding of asthma action plans (AAPs); and school days missed because of wheezing.

**Results:** The groups were comparable at baseline (except for asthma severity, which was adjusted for in the analysis). There were no significant differences in the primary outcome (number of unscheduled medical visits for asthma). School children in the intervention group missed fewer school days because of wheezing (100% < 7 days v 21% of those in the control group missed 7–14 days). Significantly more carers in the intervention group could answer questions about asthma medication, knew where their AAP was kept (84% v 56%), and were able to describe the plan (67% v 40%). In both the intervention and control groups (before-and-after comparison), there was a significantly reduced frequency of asthma exacerbations, as well as an improved QoL score and functional severity index, with no significant differences between the groups.

**Conclusions:** A community-based asthma education program conducted by trained IHCWs improves some important asthma outcomes in Indigenous children with asthma. **Trial registration:** Australian Clinical Trials Registry ACTRN012605000718640.

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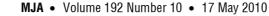
setting on Thursday Island and Horn Island, and in Bamaga, Torres Strait, Queensland, between April 2005 and March 2007, and reviewed by two paediatric respiratory physicians (ABC and IBM) using a standardised protocol for data collection. The children had a provisional diagnosis of asthma, or had been referred by IHCWs for assessment. None had previously been seen by the respiratory team.

Spirometry was performed in the standing position using a noseclip and a spirometer (calibrated daily) approved by the American Thoracic Society. Predicted values of Hibbert and colleagues were used.<sup>13</sup> Clinical asthma was defined as repeated episodes of wheeze with dyspnoea that responded to bron-chodilators. In children aged 3–6 years, two or more episodes of wheezy illness associ-

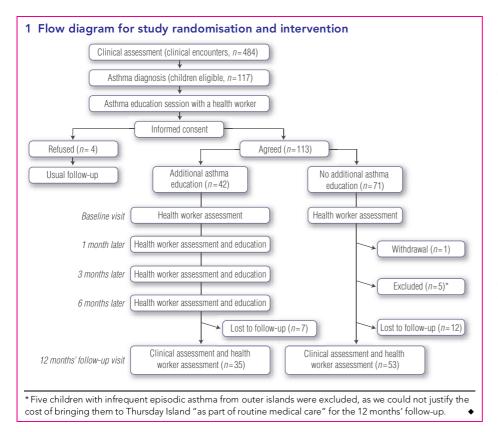
ated with cough and shortness of breath, and documented amelioration of symptoms and clinical signs after administration of a bronchodilator, supported a diagnosis of asthma.<sup>14</sup> Severity of asthma was classified as persistent, frequent episodic, or infrequent episodic, based on the clinical pattern in the past 12 months.<sup>14</sup>

#### Intervention

Before enrolment, all children had an asthma education session with a trained IHCW using the adapted asthma booklets. The intervention group had three additional education sessions with a trained IHCW at 1, 3 and 6 months after the baseline visit, using the same educational resources. Adherence to the study protocol (Box 1) was monitored by checking data collected dur-







ing these visits. Control group children were not visited by the IHCWs. At 12 months, all children completing the study had a followup clinical consultation.

# Outcomes

The primary endpoint was the number of unscheduled visits to hospital or a doctor because of asthma exacerbation in the 12 months' follow-up. Secondary analysis focused on measures of quality of life (QoL)<sup>15,16</sup> and the functional severity index for asthma;<sup>17</sup> asthma knowledge and use of asthma action plans (AAPs); and school days missed because of wheezing.

