

## **Whose values? Implications of the use of proxies in the measurement of health outcomes for program improvement and evaluation**

### **Abstract**

The Asthma Friendly Schools (AFS) program was launched in 2000 to improve the quality of life, health outcomes and wellbeing of school children with asthma through the implementation of good practice guidelines. Funded by the Australian Government Department of Health and Ageing as a component of the Asthma Management Program addressing asthma as a national health priority, the AFS program is nationally coordinated by the Asthma Foundations of Australia. It is managed in each state and territory through the individual Asthma Foundations, with TNS Social Research conducting ongoing evaluation of the program. One aspect of this evaluation involved an individual health outcomes survey administered online to students who have asthma and parents of students who have asthma. While older students (14 to 18 years) were surveyed directly, for younger students parents were used as proxies to measure health outcomes and school experiences for their child. Data was compared from students with asthma and parents of students with asthma who responded to an online survey conducted in late 2007. The results reveal that while parents maybe good proxies for senior secondary school students with mild or moderate asthma, they significantly under estimated the impact of severe asthma on the child's school experience. The purpose of this paper is to explore the implication of proxy ratings for quality management and evaluation of health programs and interventions.

### **Introduction**

Around 2.2 million people are affected by asthma in Australia. While asthma affects both children and adults, rates of asthma are higher in children. With one in six school children reported to have asthma, it is not surprising that asthma impacts on learning outcomes. While asthma cannot be cured, it can be controlled.

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The AFS program involves the Asthma Foundations working with schools and education sectors across Australia and provides a health promotion framework for asthma management practices and the dissemination of asthma information. There are two distinct target groups in the program's outcomes hierarchy, school staff and the broader school community.

In terms of the school staff, AFS provides training to schools via a National Training Package using Foundation staff and "authorised representative" trainers, these generally being health professionals. The training covers asthma as a condition, the symptoms and triggers for asthma, recognising an asthma attack and asthma first aid (a national protocol signed off by the Thoracic Society of Australia and New Zealand). In addition schools address 8 essential criteria (one of which is training) to have elements in place to ensure they are able to confidently deal with an asthma incident for any school activity including off-site (camps and excursions).

The school community includes the provision of information to (potentially) 3.3 million students and their families. DVD teaching resources are provided for all school age levels with lesson plans available through the AFS website, ([www.asthmafriendlyschools.org.au](http://www.asthmafriendlyschools.org.au)). Schools are required to inform the Foundation on how they will integrate this into their curriculum (an essential criterion). The aim is for this to contribute to a better level of knowledge and understanding of asthma amongst the student population (and into their

adulthood). Parents/carers of students are targeted by providing regular information through schools' newsletters, including connectivity with the local Asthma Foundation.

The contract schedule between the Department of Health and Ageing and the Foundations outlines the scope of these initiatives for the identified targets groups. The TNS Final Evaluation Report for the previous funding period for AFS was a critical document in informing the new program design that has been developed through this funding period (Feb 06-June 09). It was decided in contract negotiations involving the National AFS Steering Committee, the Department and TNS (as the Evaluator) that the schedule would refer to 'health outcomes' that it was believed the program contributed to. Evaluating the effectiveness of the program in contributing to the stated health outcomes has presented some interesting evaluation issues and outcomes.

Using an action research approach, the evaluation of the AFS program has included a range of research methods reflecting the different stages of the implementation of the AFS program. This paper will specifically focus on the Individual Health Outcomes survey conducted online in late 2007 with 626 school children with asthma and 1322 parents of school children with asthma drawn from an online panel of around 500,000 Australians.

The initial findings of the research were that there parents were significantly more confident in a school's ability to manage an asthma emergency when the school was registered with the Asthma Friendly Schools program even if the parent was not aware of the registration. These parents were providing ratings for children for 4 to 18 years enroled in school who had experience asthma. For the purposes of this paper, parents data relating to their children aged 14 to 18 years was directly compared to an independent sample of children aged 14 to 18 years using the sample research tool with minor wording alterations to reflect the role of the rating agent.

