**IDENTIFYING THE NEEDS OF PEOPLE WITH ASTHMA
IN NSW**

**QUANTITATIVE CONSUMER RESEARCH
FOR ASTHMA FOUNDATION NSW**

FINAL REPORT

28th December 2007

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CONTRIBUTORS

AUTHORS

Dr Helen Reddel, MB BS PhD FRACP
      Woolcock Institute of Medical Research

Dr Sinthia Bosnic-Anticevich, B.Pharm PhD
      Faculty of Pharmacy, University of Sydney

Dr Brett Toelle, DipAppSc (Nursing) BA (Psychology) PhD MAPS
      Woolcock Institute of Medical Research

Professor Christine Jenkins, MB BS MD FRACP
      Woolcock Institute of Medical Research

Professor Guy Marks, MB BS PhD FRACP
      Woolcock Institute of Medical Research and Australian Centre for Asthma Monitoring

OTHER CONTRIBUTORS TO THE PROJECT

Ms Patricia Correll, BN MPH GradDipApplEpi
      Australian Centre for Asthma Monitoring

Ms Rosario D Ampon, MAppStat
      Australian Centre for Asthma Monitoring

Dr Vicky Kritikos, BPharm MPharm PhD
      Faculty of Pharmacy, University of Sydney

Ms Sarah Newton-John, BA GradDipInfMgmt
      Woolcock Institute of Medical Research

Ms Biljana Cvetkovski, BPharm
      South Hurstville

ASTHMA FOUNDATION NSW

Ms Megan Dephoff, B Health Sci (Occupational Therapy)

Ms Jo Thomson, BA (Communications)

INTRODUCTION

This project was a collaboration between the Woolcock Institute of Medical Research, the Faculty of Pharmacy University of Sydney, and staff of the Australian Centre for Asthma Monitoring. It comprised a self-completed survey of adults with asthma and parents/carers of children aged 5-13 with asthma, in NSW, conducted under contract for Asthma Foundation NSW.

The primary objective of the study was:

> To provide quantitative information to Asthma Foundation NSW about the attitudes, behaviour and needs of a representative sample of people with asthma in NSW

Secondary objectives included identification of the needs of specific subgroups of asthmatics (age, location, health status, medication use etc) by analysing the associations between attitudes, behaviours and demographics.

Asthma Foundation NSW initiated this project in order to obtain data about the scope, magnitude and distribution of patients' attitudes, behaviours and needs in NSW, in order to facilitate the functions of Asthma Foundation NSW:

1. to appropriately represent people with asthma. By being aware of the current attitudes, behaviours and needs of people with asthma in general, and of specific subgroups, Asthma Foundation NSW will be able to act as an effective and capable consumer voice in consumer advocacy to government and peak bodies, and to the public;

2. to devise and direct relevant information, health-promotion programs and services to enable people with asthma, and specific sub-groups of that population, to effectively manage their condition throughout their lives

This report should be read in conjunction with the Project Brief (December 2006).

BACKGROUND

Meeting the information needs of people with asthma is critical if their asthma management issues are to be addressed and optimal asthma management practices are to be facilitated. The purposes of carrying out this research related to obtaining quantitative information for Asthma Foundation NSW, in order to ensure that information and services provided by the Foundation would be appropriate for its consumers.

The initiation of this project followed on from qualitative research with consumers and stakeholders which was commissioned by Asthma Foundation NSW, and carried out by Eureka Strategic Research in 2005. The results of the focus groups and interviews with consumers and stakeholders have been reported in detail elsewhere. The research identified some important areas of need for people with asthma in NSW. The present research was contracted to confirm and quantify the extent and distribution of those needs, in order to appropriately target its programs in the future.

Some of the data mentioned in the Project Brief were available from existing sources. For example, reliable data were already available for people with asthma about basic demographics, smoking rates, written action plan possession, self assessed health status and psychological distress, from representative surveys in NSW. These sources of data, such as

the NSW Department of Health Population Health Surveys, which were conducted using Computer-Assisted Telephone Interviews (CATI), are described in reports by the Australian Centre for Asthma Monitoring (http://www.asthmamonitoring.org/publications.htm). The present project offered the opportunity to provide further quantitative data that were not available from existing sources, particularly those relating to the attitudes, behaviours and needs of people with asthma which act as barriers to good asthma management.

METHODOLOGY

This quantitative study was carried out by questionnaire survey of people aged ≥14 years with asthma, and parents/carers of children aged 5-13 years with asthma, living in NSW. Ethics approval for the study was obtained from the University of Sydney. All participants provided informed consent; for adults, according to standard ethics guidelines, this consent was implied by the returning of a completed survey form. For children aged 14-16 years, the written consent of a parent/carer was required. A total of 424 adults and 39 parents/carers (67% of the total respondents) indicated that they wished to receive a copy of the survey results, and provided their names and addresses for this purpose.

Target population and recruitment strategy

The target population for this survey was English-speaking adults (or parents/carers of children) with doctor-diagnosed asthma, living in NSW. Because of the limited budget, it was not possible to obtain translations of the questionnaire into other languages; however, it was expected that the study population would still include many individuals from minority ethnic groups who could speak English sufficiently well to complete the survey.

The recruitment of a large number of people with asthma within a short time frame and limited budget was a challenge, so a variety of recruitment strategies were planned. Recruitment was initially based in community pharmacies. A random sample of 100 Quality Care Pharmacy Program (QCPP) accredited pharmacies in NSW was selected, using a computer-generated list of random numbers. In NSW, 1667 (95%) of the State's 1761 pharmacies currently hold QCPP accreditation (http://beta.guild.org.au/qcpp/stats_accredited.asp).

The owner of each randomly chosen pharmacy was contacted by telephone and invited to participate in the study by allowing recruitment of participants through the pharmacy. Those who agreed were faxed a letter including background to the purpose of the study, the duties of the pharmacists, benefits of this study to people with asthma and the community, and information about an incentive in the form of a gift voucher for respondents, which was to be spent in the pharmacy.

Pharmacists were asked to provide their consent by fax, together with an estimate of the number of people with asthma in their practice. They were then provided with further information and the study materials. Based on the known number of asthmatics, the pharmacist was asked to invite up to 30 people with asthma (or carers of children with asthma) to complete the questionnaire in the pharmacy or to provide their contact details.

In order to obtain a random sample of people with asthma, pharmacists were asked to approach every customer who visited the pharmacy for dispensing of an asthma inhaler (by prescription or over the counter) for themselves or their child (5 - 13 years). In order to identify suitable patients and to exclude COPD, the pharmacist was asked to establish whether the medication was to be used for asthma. Pharmacists were provided with several aides to

recruitment, including "shelf-talkers" and laminated cards. Pharmacists were asked to carry out recruitment activity both during normal working hours and during weekends/after hours, in order to reduce selection bias. Pharmacists were provided with a log sheet on which to record basic demographic details (gender, estimated age band) of customers with asthma who declined to participate in the survey.

Once a person agreed to participate, he/she was provided with an information sheet about the study, and was given the option of completing the questionnaire immediately in the pharmacy, or completing it at home. The questionnaires were returned by the pharmacists in reply-paid envelopes. Only 3 respondents took up the offer to complete the survey by telephone. For respondents who provided their contact details on the information sheet, but did not return the completed questionnaire, follow-up was by the pharmacist and/or study staff. Following return of a completed questionnaire, participants were provided by the pharmacist with a gift voucher which could be spent in the pharmacy; this provided a small incentive for both participants and pharmacists. Pharmacists were reimbursed for the value of the vouchers following study completion.

For children 5-13 years, parents were asked to complete the questionnaire about their child's asthma, with input from the child if appropriate. Questions about attitudes were asked relative to the parent/carer himself or herself, rather than the child.

During the development and conduct of the study, Asthma Foundation NSW was kept informed of progress with regular meetings and monthly emails. When it emerged that recruitment through pharmacies would be too slow to achieve the desired study timelines, a decision was made in June 2007, in consultation with staff of Asthma Foundation NSW, to expand recruitment to include people with asthma on the Volunteer Database held by the Woolcock Institute of Medical Research and on several databases held by Asthma Foundation NSW. The Woolcock volunteers with asthma were provided with the questionnaire and a reply-paid envelope by mail, and people from the Asthma Foundation NSW databases, depending on the contact details which were available, were provided with the questionnaire(s) and a reply-paid envelope by mail, or with a secure link to the questionnaires by email, with return either by email or to a reply-paid address. All questionnaire responses will be provided to Asthma Foundation NSW in a de-identified form.

Sample Size

The sample size calculation was based on the initial plan to recruit all participants via community pharmacies. Hence, the calculation was based on a cluster design, with pharmacists being the unit of cluster. The target was 1200 completed questionnaires, from 100 pharmacies. In recent years, response rates for Australian surveys have been low compared with studies from 20-30 years ago, and compared with current surveys from other countries. NSW Department of Health CATI surveys (Computer-Assisted Telephone Interview) now achieve response rates around 60% (Source: Margo Eyeson-Annan, NSW Health). Recent Australian postal surveys have achieved a response rate of only 30-40%. It was expected that the response rate would be higher in a study in which participants were contacted personally by their pharmacists, than if a survey document was sent in the mail without personal contact. The recruitment strategies were based on the assumption that approximately 30 people with asthma would need to be approached in each pharmacy in order to obtain 12 completed questionnaires, based on an expected overall response rate of 40%.

The sample size calculation was based on the factors of interest to Asthma Foundation NSW (see Project Brief) and an expected intra-pharmacy (intra-class) correlation coefficient of ≤0.02, which would give a design effect of 1.2. Based on data from the National Health

Survey, for factors with an expected prevalence in patients with doctor-diagnosed asthma of 30%, such as poor self-reported health, the 95% confidence interval (indicating the precision of the measurement) was expected to be ± 2.8%. For factors with an expected prevalence of 10%, the 95% confidence interval was expected to be ± 1.9%. These are regarded as satisfactory levels of precision. For factors with low (e.g. 5%) prevalence, the precision would be ± 1.3%, which indicates considerable uncertainty relative to the actual prevalence. Very large sample sizes, with many thousands of subjects, would be required to improve the precision for such factors.