Data on all acute exacerbations of asthma requiring treatment in a health facility were collected from the child's medical records (at health clinics and Thursday Island Hospital) from 12 months before to 12 months after each child's baseline visit. Data for secondary outcomes were collected at the baseline visit and at the 12 months' follow-up, and also at each education session in the intervention group. Children and their carers were asked about the written AAP and what to do if asthma symptoms worsen. Carers of children taking regular medication were assessed for basic knowledge of asthma medications (eg, dosage, how the drugs work) and drug delivery technique.11 The

functional severity index,<sup>17</sup> a measure of functional impairment caused by asthma over a period of 12 months was scored (total score, 0–24; higher scores indicate worse impairment), and children and carers completed the Paediatric Asthma Quality of Life Questionnaire.<sup>15,16</sup>

#### Sample size

Sample size calculations were based on estimates of frequency of asthma exacerbations from our previous experience in this community and determined a priori. Assuming a study power of 90%,  $\alpha = 0.05$ , and using a Poisson process, the minimal study sample needed to detect a 33% reduction in unscheduled hospital or doctor visits (three versus two visits) was 54 children in each study arm. For secondary outcome measures (eg, QoL), with 30–40 children in each arm and  $\alpha = 0.05$ , the study has 90% power to detect a 20%–25% reduction in total mean score.

#### Randomisation

Consecutive patients with a confirmed asthma diagnosis were eligible for our study. At the clinic where eligibility was assessed, informed consent was obtained from parents or guardians, and children were randomly allocated to the intervention group (additional education sessions), or to the control group (no additional education sessions) (Box 1). A randomly generated list (using a computer-generated permuted block design) within age strata (< 7 and  $\geq$  7 years) was used for study allocation; allocation group was revealed after enrolment. Staff collecting data from the medical records during the follow-up did not know the children and were blinded to the study allocation; other clinical study staff and the children were aware of the study allocation.

As study enrolment was slower than anticipated, we modified the intervention allocation based on estimates of asthma prevalence<sup>12</sup> and guided by the sample size and power calculations. If a child was allocated to "additional education" but there was no trained IHCW in the child's community to administer the intervention, we changed the allocation to "no additional education" (n = 7). If "no additional education" was not possible, either because a sibling had been allocated to "additional education" (n = 8) or the IHCW at the community health centre was familiar with the intervention (n = 5), we changed allocation to "additional education".

## Statistical analysis

We used the Statistical Package for the Social Sciences (version 15.0; SPSS Inc, Chicago, Ill, USA). Baseline characteristics are presented as mean and SD (data normally distributed), median and range (data not normally distributed) and proportion. Where variables had more than two categories, crude significance levels were calculated ( $\chi^2$  test of the association). For other variables, logistic regression was used to adjust for potential confounders. Outcome data for each group were analysed "per protocol". The potential confounder (asthma severity at baseline) was incorporated into the multivariate analysis. We used general linear models for normally distributed data, non-parametric tests (Kruskal-Wallis test) for data not normally distributed, and logistic regression models.

As all children had a clinical consultation and an asthma education session at the baseline visit, we also evaluated the effect of this intervention on QoL scores, functional severity index, and asthma exacerbations, comparing outcome measures at baseline with those at 12 months, overall and in the intervention and control groups. Non-parametric tests (Wilcoxon signed rank test) were used.



To check whether bias was introduced by per-protocol analysis instead of intention-totreat analysis, we conducted multivariate analysis including the variables "treatment allocation as per protocol", "randomisation" (randomised v non-randomised), the interaction term "randomisation"\*"treatment allocation as per protocol", and "asthma severity at baseline", and for each outcome variable. As P>0.05 applied to the interaction term in all models run (ranging from 0.093 for carers' knowledge of asthma medication to 0.999 for carers' knowledge of how preventers and relievers work), we proceeded with per-protocol analysis without adjusting for randomisation. As siblings from the same families were included in the study (11 children), we repeated the analysis including one randomly chosen child from each family. The results of subgroup analysis were very similar to those of the whole sample, so we have only presented data for the whole cohort.

