

ORIGINAL ARTICLE

Asthma deaths in children in New South Wales 2004–2013: Could we have done more?

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Aims: The aim of this study was to characterise the deaths of children from asthma in New South Wales (NSW) over the last 10 years and ascertain whether there were modifiable factors that could have prevented the deaths.

Methods: The hospital medical records, coronial reports, immunisation records and all relevant correspondence from general practitioners, medical specialists and hospitals were reviewed for children who died with asthma in the 10 years (2004–2013).

Results: In 10 years, there were 20 deaths (0–7 per year) with a male predominance (70%) occurring in children aged 4–17 years. Sixteen (80%) had persistent asthma and 4 (20%) had intermittent asthma. The majority (55%) had been hospitalised for asthma in the preceding 12 months, 25% in the preceding 6 weeks. The majority (55%) was aged 10–14 years. Ninety percent were atopic. Psychosocial issues were identified in the majority (55%) of families. Forty percent had a child protection history. Seventy-five percent had consulted a general practitioner in the year before their death, 45% had a current written asthma action plan and 50% had not seen a paediatrician ever in relation to their asthma. Of the 16 children at school, the schools were aware of the asthma in 14 (88%) cases, but only half had copies of written asthma plans.

Conclusions: Improved communication and oversight between health-care providers, education and community protection agencies could reduce mortality from asthma in children.

Key words: asthma; children; death; prevention strategy; social disadvantage.

What is already known on this topic

- 1 Asthma affects 10% of children in Australia.
- 2 Asthma deaths in childhood, while uncommon, are higher in Australia than in other developed countries including Canada, France, Japan and Italy.
- 3 In New South Wales, there were recent spikes in asthma deaths in children in 2010 and 2012.

What this paper adds

- 1 Of children dying from asthma, 55% came from vulnerable families with documented psychosocial issues that were not adequately engaged with the medical profession.
- 2 Male children aged 10–14 years comprised the highest proportion of fatalities.
- 3 Clear deficiencies in communication about asthma treatment and clinical review continue between the hospital system and general practitioners, schools and the Department of Family and Community Services.

Australia has a high prevalence of asthma with over two million Australians having asthma, including around 1 in 10 children with a male predominance.^{1,2} Male and younger children are more likely to be hospitalised with asthma, and this has been consistent in New South Wales (NSW) over the last decade.³ In Australia, there has been a decline in deaths from asthma in the last 15 years, and a corresponding decrease in the prevalence of asthma in people aged 5–34 years.⁴ However, the Australian death rate from asthma is still high when compared with other developed countries such as Canada, France, Japan and Italy.^{1,5,6}

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An unexpected increase in childhood asthma deaths occurred in NSW in 2010 and 2012, which prompted a review of all asthma deaths over the last 10 years (2004–2013) by the NSW Child Death Review Team.

Methods

The NSW Child Death Review Team reviews all deaths of children in NSW under the auspices of the NSW Ombudsman. The hospital medical records, coronial reports, school correspondence, Family and Community Services (FACS) records, immunisation records and all relevant correspondence from general practitioners and medical specialists were reviewed. Ethics Committee approval for the review was not required under the legal powers of the NSW Ombudsman.

Results

Demographics

Between 2004 and 2013, 22 children had a death certificate listing asthma as the underlying cause of death. Two cases in children <2 years were reclassified as non-asthma deaths (aspiration pneumonia in a severely neuro-cognitively impaired child, and pneumonia). Twenty children (0–7 per year) died from asthma in NSW in the 10-year period (Fig. 1). Ninety percent ($n = 18$) had a diagnosis of asthma for at least 3 years. All had the diagnosis of asthma made before the age of 7 years. Eighty percent had persistent asthma ($n = 16$) and the remainder ($n = 4$) had intermittent asthma.

Eighteen patients (90%) were allergic, atopic or had multiple triggers for their asthma documented. Two-thirds of subjects had a positive family history of asthma or atopy in a first-degree relative, including one child whose sibling also died from

asthma. Three children had a history of anaphylaxis and had previously used or been prescribed an Epipen™. Seven children (35%) had a close relative/carer who smoked. One teenager who died from asthma was a regular cigarette smoker. There was no seasonal pattern in the deaths (Fig. 2). There was a male preponderance (70%) of deaths. Deaths occurred in children aged 4–17 years, yet more than half ($n = 11$) occurred in those aged 10–14 years (Table 1).