Questionnaires

The design of the study questionnaire was crucial in order both to fulfil the study purposes and to ensure an adequate response rate and hence a representative sample. Based on previous research conducted by the Epidemiology Group at the Woolcock and by the Faculty of Pharmacy, the questionnaire needed to take no more than 20 minutes to complete, in order to avoid reducing the response rate.

In order to ensure that the questionnaire met the needs of Asthma Foundation NSW, the investigators met on several occasions with staff from the Foundation, to prioritise the questionnaire content. A low priority was assigned to questions about factors which had a very low expected prevalence based on National Health Survey data, because of the relatively poor precision for such estimates without very large sample sizes. A low priority was also given to factors for which there were existing data from other sources.

In order to facilitate interpretation, the questionnaire consisted primarily of multiple-choice questions and simple scales. For the parent/carer questionnaire, the wording was modified, as appropriate, to refer to "my child's asthma" or "him/her". Where possible, the questionnaire used existing validated questions, for example, the 6 item Asthma Control Questionnaire [1]. The developed questionnaire was pilot tested prior to finalisation and administration.

Demographics relating to the locality, Pharmacy Access/Remoteness Index of Australia (PhARIA) and size of each participating pharmacy were collected in order to assess the representativeness of the sample of pharmacies.

Copies of the final questionnaires for adults with asthma and for parents/carers of children with asthma aged 5-13 years are found in Appendices 1 and 2.

DATA ANALYSIS

Data were entered into Excel, according to the codes printed on the original questionnaires. Routine checks were performed for data quality and to clarify inconsistencies. Approximately 10% of questionnaires were double entered to check for problem areas. The data set was imported from an Excel worksheet to a SAS data set for analysis. ASGC remoteness category and SEIFA index of disadvantage were mapped using standard calculations based on postal codes.

Means and proportions of the variables in the NSW Asthma Survey were estimated using the procedure SURVEYMEANS in SAS v9.1 (Ref: SAS Institute, Inc., 2003). This procedure uses the Taylor expansion method to estimate the sampling errors of the variables of a survey with a complex design. This particular survey has a stratified, clustered design, with the sources (Woolcock, Asthma Foundation NSW and Pharmacy) the 3 strata and the different pharmacy representing the clusters. This information was included in the codes to invoke the procedure. Data from the three sources were examined to identify areas in which there were important differences in responses, but for most responses, it was appropriate to report data

from all sources combined. Predictors of poor asthma control and urgent health care utilisation were examined using multiple logistic regression, with ACQ ≥1.5 and any urgent health care utilisation (urgent doctor visit, Emergency Department visit or hospitalisation) due to asthma in the previous 12 months used in turn as the dependent variables. Data were adjusted for source.

TIMELINE

Contract signed	Dec 2006
Ethics application submission and approval	Jan – Apr 2007
Data collection	Apr – Sep 2007
Data entry	Aug – Sep 2007
Data analysis	Sep – Oct 2007
Interim report	Oct 2007
Final report	Dec 2007

RESULTS

RECRUITMENT AND RESPONSE RATE

Recruitment through pharmacies occurred between April and July 2007, and through the Woolcock and Asthma Foundation NSW databases from July 2007 and August 2007 respectively. Questionnaires were received from May 2007 until the database was closed at the end of September 2007. A total of 728 survey forms were received, 646 from adults, and 82 from parents/carers of children aged 5-13 years. A graph of progress with recruitment is included in Appendix 3.

The distribution of respondents between the three sources (Pharmacies, Woolcock and Asthma Foundation NSW [AFNSW]) is shown in Figure 1.
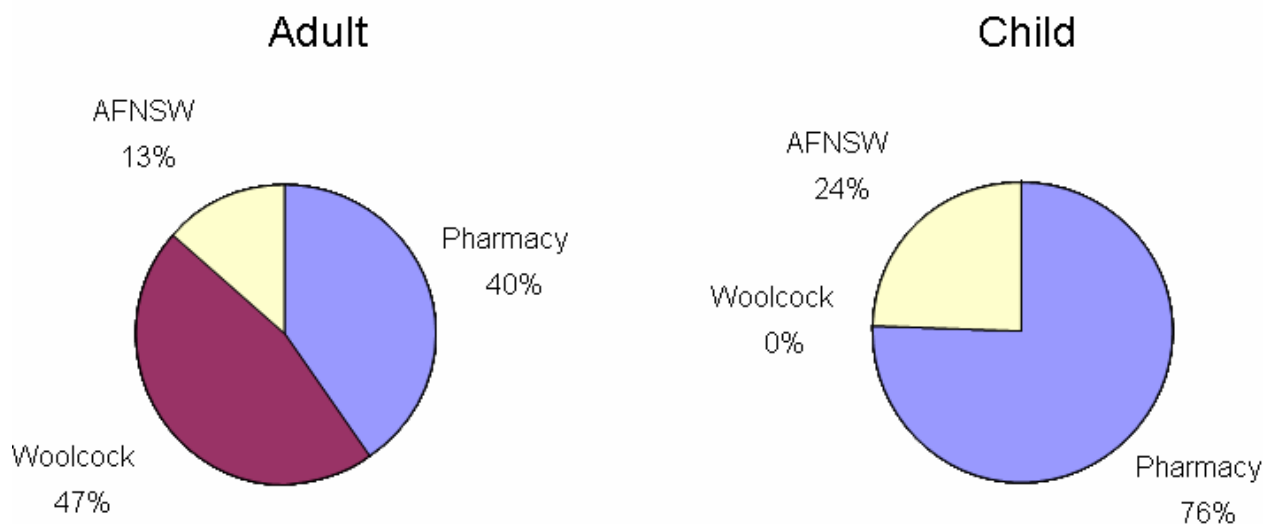
Figure 1. Distribution of respondents between sources

Response rate for pharmacies

From a list of the 1666 QCCP pharmacies in NSW, pharmacists were contacted in random order, based on a computer-generated random list. In total, 307 pharmacies were contacted, 186 (60%) agreed to participate in the study, and 84 (27%) returned their consent forms and were enrolled in the study. A total of 54 pharmacies (18% of those originally contacted, hereafter called "participating pharmacies") returned questionnaires from their customers.

The pharmacies provided participants from a broad range of socio-economic settings, and about one third of pharmacies were located outside major cities (Table 1).

Table 1. Location of Pharmacies by Socio-Economic Category and Remoteness

	Agreed (n=186)	Enrolled (n=84)	Participated (n=54)
Socio-Economic Indices For Area (SEIFA), n (%)			
SEIFA 1 (most disadvantaged)	45 (24%)	20 (24%)	12 (23%)
SEIFA 2	39 (21%)	22 (26%)	16 (30%)
SEIFA 3	37 (20%)	16 (19%)	10 (19%)
SEIFA 4	23 (12%)	10 (12%)	9 (17%)
SEIFA 5 (least disadvantaged)	42 (23%)	16 (19%)	6 (11%)
Australian Standard Geographical Classification (ASGC), n (%)			
Major cities	132 (71%)	59 (70%)	35 (66%)
Inner regional	43 (23%)	17 (20%)	13 (25%)
Outer regional	11 (6%)	8 (10%)	5 (9%)

Response rates for participants

A total of 728 questionnaires were received, 646 from adults (yrs 14+) and 82 from parents or carers of children aged 5-13 with asthma.

1. Pharmacies

The 54 participating pharmacies returned a total of 322 questionnaires (median 5, range 1-15) from their customers. The response rate from pharmacies was not able to be calculated, as only 5 pharmacists returned their "Non-responder logs" (these containing a total of 24 names), so it is not known how many pharmacy customers were approached to complete the survey. However, the true response rate would have fallen between 16% (based on the number of questionnaires posted to pharmacies [n=1998] and the number of completed questionnaires received [n=322]), and 92% (based on the number of questionnaires returned [n=322] and the number of additional consents received for pharmacy customers who did not subsequently return a completed questionnaire [n=28]).

2. Woolcock Volunteer Database

Questionnaires were mailed to volunteers on the Woolcock database who had a diagnosis of asthma (n=697). A total of 299 questionnaires were returned, giving a response rate of 43%.

3. Asthma Foundation NSW Databases

Asthma Foundation NSW contacted 918 persons on their databases. These contacts were sent questionnaires (or links) as shown in Table 2.

Table 2. Asthma Foundation NSW database response rates

Group	Sent (adult)	Returned (adult)	Sent (child)	Returned (child)	Response rate
Adult Infoline	190	50			26%
Child Infoline			94	17	18%
Mail registration	92	12	92*	2	15%
Email	550	13	550*	1	2.5%
Returns from unknown database		12			
Total	832	87	736	20	11.5%

*These contacts were sent both the adult and the child questionnaire

STUDY POPULATION

The study population for all subsequent analyses was defined as those respondents who had been given a diagnosis of asthma by a doctor or nurse, using standardised wording recommended by the Australian Centre for Asthma Monitoring [2] (Table 3). Overall, 689 respondents answered "Yes" to this question (608 adults, 81 parents/carers of children with asthma).

The majority of these respondents were classified as having "Current asthma", i.e. they had experienced symptoms or taken treatment for asthma in the last 12 months. Such people (together with their relatives/friends) comprise the primary target population for activities of Asthma Foundation NSW. In random population surveys [3] only about 50% of respondents with a diagnosis of asthma have current asthma, using the same definition.

Table 3. Diagnosed asthma and current asthma

Question		Adult	Child
Q2. Have you ever been told by a doctor or nurse that you (your child) have asthma? ("Diagnosed asthma")	Yes	608 (94%)	81 (99%)
	No	23 (4%)	0 (0%)
	Missing	15 (2%)	1 (1%)
Q2a. Have you had symptoms of asthma or taken treatment for asthma in the last 12 months? ("Current asthma")	Yes	536 (88%)	72 (89%)
	No	11 (2%)	1 (1%)
	Missing	60 (10%)	8 (10%)

The three routes of recruitment used in the present study thus provided a way of selectively accessing people with current or active asthma, rather than just those with a previous diagnosis of asthma.