## **Methodology**

The primary objective of the Individual Health Outcome survey was to identify differences in the students' experiences based on the level of involvement of their school with the AFS program. Three separate segments were important for the conduct of this analysis:

1. Schools recognised by the AFS program
2. Schools registered by the AFS program
3. Schools outside of the AFS program

In addition, the Individual Health Outcomes survey also provided an opportunity to determine the extent to which AFS program activities were received by students and parents and the extent to which this differed to students and parents involved with non AFS program schools.

### **Identifying the population of interest**

Conducting research directly with students and parents can be a difficult process. Access to parents and students may be made available with the permission of the school or through general population surveys. In this instance, it was determined to use the EmailCash™ panel<sup>1</sup> which included broad membership of the Australian population (14 years and over) where parent consent for participation in surveys for young people had already been obtained. In addition, the scope of this panel (approximately 500,000 Australians) provided sufficient scope to generate representative samples of the key segments of interest.

To select the parent and student respondents to be included in the Individual Health Outcomes survey, a poll of 70,000 panel members was conducted in November 2007. The poll asked key questions to

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<sup>1</sup> Emailcash™ is one of Australia's largest online panels. Additional information is about emailcash™ at <http://www.permissioncorp.com/>

determine that the respondent was a child, or a parent of a child, who attended school in 2007 and had asthma.

The parents' poll identified 13,643 adults who had a child at school in 2007. Of these respondents, 24% (or 3,289 people) had a child who had asthma. Where respondents had more than one child with asthma attending school, they were asked to answer with respect to the child who would next have a birthday. Seventy-two percent of these respondents identified that the child had experienced some symptoms of asthma (such as a wheeze or whistle when breathing, a cough, tightness in the chest or problems in breathing) over the last 12 months. Ninety-five percent of eligible respondents agreed to participate in a follow-up survey about their child's asthma.

The students' poll identified 5,275 young people aged between 14 and 19 years. Of these respondents, 40% (or 1,620 respondents) had asthma at some point. Sixty-nine percent of respondents identifying themselves as having asthma had symptoms (such as a wheeze or whistle when breathing, a cough, tightness in the chest or problems in breathing) in the last 12 months. Ninety-seven percent of eligible respondents enrolled in school in 2007 agreed to participate in a follow-up survey about their asthma.

The polls provided a sample of 4,544 (1,551 students and 2,993 parents) to be invited to participate in the full Individual Health Outcomes survey.

### **Individual Health Outcome questionnaire**

The Individual Health Outcomes questionnaire was developed in consultation with the Asthma Foundation. The parents' and students' questionnaires were design around a common framework to allow for comparison of results when reporting.

Core components of the questionnaires included:

- ▶ Asthma symptoms and medical care
- ▶ Asthma severity (based on experiences in the last four weeks)
- ▶ Time off school due to asthma
- ▶ Impact of asthma on the student
- ▶ Student's self management of asthma
- ▶ General sources of support (including awareness and use of the Asthma Foundation)
- ▶ School support for the student and parent
- ▶ Overall health of the student

Parents were asked some additional questions about their household and the information they received from the school about asthma. Parents were also examined on their confidence in the ability of the school to handle an asthma emergency in different school settings.

Students were asked some additional questions about their exposure to asthma in the curriculum and awareness of AFS posters in the school setting.

### **Fieldwork**

The 4544 respondents (1551 students and 2993 parents) identified through the poll were invited to undertake a further survey in December 2007. In total 1948 people participated in the full Individual Health Outcomes survey (626 students and 1322 parents). This equates to a response rate of 43% for eligible participants who had pre-consented to participate (40% for students and 44% for parents).

As parents could have been reporting findings for younger children, the parent and student samples were matched on age (14 to 18 year olds enrolled in school in 2007) for the purposes of this paper. This reduced the parent sample to 430.

## Definitions

Asthma - For the purposes of this paper asthma was defined as a wheeze when breathing, a cough, or tightness in the chest that made it hard to breathe as a result of asthma.

Asthma severity – the level of asthma experienced by a child was rated on a scale of severe moderate and mild using a composite score derived from the experience of asthma symptoms in the last four weeks.