Psychosocial considerations

Psychosocial issues were identified for the families of 55% of the children: family breakdown, parent/carer substance abuse, domestic violence and neglect. Forty percent of children who died had a child protection history. In the 3 years before their death, five children (25%) had been the subject of a report of risk of harm/significant harm to the NSW Department of Family and Community Services. Three children (15%) had not been

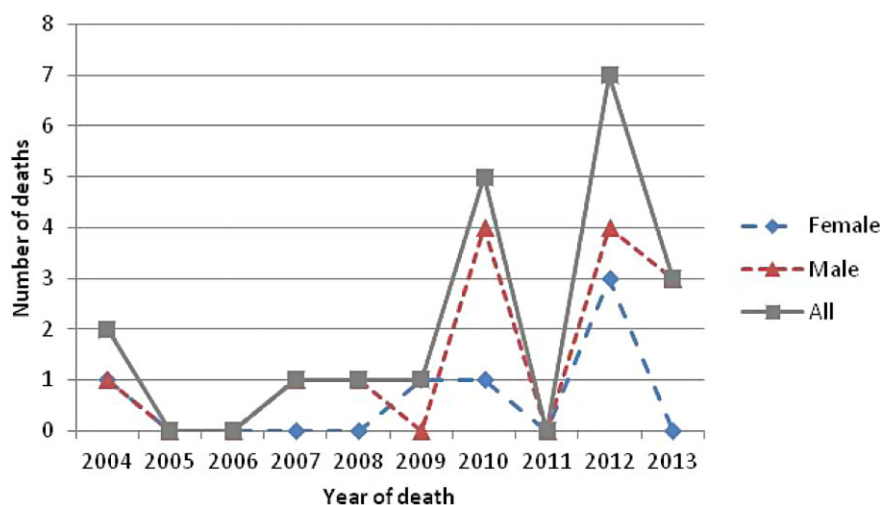


Fig. 1 Trends in deaths of children because of asthma by gender, 2004–2013.

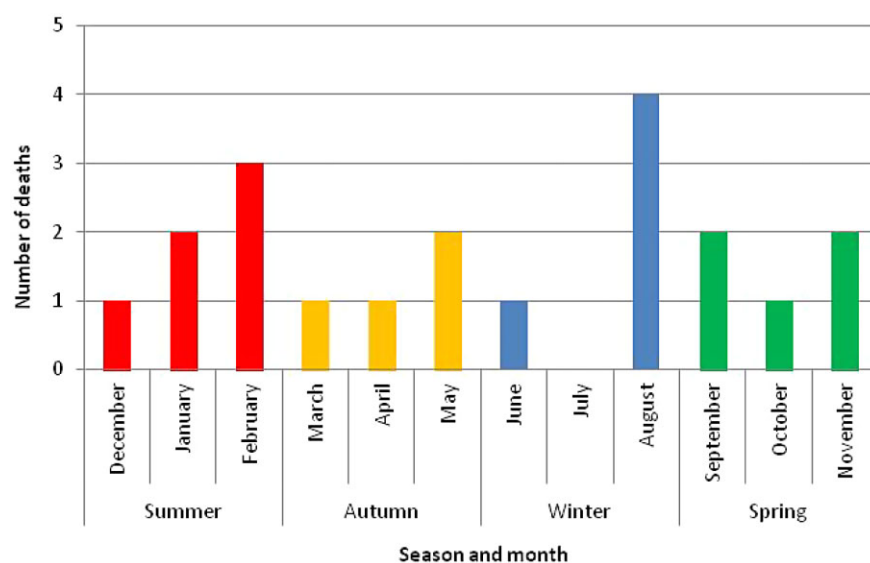


Fig. 2 Season and month of death.