Note that for all results which refer to specific questions from the survey form, the question number and the wording are those for the adult questionnaire, unless otherwise specified. The questions in the parent/carer questionnaire related to the person with asthma, unless otherwise specified. The full text of both the questionnaires is included in the Appendix.

DEMOGRAPHICS

Table 4. Demographics

		Adult (n=608)	Child (n=81)
Q124. Gender	Male	233 (38%)	41 (51%)
	Female	370 (61%)	38 (47%)
	Missing	5 (1%)	2 (2%)
Q123. Age, years, median (IQR)		56 (41, 66)	7 (6, 10)
BMI, Kg/m^2, mean (95% CI)		27.8 (27.2, 28.4)	18.0 (16.9-19.1)
Q127a. Do you smoke at least once a week?	Yes	9%	0%
Q135. In which country were you born?			
	Australia	491 (81%)	78 (96%)
	Other	105 (16%)	0 (0%)
	Missing	12 (2%)	3 (4%)
Q136. Are you of Aboriginal or Torres Strait Island origin?			
	Aboriginal	12 (2%)	2 (2%)
	Torres Strait Is	1 (0%)	0 (0%)
Q137. Do you usually speak a language other than English at home?			
	Yes	49 (8%)	7 (9%)
	No	552 (91%)	72 (89%)
	Missing	7 (1%)	2 (2%)
Socio-Economic Indices for Area (SEIFA)			
SEIFA 1 (most disadvantaged)		16%	28%
SEIFA 2		18%	30%
SEIFA 3		21%	15%
SEIFA 4		14%	14%
SEIFA 5 (least disadvantaged)		31%	11%
Remoteness (ASGC classification)			
	Major cities	438 (73%)	47 (60%)
	Inner regional	121 (20%)	14 (18%)
	Outer regional	42 (7%)	17 (21%)
	Remote	1 (0%)	0 (0%)

	Adult (n=608)	Child (n=81)
Q133. Highest level of education		
Tertiary (TAFE, Uni)	56%	-
Secondary	36%	5%
Primary	3%	4%
Still at school	2%	75%
Not yet at school	-	14%
Missing	3%	3%
Q129. Current employment		
Full-time	195 (32%)	
Part-time	65 (11%)	
Casual	46 (8%)	N/A
Unpaid work	18 (3%)	
Retired	200 (33%)	
Not working	76 (13%)	
Missing	8 (1%)	
Q128. Private Health Insurance		
Yes	363 (60%)	48 (59%)
No	236 (39%)	31 (38%)
Don't know	4 (1%)	0 (0%)
Missing	5 (1%)	2 (2%)
Q130. Government pension, allowance or benefit Yes	236 (39%)	25 (31%)
No	366 (60%)	52 (64%)
Don't know	2 (0%)	2 (2%)
Missing	4 (1%)	2 (2%)
Q131. Qualified for medication Safety Net in 2006 Yes	187(31%)	18 (22%)
No	299(49%)	46 (57%)
Don't know	117(19%)	15 (19%)
Missing	5 (1%)	2 (2%)
Q132. Concession cards		
Health care card	119(20%)	23 (28%)
Pensioner concession card	185(30%)	9 (11%)
Commonwealth seniors health card	62(10%)	N/A
Veterans Affairs treatment entitlement card	17(3%)	-
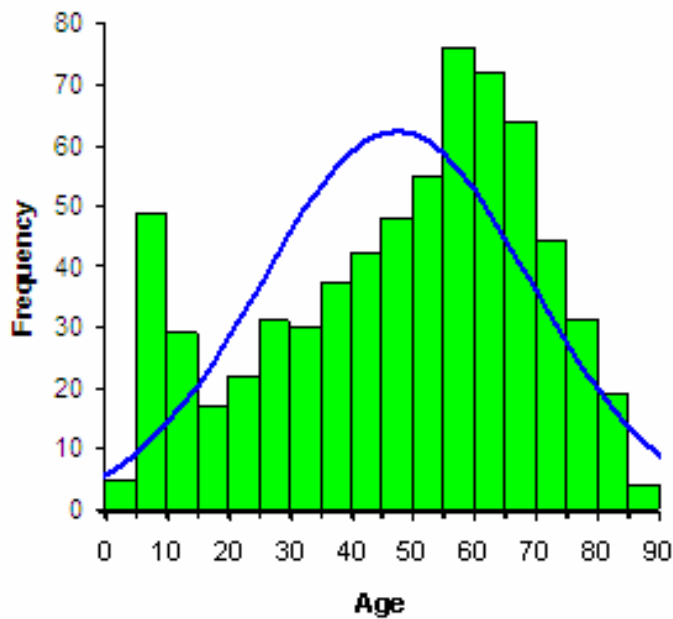
Figure 2. Frequency distribution for age of respondents (adult and child)

The frequency distribution for age of respondents (adult plus child) was left-skewed (Figure 2), with a median age of 51 years (IQR 32, 64). From the 2001 Australian census [4], the average age of persons aged ≥5 years was approximately 39 years. The proportion of total responses which were provided by parents/carers of children aged 5-13 (11%) was the same as the proportion of this age group in the Australian population, according to the 2001 Census [4]. The gender balance for adults was similar to that in the 2005 ACAM report [3] and in other asthma surveys [5].

Body mass index (BMI) data were calculated from self-reported height and weight, provided by 541 (92%) of the adult respondents. Of these, 37% of males and 26% of females were overweight (BMI 25.0-30.0), and 23% of males and 28% of females were obese (BMI >30.0). These rates are higher than those in the Australian National Health Survey 2004-5, in which 18% of males and 17% of females were obese. The proportion of current smokers was lower than current NSW rates, perhaps reflecting a greater level of health awareness by study participants.

The majority of respondents (83%) were born in Australia; the most common other countries of birth were the United Kingdom (5%) and New Zealand (2%). The questionnaire was only available in the English language, and was self-completed, so respondents were limited to those who were fluent in written English. However, 8% of adult respondents indicated that they usually spoke a language other than English at home.

The place of residence of respondents was classified using the Australian Standard Geographical Classification, based on postcode. In summary, "Major cities" includes Greater Sydney, Newcastle, Wollongong, Tweed Heads/Gold Coast; "Inner Regional" includes Blue Mountains, Hunter Valley, cities like Wagga Wagga, Orange, Tamworth, Batemans Bay area; and "Outer Regional" includes Northern, Central and Southern Tablelands, Griffith, and Broken Hill. Maps of the Australian Standard Geographical Classification (ASGC) areas can be obtained from the Australian Bureau of Statistics website at http://www.abs.gov.au/AUSSTATS/abs@.nsf/lookup/1216.0Contents12005. Amongst survey

respondents, the majority (70%) lived in major cities, with the remaining respondents living in inner and outer regional areas. This distribution was similar to that in the 2006 NSW Population Health Survey, in which 65% of participants were recorded as living in major cities, 23% in inner regional areas, 11% in outer regional areas, 1% in remote areas and 0.1% in very remote areas. However, in the present survey, the absolute number of respondents living in outer regional areas was small. Levels of socio-economic disadvantage are defined at a national level as quintiles (20% per group). In NSW, the proportions from the NSW Population Health Survey 2006 were: SEIFA 1 (most disadvantaged) 20.0%, SEIFA 2: 22.2%, SEIFA 3: 20.2%, SEIFA 4: 18.3%, SEIFA 5 (least disadvantaged): 19.3%. In the present survey, there were significantly more respondents from areas of least socio-economic disadvantage (SEIFA 5: 31%), but all SEIFA categories were well represented.

About one third of adult respondents were in full-time employment and one third retired, with about 10% in part-time work and the rest employed casually, or doing unpaid work. Of those who were retired, 63% had a pensioner concession card. The proportions of total respondents in full-time and part-time (including casual) work were similar to those reported in the 2001 Australian Census for persons aged ≥15 years (full-time: 36%, part-time: 18%) [4].

More than 50% of respondents had completed TAFE or University. This is higher than the level of 35% recorded in the 2001 Australian census [4]. The length of the present questionnaire would be likely to have discouraged respondents who had low levels of literacy.

Table 5. Characteristics of adult respondents, by source

	Pharmacy (n=237)	Woolcock (n=288)	Asthma Foundation NSW (n=83)
Age, years, median	52.8	52.8	51.3
Females, n (%)	135 (57%)	176 (61%)	59 (71%)
Current smokers, (%)	16%	5%	1%
"Current asthma"	89%	88%	86%
Written asthma action plan	32%	43%	51%
Social disadvantage, n (%)			
SEIFA 1 (most disadvantaged)	61 (26%)	26 (9%)	12 (14%)
SEIFA 2	71 (30%)	22 (8%)	14 (17%)
SEIFA 3	42 (18%)	61 (21%)	23 (28%)
SEIFA 4	32 (14%)	39 (14%)	14 (17%)
SEIFA 5 (least disadvantaged)	28 (12%)	137 (48%)	20 (24%)
Remoteness (ASGC), %			
Major cities	56%	88%	65%
Inner regional	31%	9%	27%
Outer regional	12%	2%	8%
Remote	0%	0%	1%

Respondents who were recruited through the three sources were of a similar age, but there was a higher proportion of female respondents from the Asthma Foundation NSW database than from the Woolcock and pharmacy groups.

The proportion of current smokers from the Pharmacy group was similar to current smoking rates for NSW, but smoking rates were much lower for respondents from the Woolcock and Asthma Foundation NSW, consistent with a greater level of health awareness in these populations. Likewise, a lower proportion of respondents from pharmacies possessed written asthma action plans.

For respondents recruited through pharmacies and Asthma Foundation NSW, their places of residence were distributed fairly evenly between the five SEIFA quintiles, but almost half of Woolcock respondents were from the least disadvantaged SEIFA category (SEIFA 5). While the majority of respondents from all three sources lived in major cities, the inner and outer regional areas of NSW were better represented amongst the pharmacy and Asthma Foundation NSW respondents than the Woolcock respondents.