# Ethics approval and community consultation and feedback

We received support from the Torres Strait Regional Health Council and the Torres Strait and Northern Peninsula Area Health Service District. Ethics approval was given by the Queensland Institute of Medical Research Human Research Ethics Committee and the Children's Health Services District Ethics Committee. We provided study results to communities through written reports to councils, face-to-face presentations, and local radio interviews. A flyer with a summary of the findings in clear English and the key points in Torres Strait Creole was given to those who attended a community meeting in 2008.

# RESULTS

We enrolled 113 of 117 (97%) eligible children (aged 1–17 years) between April 2005 and March 2007, five were excluded for practical reasons (Box 1): 88 children (81%) with completed follow-up are included here; 35 in the additional education group and 53 in the control group; 98% were Indigenous children. Follow-up was completed by March 2008.

# **Baseline measures**

The intervention and control groups were comparable at baseline (Box 2 and Box 3) except for asthma severity, which appeared to be worse in the control group. There were

2	<b>Sociodemographic</b>	and baseline	characteristics k	oy intervention group*

Characteristics	Additional education (n = 35)	No additional education (n = 53)	Total (n = 88)	Ρ
Age, mean (SD) years	7.5 (4.4)	6.6 (3.8)	6.9 (4.0)	0.23
Sex				
Male	26 (74%)	35 (66%)	61 (69%)	
Female	9 (26%)	18 (34%)	27 (31%)	0.44
No. of siblings, mean (SD)	2.9 (1.8)	2.6 (1.7)	2.7 (1.7)	0.59
Exposure to smoking				
Cigarette exposure in house <sup>†</sup>	22 (63%)	34 (65%)	56 (64%)	0.86
No. of smokers in house, mean (SD)	1.6 (0.9)	1.4 (0.9)	1.5 (0.9)	0.09
Mother smoked during pregnancy <sup>‡</sup>	11 (41%)	15 (40%)	26 (40%)	0.87
Asthma profile <sup>14</sup>				
Infrequent episodic	22 (63%)	21 (40%)	43 (49%)	0.07 <sup>¶</sup>
Frequent episodic	7 (20%)	12 (23%)	19 (22%)	
Persistent	6 (17%)	20 (38%)	26 (30%)	
Functional severity index band <sup>†17</sup>				
Low to mild	17 (50%)	16 (30%)	33 (38%)	0.43
Moderate to severe	17 (50%)	37 (70%)	54 (62%)	
Pulmonary function, mean (SD) $^{\$}$				
FEV <sub>1</sub> (% predicted)	100.3 (15.7)	91.2 (18.4)	94.8 (17.8)	0.08
FIVC (% predicted)	108.0 (16.8)	94.1 (15.8)	99.7 (17.4)	< 0.01

 $FEV_1 =$  forced expiratory volume in the first second. FIVC = forced expiratory vital capacity. \* Values are expressed as number (%) except where otherwise indicated. Data missing for: †1; ‡23; §40 (four children  $\ge 6$  years and 36 < 6 years). ¶ Crude *P* value.

no significant differences between the intervention and control groups in ethnicity, or parents' highest level of education. One in 10 children possessed an AAP, two-thirds of the carers could not name their child's medication, half did not know the dosage, and most could not explain how asthma medications worked (Box 3).

No significant differences were observed between the groups in the number of unscheduled hospital and doctor visits caused by asthma exacerbation in the 12 months before the intervention (median [range], 1.0 [0–7] for both groups). The median (range) total score for the functional severity index was 8.5 (0–20) for the intervention group compared with 9.0 (0–24) for the control group (P = 0.01). However, there were no significant differences in baseline QoL scores between the intervention and control groups.

## Per-protocol analysis

The mean (SD) time between the baseline visit and the final consultation was 13.7 (3.15) months for the intervention group

and 14.8 (4.95) months for controls (P = 0.32). The intended number of encounters with study personnel was two visits for controls (baseline and 12 months' follow-up) and five for the intervention group (baseline, three extra education sessions, and 12 months' follow-up). The median (range) number of actual extra encounters was 2 (0–4) for the intervention group and 0 (0–2) for controls.