## Child health

The sample was selected on students and parents of students who had *ever* had asthma. Of this groups 65% identified that the child has experienced asthma in the last 12 months. Parents were significantly more likely to identify the child had asthma than were students (69% compared to 62%).

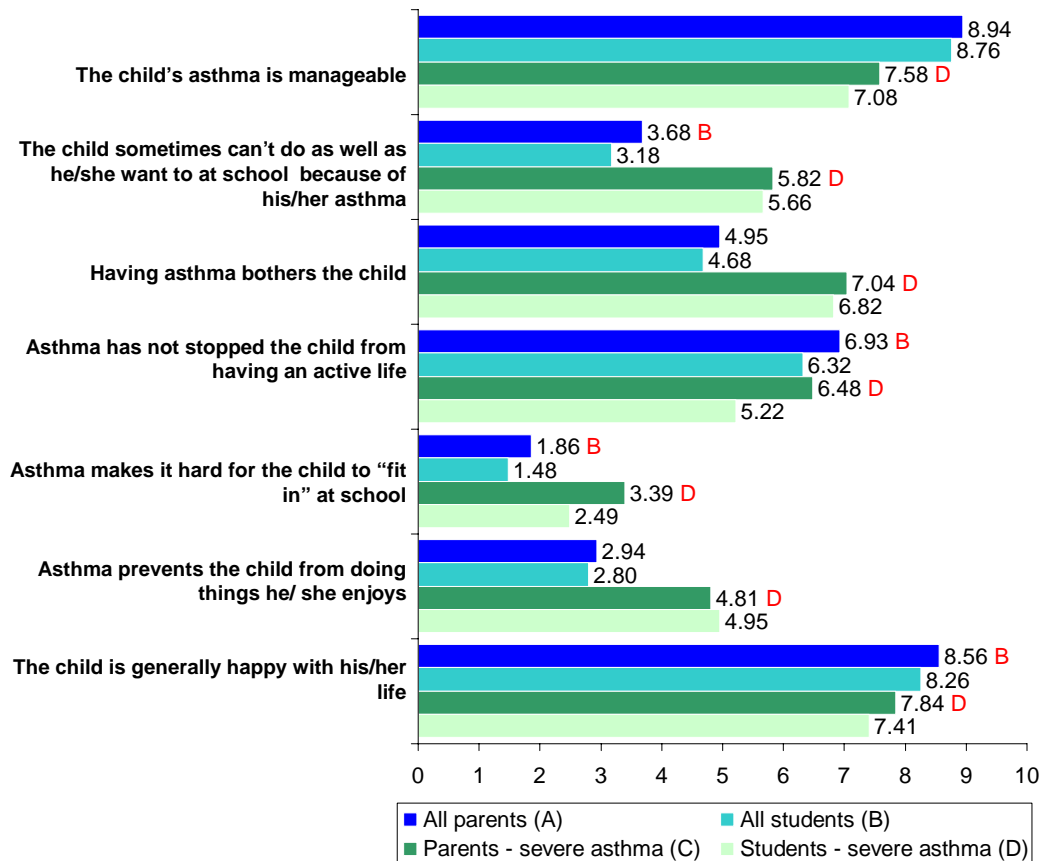
In most cases (90%) the respondent identified that a doctor had confirmed a diagnosis of asthma. Parents were significantly more likely to report a doctor’s diagnosis than were students (93% compared to 88%). Not surprisingly, a medical diagnosis was more likely where a child was considered to have severe asthma (parents 96% parents, 94% students).

Overall, 44% of respondents identified that the child has attended a doctor for asthma in 2007. Students were less likely to agree they had visited a doctor in 2007 for asthma than were parents (52% of students claimed no doctors visits compared to 34% of parents).