The Woolcock volunteer database does not include children, so the parents'/carers' questionnaire was completed only by respondents from Pharmacies and Asthma Foundation NSW. The balance of gender and age from parent/carer responses was similar from the two sources, but numbers are too small for analysis of differences in other demographic characteristics.

GENERAL HEALTH ASSESSMENT and ASTHMA CONTROL

Table 6. General health assessment, asthma history and asthma control

	Adult	Child
Q3. Age of onset of asthma symptoms, years median (IQR)	14 (4-38)	2.0 (1–4)
Q4. In general, how would you rate your health?		
Excellent	46 (8%)	15 (19%)
Very good	172 (28%)	39 (48%)
Good	239 (39%)	18 (22%)
Fair	119 (20%)	6 (7%)
Poor	27 (4%)	2 (2%)
Q6-11. Juniper Asthma Control Questionnaire, ACQ, median (IQR)	1.17 (0.5, 2.0)	1.00 (0.33, 1.83)
ACQ ≤0.75 (well-controlled), %	35%	42%
0.75 < ACQ < 1.5, %	24%	20%
ACQ ≥1.5 (not well-controlled), %	40%	38%
Q44. In the last 4 weeks, how often did your asthma interfere with your daily activities? n (%)		
All of the time	29 (5%)	0 (0%)

	Most of the time	46 (8%)	6 (7%)
	Some of the time	268 (44%)	58 (72%)
	None of the time	260 (43%)	17 (21%)

	Adult	Child
Q51. Had days away from study/work due to asthma, n (%)		
Last 4 weeks	53 (9%)	31 (38%)
Last 12 months	109 (18%)	50 (62%)
Q52. Had other days of reduced activity due to asthma, n (%)		
Last 4 weeks	177 (29%)	39 (48%)
Last 12 months	250 (41%)	55 (68%)

The distribution of responses for self-reported general health status was very similar to that reported for people with asthma in several large randomly-selected Australian population surveys such as the 2001 National Health Survey [3]. A consistent finding of these population surveys was that people with asthma had worse self-assessed health status than people without asthma.

Scores for the ACQ indicated that the clinical features of asthma were less than optimally controlled in this population. Cut-points have been identified by the authors of the questionnaire, and related to the probability of asthma being considered by physician judgement to be well-controlled [6]. To be confident that a patient has well-controlled asthma, the optimal cut-point is considered to be 0.75 (negative predictive value=0.85). To be confident that a patient has inadequately controlled asthma, the optimal cut-point is considered to be 1.50 (positive predictive value=0.88). In the present survey, overall, 40% of adult respondents had asthma that was not well-controlled, as seen by an ACQ score ≥1.5. There are no random population surveys in which ACQ has been recorded, against which these data can be compared. However, previous surveys such as the AIRE series [5] have identified a high proportion of patients with waking due to asthma, excessive reliever use, and urgent health care utilisation due to asthma.

ACQ score was higher (less well-controlled asthma) in participants recruited through community pharmacies (median ACQ 1.7, IQR 0.8-2.5), compared with Asthma Foundation NSW (median 1.0, IQR 0.3-1.8) and Woolcock (median 0.8, IQR 0.3-1.5), p<0.0001, Kruskal-Wallis. This could represent selection bias, in that people whose asthma was currently not well-controlled e.g. due to a respiratory infection, may have been more likely than others to visit a pharmacy, and hence to be invited to complete the survey. It would also be expected that people on the Woolcock volunteer database and the Asthma Foundation NSW databases might be more accepting of their diagnosis and treatment, and hence have better controlled asthma, than those accessed through community pharmacies. Of participants recruited through pharmacies, 56% had ACQ ≥1.5, compared with 37% for Asthma Foundation NSW respondents and 29% for Woolcock volunteers.

The proportion of respondents whose asthma had interfered with daily activities cannot be directly compared with previous random population surveys because of differences in wording of the relevant questions or the time period assessed. In the ABS National Health Survey 2001, 2.6% of adult respondents with asthma reported having any days away from work/school due to asthma in the last 2 weeks [3], compared with 9% in the past 4 weeks in the present survey. Eighteen percent of adults with asthma reported that they had missed

study/work in the last 12 months because of asthma; of those working full-time, 29% had lost time from work due to asthma in the last 12 months.

A high proportion of parents/carers recorded time lost from study/work because of the child's asthma, both in the last 4 weeks (38%) and the last 12 months (62%). As expected, time lost from study/work was much more likely to be reported in the last 4 weeks for children whose asthma was currently not well-controlled (ACQ ≥1.5) than for other children (60% cf 27%, p=0.007). There was some potential ambiguity in the instructions for this page in the parents'/carers' survey, in that respondents may have been recording their child's time off school or their own time off work because of the child's asthma. However, the results are likely to directly reflect the proportion of children who lost time from school, because it is unlikely that a parent would take time off work because of the child's asthma if the child was not home from school.

Predictors of poor asthma control

Multiple logistic regression analysis was used to identify factors predicting poor asthma control (ACQ ≥1.5) for adult respondents (n=608). The variables which were included in the original model were age, gender, current smoker, SEIFA category, remoteness, employment status, concession card holder, health insurance, education, and non-English-speaking background, with adjustment for source (pharmacy, Woolcock, Asthma Foundation NSW). Other predictors which were examined were: use of ICS or ICS/LABA, and possession of written asthma action plan.

Significant independent predictors for current poor asthma control (ACQ ≥1.5), with the odds ratios [95% CI], were:

- younger age, per year   OR 1.02 [1.01, 1.03]
  (odds ratio 1.19 for a 10 year decrease in age)

- current smoking (Yes vs No)   OR 2.78 [1.63, 4.73]

- living in more disadvantaged areas (SEIFA 5 = least disadvantaged)
  - SEIFA 1 vs least disadvantaged   OR 2.43 [1.75, 3.36]
  - SIEFA 2 vs least disadvantaged   OR 1.75 [1.19, 2.57]
  - SEIFA 3 vs least disadvantaged   OR 1.88 [1.40, 2.54]
  - SEIFA 4 vs least disadvantaged   OR 1.60 [1.16, 2.20]

- being retired vs employed full-time   OR 1.54 [1.07, 2.21]

- having only primary education vs completed tertiary   OR 3.72 [1.17, 11.78]

- holding a concession card (Yes vs No)   OR 1.69 [1.22, 2.36]

The risk of current poorly-controlled asthma was not reduced either by current use of ICS nor by possession of a written asthma action plan. This apparent lack of protection is likely to be due to confounding by severity. However, of the 81 adult respondents who were not using an ICS-containing medication in the previous 4 weeks, 30 (37%) had poorly-controlled asthma (ACQ ≥1.5).

HEALTH CARE UTILISATION DUE TO ASTHMA

Urgent health care utilisation is defined as an urgent doctor visit, Emergency Department presentation, or admission to hospital due to asthma. This is used in asthma research both as a marker of the impact of poor asthma control on the patient and the community, and as a surrogate measure for poor asthma control when only administrative datasets are available.

Table 7. Health Care Utilisation due to asthma

	Adult		Child	
Q47. Hospitalisation				
Last 4 weeks, n (%)	8	(1%)	1	(1%)
Last 12 months, n (%)	49	(8%)	10	(12%)
No. times in last 12 mths*, median (range)	1	(1-9)	1	(1 3)
Q48. Emergency Department visit				
Last 4 weeks, n (%)	21	(3%)	7	(9%)
Last 12 months, n (%)	52	(9%)	19	(23%)
No. times in last 12 mths*, median (range)	1	(1-15)	2	(1-4)
Q49 Urgent doctor visit				
Last 4 weeks, n (%)	81	(13%)	23	(28%)
Last 12 months, n (%)	151	(25%)	42	(52%)
No. times in last 12 mths*, median (range)	2	(1-50)	2	(1-17)
Any urgent health care utilisation				
Last 4 weeks, n (%)	108	(18%)	27	(34%)
Last 12 months, n (%)	172	(28%)	49	(62%)
Non-urgent doctor visit about asthma				
Last 4 weeks, n (%)	218	(36%)	35	(43%)
Last 12 months, n (%)	334	(55%)	60	(74%)
No. times in last 12 mths*, median (range)	2(1-4, 1-24)		2	(1-15)

* Data for number of times in the last 12 months are for respondents with any such visits in the 12 months.

The overall level of sub-optimal asthma control in the study population was reflected in a high level of urgent health care utilisation, particularly for children with asthma. Overall, 28% of adults and 62% of children had experienced at least one episode requiring urgent health care (hospitalisation, Emergency Department visit and/or urgent doctor visit) due to asthma in the last 12 months. The majority of these attendances, for both adults and children, were urgent doctor visits.

In univariate analysis for adult respondents, urgent health care utilisation in the last 12 months was significantly associated with worse asthma control, as assessed by ACQ (p<0.0001), and with younger age (p=0.001). There was also a significant association with social disadvantage

(SEIFA category), with urgent health care utilisation being reported by 41% of respondents in SEIFA category 1 [most disadvantaged], ranging down to 24% of respondents in SEIFA category 5 [least disadvantaged], p=0.03 (Chi-square).

Respondents who reported having a written asthma action plan were more likely to have had urgent health care utilisation in the past 12 months; however, this does not represent failure of written action plans, as these plans encourage people with asthma to seek urgent medical care if their asthma is out of control. Instead, it probably reflects the increased likelihood of a person with troublesome asthma being issued with a written asthma action plan, and the issuing of action plans in the follow-up to Emergency Department visits. Participants who were using an ICS-containing medication were more likely to have urgent health care utilisation than those who were using short-acting β_2-agonist alone (32% cf 15%, p=0.004 Chi-square), but this result is confounded by severity.