Half the children (52%) had no asthma episode that required a visit to hospital or a doctor in the follow-up period (Box 4). The median number (range) of unscheduled hospital or doctor visits was 1.0 (0–4) for the intervention group and 0 (0–4) for controls (P = 0.25). There were eight asthma-related hospital admissions (four in each group). The mean difference between the number of episodes of asthma for the intervention group (mean, 1.0) and controls (mean, 0.7) was 0.30 (95% CI, 0.22–0.39).

In the intervention group, compared with the control group, there was a significant improvement in asthma knowledge, and more carers knew where their child's



#### 3 Carers' knowledge of asthma at baseline\*

A sheer a los anda dasa	education	No additional education	Total	Р
Asthma knowledge	(n = 35)	(n = 53)	(n = 88)	Ρ
Medication name				
All known	11 (34%)	15 (34%)	26 (34%)	0.67
None or some known	21 (66%)	29 (66%)	50 (66%)	
Medication dosage $^{\dagger}$				
All known	17 (57%)	21 (50%)	38 (53%)	0.99
None or some known	13 (43%)	21 (50%)	34 (47%)	
How $\beta_2$ agonists work $^\dagger$				
All known	12 (37%)	10 (25%)	22 (31%)	0.84
None or some known	20 (63%)	30 (75%)	50 (69%)	
How preventers and re	lievers work <sup>:</sup>	ŧ		
All known	5 (19%)	3 (8%)	8 (13%)	0.32
None or some known	21 (81%)	34 (92%)	55 (87%)	
Spacer technique <sup>§</sup>				
Shakes canister, canister in spacer and correct breathing	7 (33%)	8 (22%)	15 (26%)	0.34
All or some of the technique inappropriate	14 (67%)	28 (78%)	42 (74%)	

\* 12 carers of children who had had no asthma medication in the previous 12 months were not assessed. Data missing for: †4; ‡13; § 19 (57 children used a spacer to deliver their asthma medication).

# 4 Number of visits to hospital or a doctor because of wheezing — 12 months before and after study entry

Visits to hospital or doctor	Additional education (n = 35)	No additional education (n = 53)	Total (n = 88)		
Visits, median (range)					
12 months before	1.0 (0–7)	1.0 (0–7)	1.0 (0–7)		
12 months after	1.0 (0–4)	0 (0–4)	0 (0–4)		
No. (%) of visits during the 12 months after study entry					
None	16 (46%)	30 (57%)	46 (52%)		
One visit	9(26%)	12 (23%)	21 (24%)		
Two	6 (17%)	9(17%)	15 (17%)		
Three or more	4 (11%)	2 (4%)	6 (7%)		

AAP was kept and were able to interpret it (Box 5); more intervention group carers could accurately recall their child's medication dosage (difference, 37%; 95% CI, 19%–54%), knew how  $\beta_2$  agonists worked (difference, 55%; 95% CI, 38%–72%), and knew how preventers and relievers worked (difference, 31%; 95% CI, 11%–51%). They also reported having used their AAP (difference, 32%; 95% CI, 4%–60%) and could describe it accurately (difference, 29%; 95% CI, 9%–49%).

Children in both groups reported missing school days because of wheezing in the previous year (difference, 4%; 95% CI, -25% to 33%); however, control group children missed more days than those in the intervention group (all school-aged children in the intervention group missed between 0 and 6 days, whereas 21% of those in the control group missed 7–14 days; difference, 21% (95% CI, 5%–36%). The median (range) total score for the functional severity index was 5.0 (0–22) for the intervention