Table 1 Age at death

	Number	Percentage	Crude mortality rate	95% confidence interval	Incident rate ratio	P
Total	20	100	1.2	0.73–1.85		
Gender						
Female	6	30	0.7	0.27–1.61		
Male	14	70	1.6	0.89–2.73	2.2	0.05
Age (years)						
Under 1	0	0	–	–		
1–4	1	5	–	–		
5–9	5	25	1.1	0.35–2.51		
10–14	11	55	2.5	1.23–4.41		
15–17	3	15	–	–		
Aboriginal and Torres Strait Islander status						
Not Aboriginal or Torres Strait Islander	19	95	1.2	1.49–3.86		
Aboriginal or Torres Strait Islander	1	5	–	–	–	–
Remoteness†						
Major cities	12	60	1.0	0.52–1.74		
Inner regional areas	4	20	1.2	0.33–3.09		
Outer regional areas	4	20	3.8	1.03–9.68		
Remote areas	0	0	–	–		
Very remote areas	0	0	–	–		
Socio-economic status†						
Quintile 5 (highest)	3	15	–	–		
Quintile 4	2	10	–	–		
Quintile 3	3	15	–	–		
Quintile 2	5	25	1.6	0.52–3.72		
Quintile 1 (lowest)	7	35	2.1	0.84–4.30		

†Estimated based on the child's postcode of usual residence.

the subject of a child protection report, but had a sibling who had been the subject of a child protection report. One child (5%) who had a child protection history was in out of home care at the time of death.

Of the teenagers who died, there were identified issues about mental health ($n = 3$), criminal behaviour ($n = 2$), poor/minimal attendance for schooling ($n = 2$) and substance abuse ($n = 1$). Four male children aged 11–16 years (20%) had diagnosed or suspected neuro-behavioural health concerns, which included respectively: attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder, anxiety and ADHD, depression and suicidal ideation.

Hospital presentations

Three-quarters of children had a hospital emergency presentation for asthma within 5 years of death. Most (11/15) had been admitted in the 12 months prior to their death. Four of the children (4/15) had required admission to an intensive care unit (ICU) in their last 5 years. One child had four admissions for asthma in the year before death, although most (8/11) had only one non-ICU admission for asthma in that time. Three of the children had been in hospital for asthma in the 6 weeks before their death. The majority of those admitted without going to ICU for asthma in the year before their death (8/11) did not have a clinical review arranged with any medical or nursing

professional after discharge from the Emergency Department or hospital ward. All of these children had a well-documented history of poor adherence with asthma preventative medications.

Immunisation profiles

Immunisation status was determined on 17 of the children. Sixteen children were up to date with the scheduled immunisation programme. Two children had been immunised against influenza, but not in the year prior to their death.

Medical review for asthma

Information on medical review was available for 19 of the children. All children had seen a general practitioner previously for asthma (Table 2). For all except one child (18/19) there was no evidence in the medical records of regular review of the patient for asthma treatment or assessment of the level of asthma control. Seven of 19 children (36%) did not appear to have a nominated consistent general practitioner, and others had been symptomatic using salbutamol as their only treatment, but had not seen a general practitioner for more than 2 years. The overwhelming majority (17/19) only appeared to see any general practitioner at times of crisis, rather than for a planned review. Fourteen of the children (74%) had consulted a general

Table 2 Frequency and nature of contact with general practitioners

	Length of time since last GP contact		
	Within 6 months	>6 to <12 months	>12 months
Number of children (N = 19)	11	4	4
Primary reason/s for last contact	Prescription – asthma medication (5) Asthma exacerbation (4) Review following hospital admission for asthma (2) Respiratory tract infection or cold symptoms (2) Allergy (1)	Asthma exacerbation (1) Asthma review (1) Review following hospital admission for asthma (1) Prescription – asthma medication /eczema (1)	Reason not recorded (2) Asthma exacerbation (1) Respiratory tract infection or cold symptoms (1)

GP, general practitioner.

Table 3 Frequency and nature of contact with specialists

Type of specialist	Number of children	Length of time since last contact (number of children)			Primary reason for last contact
		<6 months	>6 to <12 months	>12 months	
Paediatrician	6	0	2	4	Asthma review (5) Allergy/asthma/eczema review (1)
Allergist/immunologist	1	1	0	0	Allergy/asthma/eczema review (1)
Respiratory physician	2	0	0	2	Asthma (2)

Information only relates to the eight children (40%) who saw specialists in relation to their asthma.

practitioner about asthma in the year before their death. Eleven of 19 children (58%) had seen a medical specialist in relation to asthma, allergy or atopy at some time, but most (6/11) had not seen a specialist in the year before their death. Ten children (10/19) had not seen a specialist in relation to asthma ever (Table 3).