The Asthma Management Handbook recommends that people with asthma should visit their GP regularly for review of asthma management, with a suggested frequency of twice a year [7]. However, only 55% of adult respondents reported having a non-urgent visit with a GP (or clinic) about their asthma in the last 12 months. Of the 172 respondents who required urgent health care in the last 12 months, 36 (21%) reported not having a non-urgent GP or clinic visit during the same period (15 (9%) did not answer). Almost three-quarters of children with asthma had had a non-urgent visit to a doctor or clinic about their asthma in the previous 12 months, and those who had had a non-urgent visit were no less likely to have an urgent visit. However, of the 48 children who had required urgent health care in the previous 12 months, 11 (23%) had not had a non-urgent visit about their asthma in that time.

In multiple logistic regression analysis, the significant independent predictors for urgent health care utilisation by adults in the previous 12 months were:

- younger age, per year   OR 1.03 [1.02, 1.04]
  (odds ratio 1.32 for a 10 year decrease in age)

- employment status (greater risk for those in full-time employment)
  - full-time vs casual   OR 2.48 [1.49, 4.11]
  - full-time vs part-time   OR 2.19 [1.57, 3.07]

- having only primary education vs completed tertiary   OR 6.23 [1.87, 20.77]

- being of non-English speaking background   OR 1.59 [1.02, 2.48]

The risk of urgent health care utilisation was not reduced by current use of ICS nor by possession of a written asthma action plan. For use of ICS, there is likely to be confounding by severity. No direct protective effect of possession of a written asthma action plan would be expected, as such plans actively direct patients to see their doctor or go to the Emergency Department if their asthma symptoms are severe.

When direct clinical assessment is not possible, urgent health care utilisation is often used as an indirect measure of asthma control. However, the multivariate analysis for urgent health care utilisation and poor asthma control identified different predictive factors, perhaps because urgent health care utilisation represents a complex balance between needs and access.

ASTHMA MANAGEMENT AND MEDICATIONS

Table 8. Asthma management and medications

	Adult	Child
Q5. Do you have a written asthma action plan Yes	242 (40%)	51 (63%)
No	352 (58%)	29 (35%)
Don't know	9 (1%)	1 (1%)
Missing	5 (1%)	0 (0%)
Reliever inhaler used in last 4 wks, n (%)	489 (80%)	72 (89%)
Pattern of reliever usage:		
Most days	129 (26%)	12 (17%)
Symptoms	258 (53%)	48 (67%)
Both	74 (15%)	11 (15%)
No. days/week reliever taken in last 4 wks, median (IQR)	5 (2-7)	3 (2-6.5)
ICS-containing inhaler used in last 4 wks, n (%)		
Taking any ICS-containing medication	527 (87%)	57 (70%)
ICS alone	107(20% of ICS users)	20 (35% of ICS users)
Seretide	289(55% of ICS users)	30 (53% of ICS users)
Symbicort	131(25% of ICS users)	7 (12% of ICS users)
Pattern of ICS usage		
Most days	390 (74%)	31 (54%)
Symptoms	47 (9%)	16 (28%)
Both	64 (12%)	9 (16%)
No. days/week ICS taken in last 4 wks median (IQR)	7 (7-7)	7 (5-7)
LTRA in last 4 wks, n (%)	15 (2%)	18 (22%)

	Adult	Child
Inhaler Adherence Score (Toelle, range 0-4), median (IQR)	4 (2-4)	* 4 (2.75-4)
In the last 4 wks:		
Q20. Have you at times been careless about using this medication?	Yes: 18%	Yes: 14%
Q21. Have you ever forgotten to use this medication?	Yes: 27%	Yes: 25%
Q22. Have you ever stopped using this medication because you felt better?	Yes: 14%	Yes: 20%
Q23. Have you ever used this medication less than prescribed because you felt better?	Yes: 16%	Yes: 20%

* Note that the IAQ has not been validated for use in children

Adherence with preventer medications

In the study population, most adult respondents (76%) said that they used their ICS inhaler 7 days/week in the last 4 weeks. This self-reported adherence is very high compared with other surveys and with many studies using electronic monitoring, suggesting either that our sample was not representative of the populations which have been studied in clinical trial contexts, or that respondents were not necessarily answering this question honestly. The proportion of respondents scoring 2 or less on the Inhaler Adherence Score, the value which was found by Toelle and colleagues to be associated with poor adherence on electronic monitoring was 27% (Figure 3), which was also very low.
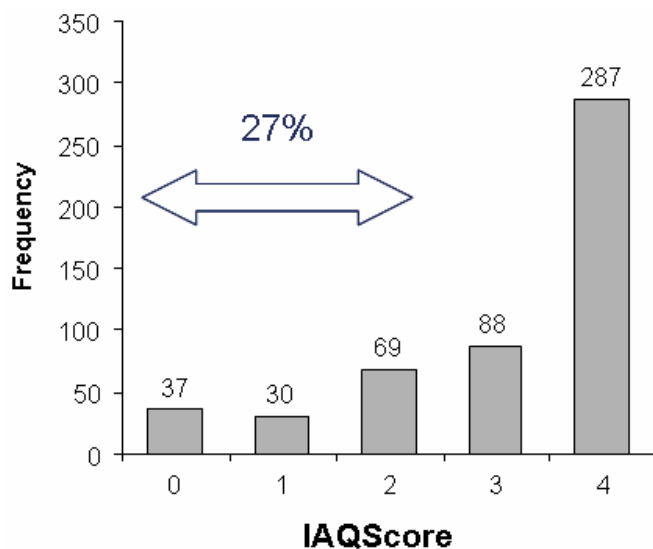
Figure 3. Frequency distribution of Inhaler Adherence Score [8]. A score of ≤2 is associated with poor medication adherence on electronic monitoring.

Relationship between adherence responses and asthma control

In adult respondents, there was no significant association between IAQ score and ACQ score (p=0.3, Kruskal-Wallis analysis), even when the analysis was limited to respondents ≤40 years old (p=0.4). Other studies have suggested that when patients admit to poor adherence, this is likely to be reliable [9]; however, when analysis was restricted to those respondents who did not have a perfect IAQ score (n=217), there was still no association between IAQ score and ACQ. This suggests either there was an overall tendency by respondents to over-report adherence in this survey, or that factors other than poor adherence, such as inadequate treatment or dose, poor inhaler technique or co-morbidities, were contributing to poor asthma control in this population. In fact, paradoxically, IAQ score was significantly higher for respondents with poorly-controlled asthma (ACQ ≥1.5, n=210, median 4 [IQR 3-4]) compared with respondents whose asthma was not poorly-controlled (n=294, median 4 [2-4], p=0.016 Mann-Whitney test).

Number of medications and inhalers

Obtaining information about medications is more difficult from self-report than from interview, and we could not assume that respondents would know whether each medication was a "reliever" or a "preventer" (also called "controller" in US publications). Therefore, we chose to ask respondents about all medications that they had used for their asthma in the previous 4 weeks, providing a colour chart with the questionnaire to help respondents identify the names of their inhalers. Study staff then categorised the medications according to the name and/or description provided. Despite pilot testing, some respondents had difficulty with completing the medication table. This was particularly noticeable for elderly patients, and appeared to relate to a lack of familiarity with the concept of the way columns and rows interact in a table.

During the previous 4 weeks, 489 adult respondents (80%) had used a reliever inhaler for their asthma. Most of these respondents (481, 94%) listed only one type of reliever inhaler, but 28 (6%) listed two different names. In total, 527 adult respondents (87%) had used an ICS-containing inhaler during the previous 4 weeks, with 509 (97%) listing one name of ICS-containing inhaler and 17 respondents listing 2 names and 1 giving 3 names for ICS-containing inhalers.

Data about the number of inhalers owned by each respondent, and the location in which they were kept were derived from the responses relating to the reliever and ICS-containing inhaler listed *first* by each participant in the medication table. This avoided over-counting if the different inhalers had been used sequentially rather than concurrently during the four week period. Adult participants owned significantly more reliever inhalers than ICS-containing inhalers (p<0.0001): the median was 3 (IQR 2-5, range 0-18), and for ICS-containing inhalers, the median was 2 (IQR 1-3, range 0-9). Some of these may be "spares", ready for when the previous inhaler runs out. However, with most respondents owning multiple inhalers, it seems likely that many people with asthma might find it difficult to keep track of their storage conditions, expiry dates, and particularly of the number of doses left, leaving them vulnerable to running out of medication or having a less than optimal therapeutic response.
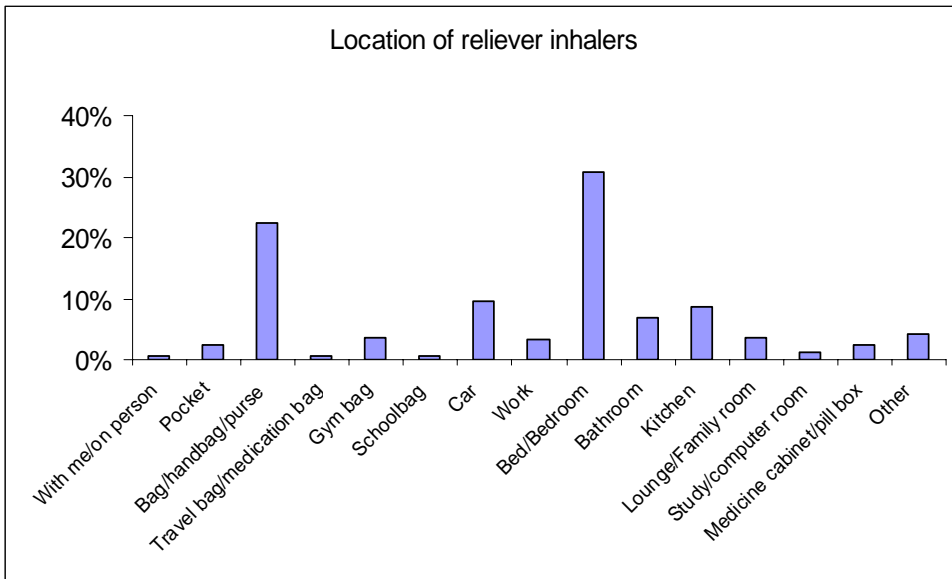
Figure 4a. Number of respondents who nominated specific locations for their reliever inhalers