# 5 Carers' knowledge of asthma and the asthma action plan (AAP) at 12 months' follow-up

Carers' knowledge	Additional education (n = 35)	No additional education (n = 53)	Total (n = 88)	Р		
Medication name*						
All known	19 (63%)	18 (37%)	37 (47%)	0.06		
None or some known	11 (37%)	31 (63%)	42 (53%)			
Medication dosage <sup>†</sup>						
All known	26 (87%)	23 (50%)	49 (65%)	< 0.01		
None or some known	4 (13%)	23 (50%)	27 (35%)			
How $\beta_2$ agonists work $\!\!\!\!^\ddagger$						
All known	19 (86%)	11 (31%)	30 (52%)	< 0.01		
None or some known	3 (14%)	25 (69%)	28 (48%)			
How preventers and relie	evers work <sup>§</sup>					
All known	16 (55%)	10 (24%)	26 (37%)	0.02		
None or some known	13 (45%)	32 (76%)	45 (63%)			
Spacer technique <sup>¶</sup>						
Shakes canister, canister in spacer and correct breathing	17 (74%)	15 (47%)	32 (58%)	0.07		
All or some of the technique inappropriate	6 (26%)	17 (53%)	23 (42%)			
Where do you keep your	AAP?**					
Knew where AAP was	26 (84%)	25 (56%)	51 (67%)	0.01		
AAP lost or could not recall where it was	5 (16%)	20 (44%)	25 (33%)			
Do you use your AAP?†						
Yes	24 (75%)	19 (43%)	43 (57%)	< 0.01		
No	8 (25%)	25 (57%)	33 (43%)			
Carer's description of AAP when child is well**						
Described properly	20 (67%)	17 (40%)	37 (51%)	0.01		
Not described properly	10 (33%)	26 (60%)	36 (49%)			
Carer's description of AAP when child is sick (wheezing) $^{\dagger\dagger}$						
Described properly	18 (62%)	13 (33%)	31 (45%)	0.01		
	11 (38%)	27 (67%)	38 (55%)			

group and 5.0 (0–20) for the control group (P = 0.65). The median (range) QoL scores for carers were 6.7 (1.9–7.0) for the intervention group and 6.8 (2.7–7.0) for the control group (P = 0.86); for children, QoL scores were 7.0 (2.5–7.0) and 6.9 (3.5–7.0), respectively (P = 0.57).

# Before-and-after comparison

Among the whole group, there was a decrease in the number of unscheduled hospital or doctor visits from the 12-month



period before (median [range], 1.0 [0–7]) to the 12-month period after study entry (median, 0.0 [0–4]; P = 0.038) (Box 4). Likewise, the median (range) functional severity index score for the total cohort was reduced from 9.0 (0–22) to 5.0 (0–24); (P < 0.01). The median (range) QoL scores for carers increased from 5.2 (1.9–7.0) to 6.8 (1.9–7.0); (P < 0.01), and the QoL scores for children increased slightly from 6.0 (2.6–7.0) to 6.9 (2.5–7.0); (P = 0.053). These results were similar when the intervention and control groups were analysed separately.

## DISCUSSION

Additional asthma education by IHCWs improved some, but not all, asthma outcomes in the children in our study. In the intervention group, there were fewer school days missed because of wheezing, and carers had significantly better knowledge of asthma medications and where their AAP was kept, and were better able to interpret it. There was no difference between the groups in the primary outcome (clinic presentations for acute wheeze). Longitudinal improvement in QoL score and functional severity index, and reductions in number of asthma exacerbations were seen in both groups in the before-and-after comparison.

Several studies have shown that asthma education improves asthma outcomes: selfmanagement education reduced hospitalisations, emergency room visits, days off work or school, and improved OoL scores.<sup>6</sup> A review of four studies examined the effect of culture-specific programs on asthma outcomes in ethnic minorities and found significantly improved QoL measures and asthma knowledge, as well as significantly reduced hospital or emergency department visits.<sup>9</sup> Our findings for improvement in asthma knowledge are consistent with this review, but in our study there was no change in clinic presentations. This may relate to sample size, or our inclusion of all grades of asthma; children with severe disease may have benefited more from asthma education provided by IHCWs.