Thirteen children had a documented written asthma action plan. Nine children (45%) had a written asthma plan reviewed in the 12 months before their death. Six children had no evidence of an asthma plan ever being provided.

School awareness of asthma

The majority of children (16/20) were attending schools in NSW (one was living interstate, but of school age, one was aged 4 years and two teenagers living in NSW were not attending school). Thirteen attended public schools and three attended private schools. In most cases (14/16), the school was aware that the child had asthma. Written asthma plans were on the child's school record in half (7/14) of the cases where the school was aware that the child had asthma. In five of the fourteen cases (36%), the school was aware that the child had asthma, but did not have a written asthma management plan despite documentation of 'chronic asthma', acute treatment at school, school absences because of asthma, and another child repeatedly being sent home for medical review because of symptomatic asthma.

Asthma treatment

Seventeen of the 19 for whom asthma treatment was documented were prescribed preventative treatment with inhaled corticosteroids. In addition, the majority (15/19) of these children were prescribed long-acting beta-agonists. In the 3 months before the fatal asthma attack, five (5/17) had a documented change in their asthma medications with the introduction of a preventer (2/17) or a change in the preventer (3/17). It was not possible to ascertain the degree of adherence with prescribed medications.

In nine of 19 children (47%), the records from the fatal attack indicated that the parents/carers had not given the preventative medications as prescribed. Primarily, this involved the underuse/intermittent usage of preventative medications (8/9) and the regular (excessive) use of a reliever medication (1/9). Most of these children (8/9) were aged between 8 and 11 years and either had a child protection history and/or psychosocial factors within their family. Most (8/9) had also been admitted to a hospital with an exacerbation of asthma in the year before they died.

Fatal asthma attack

Most of the children (80%) were at home or at a relative's home with family when they were recognised to be symptomatic with asthma in their ultimately fatal attack. Three children (15%)

Table 4 Children by age group with the highest risk factors for a fatal asthma attack

Age group (years)	Suboptimal level of asthma control	Child protection history/psychosocial issues	Poor adherence medication or asthma plan	Hospital presentation/admission in last year	Inadequate follow-up after hospital visit	Exposure to tobacco smoke	No written asthma action plan	Total
10–14	√	√	√	√	√	√	√	7
15–17	√	√	√	√	√	–	√	6
10–14	√	√	√	√	√	√	–	6
10–14	√	√	√	√	√	√	–	6
15–17	√	√	√	√	–	√	–	5
10–14	√	√	√	√	√	–	–	5
10–14	√	√	√	√	√	–	–	5
4–9	√	–	√	√	√	–	–	4
4–9	√	–	√	√	√	–	–	4
10–14	Unclear	–	–	√	–	√	√	3
4–9	√	–	√	√	–	–	–	3
4–9	–	√	–	–	–	√	√	3
15–17	Unclear	√	√	–	–	–	–	2
10–14	–	√	–	–	–	–	√	2
10–14	√	–	–	–	–	√	–	2
10–14	√	–	–	–	–	–	√	2
4–9	Unclear	√	–	–	–	–	–	1
4–9	√	–	–	–	–	–	–	1
10–14	Unclear	Missing	Unclear	–	–	Missing	Missing	0
10–14	–	–	–	–	–	–	–	0
Total	13	11	11	11	8	7	6	–

were at other places when their fatal attack had begun, including at an after-school care programme, a showground and on a family holiday.

More than half (11/20) had a rapid onset of asthma symptoms, within hours of death. Half (10/20) were well in the weeks leading up to their death, engaged in their usual daily activities including attending school, playing sport and leisure pursuits. A smaller group (5/20) had a grumbling onset of symptoms prior to death, with documented sleep disruption and increasing use of bronchodilators in the days prior to death. Four of the five had been admitted to the hospital with asthma between 3 and 6 weeks prior to their deaths. In the remaining four children (4/20), it was unclear whether the onset of symptoms was rapid or slow. The majority of children (17/20) were transported to the hospital by ambulance, and three children were taken directly to the hospital by their parents. The average ambulance response time was 12 min. Most of the children (17/20) were neurologically non-responsive at the time of arrival in the Emergency Department. The profiles of children, by age group, with the highest risk factors for a fatal asthma attack are listed in Table 4.