Figure 4a shows the number of respondents who nominated various locations for their reliever inhalers. The inhalers were kept in a range of both fixed and mobile locations. Reliever inhalers tended to be kept on or with the person, or around the house. Q19 asked how many inhalers were carried around with the respondent; of the 489 respondents who listed a reliever inhaler, 342 (70%) said they carried around one of these inhalers with them; 23 (5%) said they carried around two of these inhalers, and 11% had missing data. Fifteen percent of respondents kept a reliever inhaler in the car.
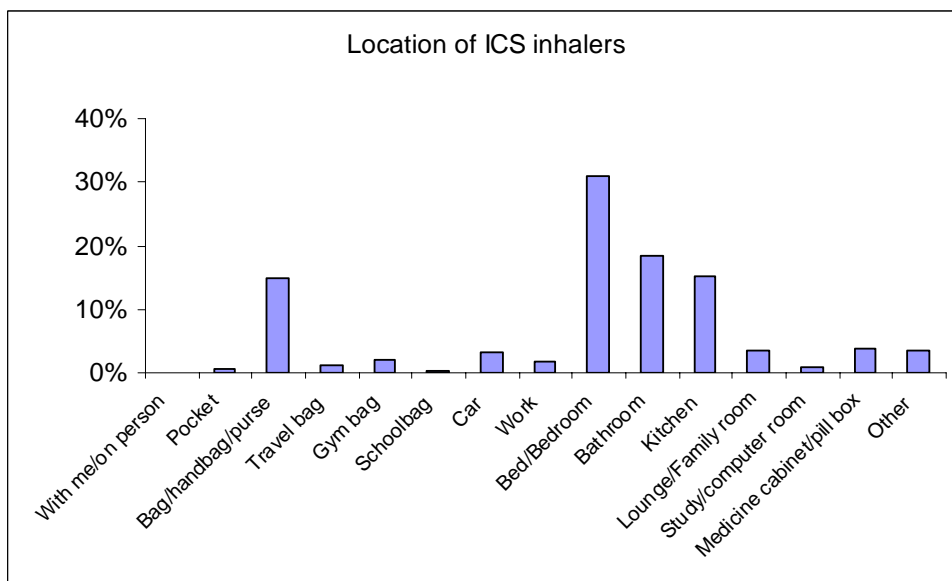
Figure 4b. Number of respondents who nominated specific locations for their ICS-containing inhalers

Figure 4b shows the number of respondents who nominated various locations for their ICS-containing inhalers. The inhalers were kept in a range of both fixed and mobile locations. ICS-containing inhalers tended to be kept in the house, but a significant proportion of respondents kept them in a bag (with some stating that this was a medication bag for travel rather than a handbag). However, of adult respondents who recorded using an ICS-containing inhaler, 119 (23%) said that they carried one of these inhalers around with them, and 6 (1%) said that they carried two of these inhalers around with them. These data cannot be solely explained by the introduction of the Symbicort SMART treatment regimen (Symbicort for Maintenance and Reliever Therapy) into Australia in August 2006, with 53% of these respondents reporting that the medication carried around was Seretide, and only 29% referring to Symbicort. An ICS-containing inhaler was kept in the car by 3% of respondents. Exposure of inhalers to the very high temperatures found in parked cars may reduce the therapeutic response.

Health care professionals often advise adults with asthma to keep their preventer inhaler in the bathroom, next to the toothbrush, to assist with adherence. However, only a minority of respondents in the present survey (18%) kept their ICS-containing inhaler in the bathroom. Although the kitchen was also a favoured location (15% of respondents), many of the other locations which were listed were not likely to be close to a sink or basin, reducing the chance that the person with asthma would consistently follow instructions to rinse out the mouth after using an ICS-containing inhaler.

ASTHMA-RELATED QUALITY OF LIFE

Adult respondents and parents/carers completed different quality of life questionnaires. The data for these two questionnaires cannot be compared. In the Marks AQOL questionnaire [10], the range of scores is 0-4, with higher scores indicating worse quality of life. In the Juniper Pediatric Carers Asthma-related Quality of Life Questionnaire (PCAQLQ) [11], the range of scores is 1-7, with higher scores indicating *better* quality of life. Because of the distribution of the data, results for the PCAQLQ are reported as median and IQR.

Table 9. Marks Asthma-Related Quality of Life Questionnaire for adults (range 0-4)

Question	Adult AQLQ Mean (95% CI)
Total score, mean (95% CI)	0.87 (0.81, 0.93)
Breathless sub-score	1.02 (0.95, 1.10)
Mood sub-score	0.94 (0.87, 1.01)
Social sub-score	0.66 (0.59, 0.72)
Concerns sub-score	0.79 (0.72, 0.86)
Individual quality of life questions (previous 4 weeks)	
24. I have been troubled by episodes of shortness of breath._____	1.36 (1.29, 1.44)
25. I have been troubled by wheezing attacks_____	0.92 (0.84, 1.00)
26. I have been troubled by tightness in the chest_____	1.02 (0.94, 1.11)

27. I have been restricted in walking down the street on level ground or doing light housework because of asthma_____	0.69 (0.61, 0.77)
28. I have been restricted in walking up hills or doing heavy housework because of asthma_____	1.12 (1.02, 1.21)
29. I have felt tired or a general lack of energy_____	1.32 (1.23, 1.40)
30. I have been unable to sleep at night_____	0.79 (0.70, 0.87)
31. I have felt sad or depressed_____	0.70 (0.63, 0.78)
32. I have felt frustrated with myself_____	0.89 (0.81, 0.98)
33. I have felt anxious, under tension or stressed_____	0.99 (0.90, 1.07)
34. I have felt that asthma is preventing me from achieving what I want from life_____	0.68 (0.60, 0.77)
35. Asthma has interfered with my social life_____	0.62 (0.54, 0.71)
36. I have been limited in going to certain places because they are bad for my asthma_____	0.81 (0.73, 0.89)
37. I have been limited in going to certain places because I have been afraid of getting an asthma attack and not being able to get help_____	0.41 (0.34, 0.48)
38. I have been restricted in the sports, hobbies or other recreations I can engage in because of my asthma. _____	0.90 (0.81, 0.98)
39. I have felt generally restricted._____	0.65 (0.58, 0.73)
40. I have felt that asthma is controlling my life. _____	0.51 (0.44, 0.59)
41. I have been worried about my present or future health because of asthma. _____	0.84 (0.75, 0.92)
42. I have worried about asthma shortening my life. _____	0.73 (0.65, 0.82)
43. I have felt dependent on my asthma inhalers._____	1.44 (1.33, 1.54)

In adults, overall, there was only mild impairment of quality of life due to asthma, with most adult respondents scoring 0 ("not at all") or 1 ("mildly") for most questions. Asthma-related quality of life scores were significantly higher (greater impairment of quality of life) in respondents recruited through pharmacies compared with those recruited through Woolcock (mean 1.02 [0.92, 1.15] cf. 0.71 [0.63, 0.78]), consistent with asthma being less well-controlled in the Pharmacy group. The highest mean score for an individual AQLQ question, with the greatest variation between individual responses (mean 1.44, 95% CI 1.33, 1.54), was seen for the final question, "I have felt dependent on my asthma inhalers", with 42% of respondents answering "moderately", "severely" or "very severely".

In univariate analysis, current asthma-related quality of life for adults was significantly worse with higher ACQ scores (less well-controlled asthma, r=0.74, p<0.0001), extent of limitation of activity (r=0.67, p<0.0001), any urgent health care utilisation in the last 4 weeks (p<0.0001) or 12 months (p<0.0001), but not with age, gender or SEIFA category. For the AQLQ sub-scores, there were highly significant correlations (Pearson r [95% CI]) with ACQ - Breathless 0.80 [0.77, 0.83]; Mood 0.60 [0.54, 0.65]; Social 0.61 [0.55, 0.65] and Concerns 0.61 [0.55, 0.65]. In multiple regression analysis, asthma-related quality of life for adults was

significantly worse with higher ACQ (p<0.0001), more limitation of activity (p<0.0001), older age (p=0.0025), and urgent health care in the last 4 weeks (p=0.005) and the last 12 months (p=0.0001), with these five independent factors explaining two thirds of the variation in asthma-related quality of life (p<0.0001).

Table 10. Juniper Pediatric Carers Asthma-related Quality of Life Questionnaire

Question	Parent/carer QOL Median (IQR)
Total score, median (IQR)	6.15 (5.00, 6.77)
Activity sub-score	6.75 (4.75, 7.00)
Emotional sub-score	6.11 (5.00, 6.67)
Individual quality of life questions (relating to the previous 1 wk)	
Q12. In the last week, how often did you feel helpless or frightened when your child experienced bouts of coughing, wheezing, or breathlessness?	6 (5 - 7)
Q13. In the past week, how often did your family need to change plans because of your child's asthma?	7 (5 – 7)
Q14. In the past week, how often did you feel frustrated or impatient because your child was irritable due to asthma?	7 (5 - 7)
Q15. In the past week, how often did your child's asthma interfere with your job or work around the house?	7 (5 - 7)
Q16. In the past week, how often did you feel upset because of your child's cough, wheeze or breathlessness?	6 (4 - 7)
Q17. In the past week, how often did you have sleepless nights because of your child's asthma?	7 (4 - 7)
Q18. In the past week, how often were you bothered because your child's asthma interfered with family relationships?	7 (6 - 7)
Q19. In the past week, how often were you awakened during the night because of your child's asthma?	7 (5 - 7)
Q20. In the past week, how often did you feel distressed that your child has asthma?	6 (4 - 7)
Q21. In the past week, how worried or concerned were you about your child's performance of normal daily activities?	6 (5 - 7)
Q22. In the past week, how worried or concerned were you about your child's asthma medications and side effects?	6 (5 - 7)
Q23. In the past week, how worried or concerned were you about being overprotective of your child?	6 (5 - 7)
Q24. In the past week, how worried or concerned were you about your child being able to lead a normal life?	6 (5 – 7)

Responses by parents/carers to the PCAQLQ were highly skewed, with only a small proportion of parents/carers having substantially impaired quality of life due to asthma. There was no significant difference in asthma-related quality of life between parents/carers recruited through pharmacies (n=61) and those recruited through Asthma Foundation NSW (n=20). The questions on which there was the greatest variation in responses were those relating to the respondent being upset or having sleepless nights because of the child's asthma symptoms (Q16 and Q17 respectively). Overall, for each question in the PACQLQ, approximately 10-15% of respondents recorded a score of ≤3 (e.g. Q12, "quite often", "most of the time" or "all of the time"), with the exception of Q18 (4%).