## Child well-being

Both parents and students were asked a series of questions related to the well-being of the child (Figure 1)

Figure 1: Well-being of child with asthma



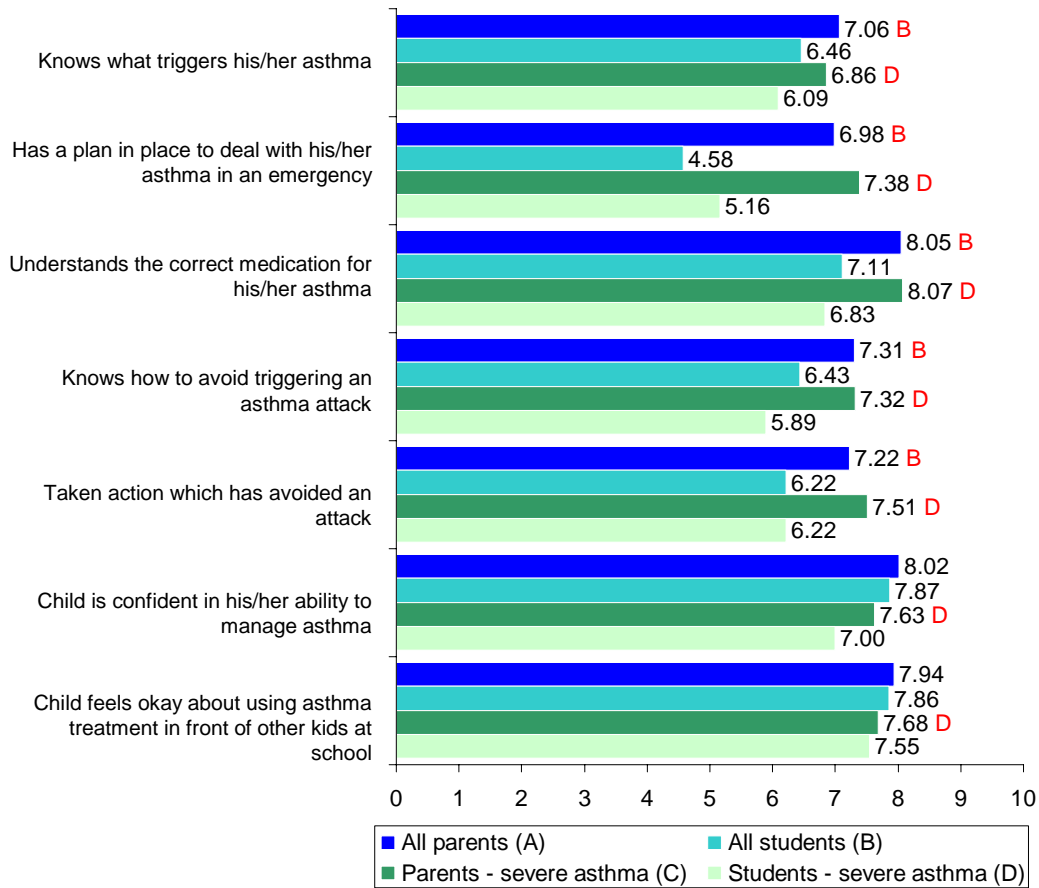
While there were some significant difference between the perspectives of parents and student these differences were exacerbated when looking at ratings related to children with severe asthma – parents underestimated the impact of severe asthma compared to the ratings provided by students.

Parents were more pessimistic than students in their ratings of the performance of children with severe asthma at school, being bothered by asthma and social adjustment at school. Parents were more positive than students about the capacity of children with severe asthma to self manage, participate in activities and the overall happiness of the child.

**Management of asthma**

Parents consistently provided higher ratings than students of the capacity of children with asthma to self manage in areas such as identifying asthma triggers, avoiding triggers and having taken action to avoid a trigger. Responses to questions related to confidence and use of medication with peers revealed significant differences between parent and student ratings in relation to children with severe asthma.

Figure 2: Child’s management of asthma



## **Conclusions**

The overall conclusion presented in this paper is that parents and students with asthma have significantly different views on many areas related to self management and child well-being.

Parents tend to offer higher ratings of the children's capacity to self manage and are more pessimistic about social adaptation and acceptance of the child than were students' when self rating. This disparity is increased for children with severe asthma.

Whenever possible, particularly for older students, the findings emphasises the need to engage the child directly in the research when looking for assessments of the impact of asthma on their overall well-being and Quality of Life.