Discussion

The present review demonstrated that 55% (11/20) children dying from asthma came from vulnerable families with known psychosocial issues who were not sufficiently engaged with the medical profession. The majority of these families (8/11) had been reported to the Department of Family and Community

Services within the 3 years before the child's death. The children and their parents/carers were often poor perceivers of symptoms and signs of asthma and the need for escalation in treatment. Young male children in the 10–14 years age group appeared the most vulnerable to a fatal asthma attack.

Most, but not all, asthma deaths should have been preventable. A recent analysis of predominantly adult asthma deaths in Australia between 2005 and 2009 suggested that 70% were preventable.⁶ Our data would support this view in the paediatric range for a similar period, 2004–2013. It has previously been suggested that some fatal asthma attacks are so rapid and probably not preventable while others are more gradual in onset and preventable.⁷ Their pathophysiology is thought to differ based upon the appearance of the airways: the former, thought to be triggered by infection and has airways clogged with thick mucus, while the latter, thought to be triggered by allergen and has dry airways suggestive of sudden airway closure by different, possibly neural mechanism.^{7,8} A previous report of deaths from asthma in adults and children from Michigan has suggested that the slower-onset type, with its inherent psychological, social and cultural factors, was more common.⁸ Recent findings by Goeman *et al.* from Australia on primarily adult asthma deaths found asthma deaths to be associated with health inequalities, drug and alcohol use, psychosocial issues, poor health literacy, and social isolation.⁶ The authors concluded that there was an urgent need to 'reach the unreachable'. This reiterates the findings of Robertson *et al.* from Victoria 25 years ago.⁹ From our data, it would seem that the problem remains unresolved in our universal health-care system today despite having

advanced electronic communications, better resourced Emergency Departments and the funding for asthma nurse educators in paediatric hospitals. Despite progress in the community's awareness of asthma,¹⁰ there remains a concern regarding the apparent inability of our medical system to adequately liaise with schools, the educational system policymakers and the Department of Family and Community Services.

Consistent with previous reports from Australia and overseas, recurring contributory factors in the deaths included sub-optimal asthma control, insufficient follow-up after recent hospital admission, poor adherence with written asthma management plans, inconsistent communication with schools regarding current asthma management, variable engagement by schools with school students identified with severe asthma, and a preponderance of children from families with lower socio-economic status and families notified to child protection agencies.^{6,8,9,11–13} From Table 3 it is evident that for the majority (13/19), there was scope to have improved the asthma care of the patients through regular review with general practitioners, general paediatricians or respiratory paediatricians. In relation to the fatal attack, there was evidence in approximately a third of cases (6/19) that the family members may not have recognised the early signs of the attack or may not have appreciated that their child's respiratory status was deteriorating.

While comparatively few in number, the deaths may represent the 'tip of the iceberg' in terms of severe or near fatal asthma attacks, for which there are no reliable statistics available in NSW. Each year in NSW, more than 6000 children aged 1–17 years are hospitalised with a diagnosis of asthma, which represents two-thirds of all asthma hospitalisations across the state.³ Adolescents have among the highest mortality rates for asthma,^{4,8,9} and the present study confirmed this for predominantly atopic teenagers rather than preschoolers. There was a disproportionate presence of family dysfunction (8/20 families notified within 3 years of death to FACS) and socio-economic disadvantage across the age range.

The control of asthma severity may be modified by better education, engagement with health-care professionals and adherence to preventative therapies,^{10,14,15} characteristics that appeared to be lacking in many of our cases. Reflecting poor parental compliance with giving therapy, Brand *et al.* demonstrated that poor adherence with inhaled medications was associated with greater symptoms and more frequent hospitalisation in children with asthma.¹⁶ Weinstein reported treatment adherence in 24 children with moderate to severe persistent asthma with diary cards and undisclosed electronic monitoring.¹⁷ The diary cards reported use of all doses of medication (twice daily inhaled steroids) on a median of 54% of days and at least one dose on 97% of days. In contrast, the figures revealed by the electronic monitoring were 5% and 58%, respectively. An English study where pharmacists were surveyed by telephone found that less than 50% of families filled prescriptions for preventative asthma medications.¹⁸ Thus, as exemplified in our subjects, what is prescribed is seldom taken as recommended. This is especially evident in male children aged 10–14 years who were potentially viewed as 'old enough' to take responsibility for their treatment. Importantly, targeted strategies for improving patient engagement and adherence with medication,

through better communication, is essential at all levels of health-care delivery.^{16,19,20}