For parents/carers of children with asthma, univariate analysis showed that current asthma-related quality of life was significantly worse with higher ACQ scores i.e. with less well-controlled asthma (r=-0.74, p<0.0001). There were also significant negative associations between PCAQLQ and any urgent health care utilisation either in the past 4 weeks (p<0.0001) or the past 12 months (p=0.0003), and to a lesser extent with younger age of the child (r=0.27, p=0.01), or living in a more socially-disadvantaged area (lower SEIFA category, r=0.23, p=0.04). In multiple regression analysis, the significant independent factors for worse quality of life in parents/carers were higher ACQ scores (p<0.0001), and urgent health care utilisation in the previous 4 weeks (p<0.0001), with these two factors explaining two thirds of the variation in PACQLQ (p<0.0001).

PROBLEMS INTERFERING WITH ASTHMA MANAGEMENT

The survey asked respondents whether any of the following problems had interfered with the management of their asthma (or their child's asthma) in the previous 12 months.

Table 11. Problems interfering with the management of asthma in the last 12 months

Problem	Adult		Child	
Q118. Difficulty getting an appointment with a GP about my asthma?				
Yes	81	(13%)	25	(31%)
No	458	(75%)	50	(62%)
Not applicable	62	(10%)	0	(0%)
Q119. Difficulty getting a referral to a specialist for my asthma if I think I need one?				
Yes	36	(6%)	8	(10%)
No	403	(66%)	53	(65%)
Not applicable	160	(26%)	0	(0%)
Q120. Cost of seeing a GP or specialist?				
Yes	87	(14%)	13	(16%)
No	445	(73%)	59	(73%)
Not applicable	68	(11%)	0	(0%)
Q121. Cost or difficulty of transport to doctor or pharmacist?				
Yes	40	(7%)	4	(5%)
No	497	(82%)	68	(84%)
Not applicable	62	(10%)	0	(0%)
Q122. Cost of medications?				
Yes	147	(24%)	19	(23%)
No	415	(68%)	55	(66%)
Not applicable	39	(6%)	0	(0%)

Overall, a minority of respondents reported that any of the specified problems had interfered with their management of their asthma in the previous 12 months. For adults, the most

common problem was cost of medications, reported by almost one quarter of respondents. Amongst adult respondents, younger age was a significant factor for each of these problems, particularly for those relating to cost. Respondents reporting any of these problems were more likely to have higher ACQ (less well-controlled asthma); however, this relationship may be secondary rather than causal, given the increased clinical needs associated with poorly-controlled asthma. There was no association between the ASGC classification (remoteness) for the respondents' location of residence and their reporting of any of the above problems. Retired persons were significantly *less* likely than people in other employment categories to have difficulties due to cost of medications; this was not dependent on whether or not they were on the pension or had a health care card.

About one quarter of parents/carers also reported cost of medications as having been a problem, and over 30% perceived that difficulty in obtaining an appointment with a GP had interfered with the management of their child's asthma in the previous 12 months.

ATTITUDES, BELIEFS & BEHAVIOURS

The majority of questions in this section of the questionnaire came from the Beliefs and Behaviours Questionnaire, developed by George et al [12] and used with the permission of the authors. The Beliefs and Behaviours Questionnaire was developed for use in chronic illness, and it has not previously been studied in asthma. With rewording of the questions to refer to "my asthma" instead of "my illness", the questions all had face validity for asthma. Wording of the questions for parents/carers are given in the Appendix. In most cases, the parent/carer was asked to record their own attitudes rather than those of their child. However, as the parent/carer completed the questionnaire for children as old as 13 years, some of whom may already have been responsible for administering their own asthma medication, the questions about adherence were worded to indicate that the answer could relate to either the parent/carer's behaviour or to the child's behaviour relating to the taking of medications.

In the table below, the question numbers and wording are those for the adult questionnaire. The corresponding question numbers in the questionnaire for parents/carers of children aged 5-13 yrs are CQ48 to CQ81 inclusive (see Appendix). For each question, responses were recoded for a range between 1 and 5. There are no established ranges for BBQ score or sub-scores for people with asthma.

Table 12. Attitudes, beliefs and behaviours about asthma and asthma medications

	Adult	Parent/carer
BBQ total score (range 5-150)	99.4(98.6, 100.2)	103.8(101.9, 105.7)
Confidence (range 9 – 45)	37.8(37.4, 38.3)	38.5(37.3, 39.7)
Concerns (range 5 – 25)	14.0(13.8, 14.3)	14.7(14.1, 15.4)
Disappointment (range 5 – 25)	11.9(11.6, 12.1)	13.0(12.5, 13.5)
Satisfaction (range 3 – 15)	9.4(9.2, 9.7)	10.7(9.8, 11.7)
Non-adherence (range 4 – 20)	17.6(17.4, 17.8)	18.6(18.2, 19.0)
Adherence (range 4 - 20)	8.7(8.4, 8.9)	8.3(7.7, 8.9)
Q55. I have sufficient understanding about my asthma_____	4.34 (4.28, 4.40)	4.25(4.08, 4.42)
Q56. I know what to expect from my asthma management_____	4.38 (4.33, 4.44)	4.31(4.15, 4.47)

	Adult	Parent/carer
Q58. My current management will keep my asthma at bay	4.21(4.15, 4.28)	4.09(3.91, 4.27)
Q59. I am receiving the best possible management	4.19(4.12, 4.26)	4.29(4.11, 4.47)
Q60. The management of my asthma is a mystery for me (reverse scored)	4.04(3.95, 4.14)	4.06(3.78, 4.35)
Q61. It is helpful to know the experiences of others with asthma	3.68(3.59, 3.77)	4.20(4.00, 4.40)
Q62. Natural remedies are safer than medicines	2.34(2.26, 2.43)	2.44(2.24, 2.65)
Q63. My doctors have limited management options to offer me	2.37(2.26, 2.47)	2.13(1.87, 2.38)
Q64. My medications are working	4.40(4.34, 4.46)	4.40(4.25, 4.55)
Q65. Using any medication involves some risk	3.76(3.67, 3.85)	3.94(3.71, 4.16)
Q66. I am on too many medications	2.18(2.08, 2.28)	2.10(1.86, 2.34)
Q67. I have a say in the way my asthma is managed	4.17(4.09, 4.25)	4.45(4.28, 4.62)
Q68. I have sufficient understanding about the options for managing my asthma	4.17(4.10, 4.24)	4.25(4.07, 4.43)
Q69. My doctors are very knowledgeable	4.31(4.24, 4.38)	4.46(4.31, 4.61)
Q72. I am concerned about the side effects from my medications	2.73(2.63, 2.84)	3.03(2.76, 3.29)
Q73. It is unpleasant (e.g. taste, smell) to use some of my medications	1.81(1.72, 1.90)	2.35(2.05, 2.65)
Q74. It is physically difficult to handle some of my medications	1.21(1.16, 1.26)	1.88(1.60, 2.15)
Q75. I am satisfied with the information my doctors share with me	3.93(3.84, 4.02)	4.28(4.07, 4.48)
Q76. My doctors are compassionate	4.07(3.98, 4.15)	4.35(4.18, 4.52)
Q77. Financial difficulties limit my access to the best healthcare	1.92(1.81, 2.02)	1.82(1.53, 2.12)
Q78. My doctors spend adequate time with me	3.94(3.85, 4.02)	4.36(4.16, 4.56)
Q79. The management of my asthma disrupts my life	1.84(1.75, 1.92)	1.69(1.50, 1.87)
Q81. I get confused about my medications	1.42(1.36, 1.47)	1.95(1.74, 2.16)
Q82. I have strict routines for using my regular medications	4.10(4.00, 4.20)	4.34(4.15, 4.53)

	Adult	Parent/carer
Q83. I keep my medications close to where I need to use them	4.67(4.62, 4.73)	4.64(4.48, 4.80)
Q84. I ensure I have enough medications so I do not run out	4.57(4.51, 4.63)	4.83(4.73, 4.92)
Q85. I strive to follow the instructions of my doctors	4.40(4.32, 4.47)	4.76(4.63, 4.90)
Q86. I make changes in the recommended asthma management to suit my lifestyle	2.67(2.56, 2.78)	2.33(2.04, 2.61)
Q87. I vary my recommended asthma management based on how I am feeling	2.53(2.42, 2.63)	2.47(2.21, 2.73)
Q88. I put up with my asthma before taking any action	2.16(2.07, 2.26)	1.59(1.38, 1.80)

There was wide variation in the response to some items, as seen by the confidence intervals in the table above. For adults, there was a high level of variation (coefficient of variation ≥50%) for Q63 (limited management options), Q66 (too many medications), Q73 (unpleasant to use some medications), Q74 (physically difficult to handle some medications), Q77 (financial difficulties limit my access to the best health-care), Q79 (management of asthma disrupts life), Q86 (making changes to the recommended management to suit lifestyle), Q87 (varying recommended asthma management based on how the respondent was feeling), and Q88 (I put up with my asthma before taking any action). Overall, respondents recorded high scores for the questions relating to adherence, and low scores for those relating to non-adherence, consistent with the responses to the Inhaler Adherence Questionnaire. Adults scored low for Q61, about whether it was helpful to know the experiences of others with asthma.