To our knowledge, this is the only culture-specific study in an affluent country of an education intervention by IHCWs for Indigenous children. It provides a model for addressing the gap in health outcomes between Indigenous and non-Indigenous Australians. We have previously raised the issue of inequity in asthma management in children in the Torres Strait.<sup>11</sup>

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The before-and-after differences in QoL score, functional severity index and number of asthma exacerbations are consistent with findings from other studies evaluating asthma programs delivered in relevant dialects or using health workers with the same ethnic background as the patients.<sup>18-20</sup> The change in QoL score from 5.2 to 6.8 is clinically important (the minimum important difference for the questionnaire we used is 0.5) and  $\geq 1.5$  is classified as a large change.<sup>21</sup> The decrease in functional severity index was also a clinically important indication of a reduction in asthma severity.

Our response and follow-up rates were high, limiting the potential for selection bias. We took steps to reduce recall bias by using face-to-face interviews and a standardised protocol for data collection.<sup>11,15-17</sup> Our study had limited power to detect small differences between the groups with certainty; consequently, there may have been differences that the study did not detect, and we did not achieve our planned sample size despite the change in allocation. Moreover, the effect of random measurement error will tend to bias estimates towards the null, which should be borne in mind when interpreting weak and statistically non-significant associations. The open nature of our study was unavoidable and, although it is unlikely that the pattern of care delivered by local clinic staff changed, it is possible that families in the control group became aware of the intervention. Given the nature of the setting (small Indigenous communities), it would be inevitable that trained IHCWs would educate any family they had contact with (not just intervention group families), leading to "cross-group contamination". Also, all children had an "intervention" at baseline: the specialist assessment and an education session with a trained IHCW. This potentially diminished the impact of additional asthma education sessions by IHCWs. We suspect these factors also contributed to the differences in the before-and-after comparison being more marked than those between the intervention and control groups.

The non-significant unequal distribution in asthma severity between the intervention and control groups (Box 2) was a limitation. This was caused mostly by children from outer islands generally having more severe asthma. As we could not feasibly conduct the study in the outer islands, these children were re-allocated to the control group.

Acknowledging the study limitations, we conclude that delivery of a communitybased asthma program by trained IHCWs improves important asthma outcomes in Indigenous children with asthma. Our findings provide empirical support for the effectiveness of a culturally tailored asthma education program for Indigenous children.

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## **COMPETING INTERESTS**

None identified.

#### **AUTHOR DETAILS**

Patricia C Valery, MD, MPH, PhD, Senior Research Officer<sup>1</sup> Ian B Masters, MB BS, FRACP, PhD, Director and Respiratory Physician<sup>2</sup> Brett Taylor, MEd, GradDipExSpSc, BEd(Hons), Education and Training Manager<sup>3</sup> Yancy Laifoo, IndigCommMgntDev, Coordinator, Maternal and Child Health Program<sup>4</sup> Peter K O'Rourke, BSc(Hons), BA(Hons), PhD, Senior Biostatistician<sup>1</sup> Anne B Chang, FRACP, MPHTM, PhD, Professor and Head, Child Health Division, and Respiratory Physician<sup>5,6</sup>

- 1 Queensland Institute of Medical Research, and Australian Centre for International and Tropical Health, University of Queensland, Brisbane, QLD.
- 2 Department of Respiratory Medicine, Royal Children's Hospital, Brisbane, QLD.
- 3 The Asthma Foundation of Queensland, Brisbane, QLD.
- 4 Thursday Island Primary Health Care Centre, Thursday Island, QLD.
- 5 Menzies School of Health Research, Charles Darwin University, Darwin, NT.
- 6 Queensland Children's Respiratory Centre and Queensland Children's Medical Research Institute, Royal Children's Hospital, Brisbane, QLD.

Correspondence: Patricia.Valery@qimr.edu.au

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