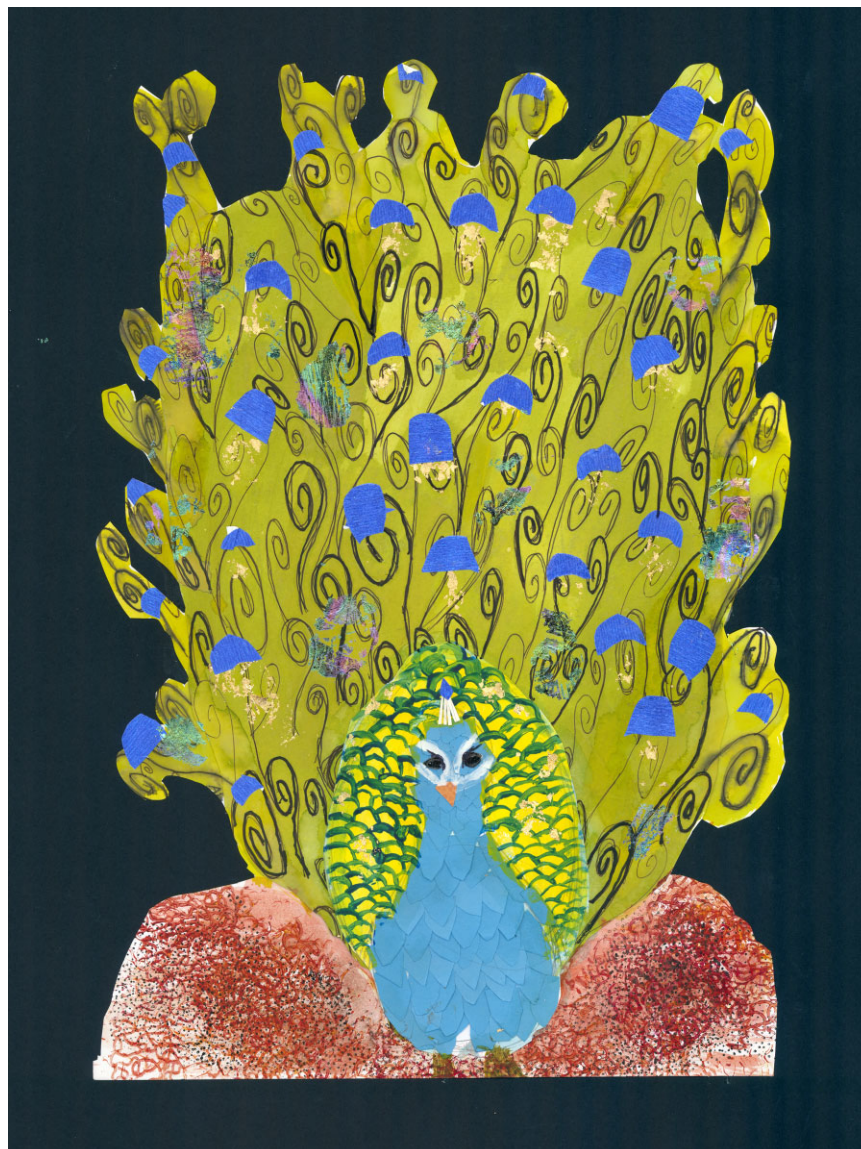
The limitations of our data included its retrospective nature and thus the reliance upon written communications in patients' records in both the hospital and community settings. Pharmaceutical records were not accessed to determine the number of prescriptions filled as a measure of treatment adherence. We surveyed only the last 10 years, but did demonstrate consistency in numbers of asthma deaths in the early years of the review (Fig. 1). Our total of 20 deaths was small, but the data included in the description of cases are unusually detailed and strengthens the study. It is also a testament to the utility of the NSW Child Death Review Team for the ability to identify remediable factors that may have contributed to child deaths in our community.

There are three potential areas of improvement in the coordination of asthma care for vulnerable children that emerge from this review. They relate to medical oversight of children with persistent asthma in the hospital and community setting, consistent approaches in schools for children identified as having asthma and better diligence in addressing asthma as a significant health problem in children notified to child protection agencies.

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