For adults, there were weak, although statistically significant, correlations with <u>age</u> for some questions, e.g. Q86, making changes to suit one's lifestyle (r_s=-0.21, p<0.0001), i.e. older respondents were less likely to change their medications (at least for this reason); and Q82, having strict routines for taking medications (r_s=0.40, p<0.0001). For Q82, about having strict routines about medications, a score of "Often" or "Always" was recorded by 38% of those aged 14-24 years, 54% of those aged 25-34 years, 67% of those aged 35-44 years, 74% of those aged 45-54, 84% of those aged 55-64 years, and 89% of those aged ≥65 years. There was a weak correlation between the response to this question and the Inhaler Adherence Score (rs=0.20, p<0.0001), and no association with asthma control as assessed by ACQ.

For parents/carers, 83% recorded "Often" or "Always" in response to the statement CQ74 ("I [or my child] have strict routines for using their regular medications"). There was a high degree of variation (coefficient of variation ≥50%) for CQ60 (limited management options available), CQ62 (too many medications), CQ69 (unpleasant for child to use some of his/her medications), CQ70 (physically difficult for child to use some medications), CQ71 (financial difficulties limit access to best healthcare), Q72 (management of child's asthma disrupts life), CQ78 (I (or my child) get confused about their medications), CQ79 (making changes to the recommended management to suit lifestyle), and CQ81 (I (or my child) put up with their asthma before taking any action).

Some statistically significant differences were observed in responses between adults and parents/carers of children with asthma. On average, parents/carers scored half a point higher

in their response to the question about whether it was helpful to know the experiences of others with asthma (CQ58), compared with the response to the same question for adults (Q61). Parents/carers appeared to have had a more satisfactory experience with the doctor's management of their child's asthma compared with the experience of adults with asthma, as seen by significantly higher scores for parents/carers in having a say in the way the asthma was managed (CQ55 cf. Q67), the doctor spending adequate time with them (CQ67 cf. Q78), being satisfied with the information provided by the doctor (CQ66 cf Q75), and their doctors being compassionate (CQ65 cf Q76). However, parents/carers perceived more problems with the medications themselves compared with adults, with higher scores for unpleasantness of the medications (CQ69) and physical difficulty in using medications (CQ70), and for confusion about medications (by the parent/carer or the child, CQ78). Parents/carers scored significantly higher than adults with asthma for having enough medication to not run out (CQ 76 cf. Q84) and for striving to follow the instructions of the doctors (CQ77 cf. Q85).

Attitudes to asthma symptoms and inhalers in public

We asked two additional questions about attitudes, firstly whether respondents disliked having asthma symptoms in public (or their child having symptoms in public), and whether they disliked using inhalers in public (or their child using inhalers in public). The responses were particularly interesting, with significant differences between the responses to these questions within both groups, and significant differences for both questions between adults and parents/carers.

Table 13. Questions about being symptomatic or using inhalers in public

Additional questions	Adult	Parent/carer
Q57. I dislike being wheezy, short of breath or coughing in public_____	4.56(4.49, 4.63)	3.51(3.15, 3.86)
Q70. I dislike using inhalers in public_____	2.71(2.58, 2.83)	1.41(1.25, 1.56)
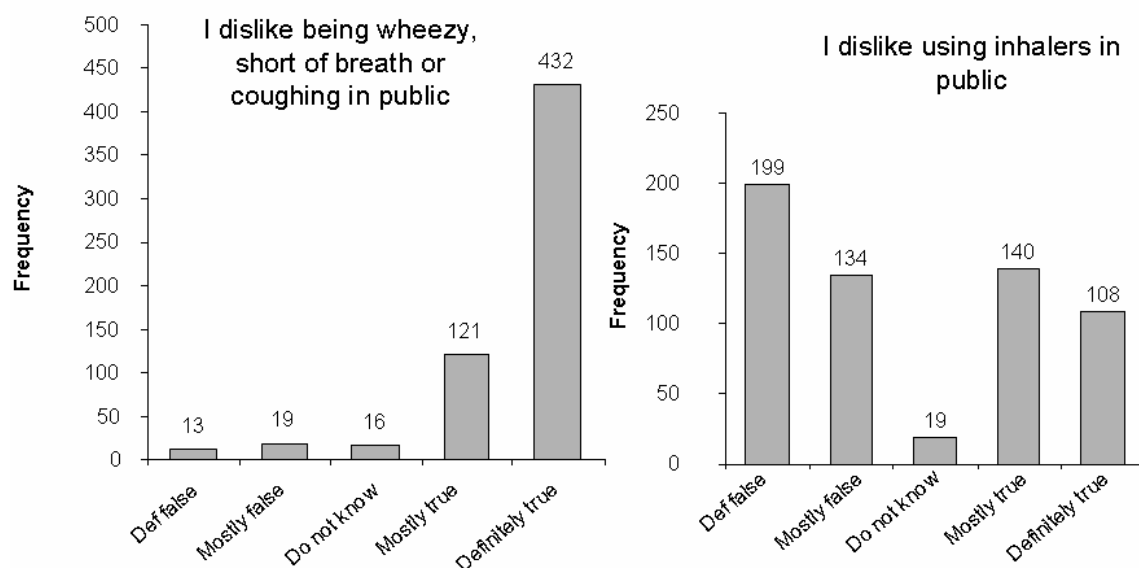
Figure 5 Responses by adults to Q57 and Q70

Figure 5 shows the differing responses by adults to Q57 (I dislike being wheezy, short of breath or coughing in public) and Q 70 (I dislike using inhalers in public). Most adult respondents (71%) strongly disliked being symptomatic in public. However, when it came to a dislike of using inhalers in public, there was a strikingly different response, with 41% of adults agreeing or strongly agreeing, and 55% disagreeing or strongly disagreeing. The correlation between the responses by adults to these two questions was very weak (rs=0.18, p<0.0001). The response about dislike of using inhalers in public was not significantly different for males and females, and there was only an extremely weak (albeit statistically significant) correlation with age. The response about dislike of using inhalers in public was also not associated with the respondent's age at onset of asthma symptoms, his/her level of asthma control or frequency of use of reliever medication. Some BBQ responses which were statistically although weakly associated with a dislike of using inhalers in public included Q88 "I put up with my asthma before taking any action" (rs=0.18, p<0.0001), and Q72 "I am concerned about the side-effects from my medications" (rs=0.22, p<0.0001), perhaps suggesting more general issues about asthma medications than just being seen using them in public.
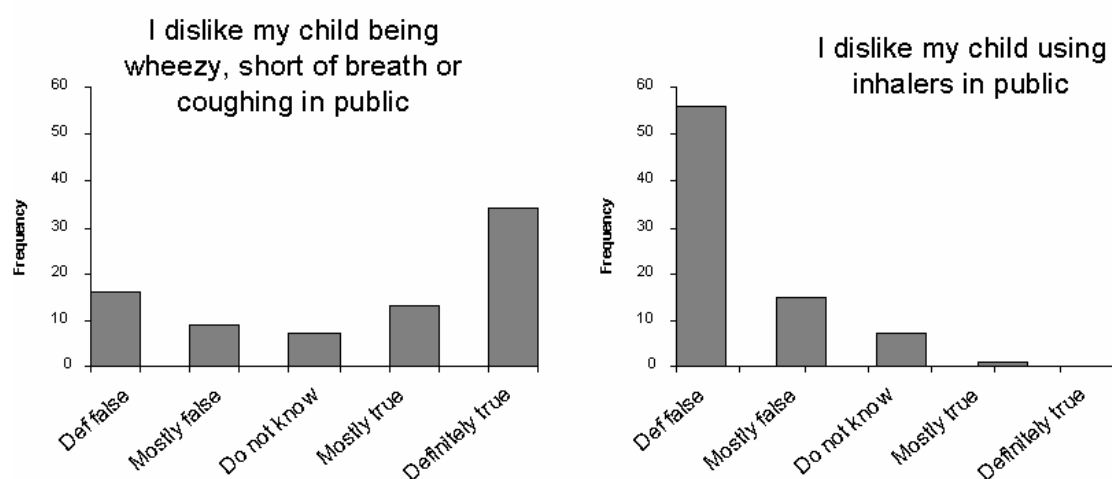
Figure 6 Responses by parents/carers to CQ50 and CQ64

The pattern of responses was quite different when parents/carers were asked the same two questions with regard to their child. Although many parents/carers (42%) strongly agreed that they disliked their child being symptomatic in public, there was a much less skewed distribution of responses than for adults, showing a broader range of opinions on this issue. By contrast with adults, there was a very strong unimodal disagreement with the statement that the parent/carer disliked his/her child using inhalers in public (69% scored this as "Definitely false"). There was no significant association between the parents'/carers' responses to these two questions. The difference compared with the response by adults with asthma may possibly reflect a generational change in attitude to inhalers.

Additional questions about pharmacists

In addition to the questions in the BBQ about satisfaction with medical care, we included two questions with similar wording, relating to patient satisfaction with the pharmacist.

Table 14. Questions about satisfaction with pharmacist interactions

	Adult	Parent/carer
Q71. My pharmacist is very knowledgeable	4.10 (4.03, 4.17)	4.38 (4.23, 4.53)
Q80. My pharmacist spends adequate time with me	3.36 (3.25, 3.47)	3.75 (3.47, 4.03)

Once again, parents/carers were more satisfied with their interaction with their pharmacist than were adults with asthma. As might be expected, respondents recruited through pharmacies were significantly more likely to record higher scores for satisfaction with the pharmacist than those recruited through the Woolcock or Asthma Foundation NSW. There was also a striking difference in the responses about interactions with health care professionals, according to geographical remoteness. For the two questions about doctors (Q69 – my doctor is knowledgeable, and Q78 – my doctor spends adequate time with me), there was no relationship with geographical remoteness. However, there was a strong relationship for the two equivalent questions relating to pharmacists (Q71 $p<0.0001$ and Q80 $p=0.0002$), with patients in inner and outer regional areas significantly more likely to give higher scores for the pharmacist questions, regardless of recruitment source.

INFORMATION SOURCES AND ACCESS TO INFORMATION

Given the interest by Asthma Foundation NSW in providing information about asthma to consumers, a section of the questionnaire dealt with the respondents' existing information sources, and access to the internet.

Table 15. Sources of information about asthma in the past 12 months

Q54. Sources of information about asthma in the past 12 months, no. saying Yes (%)	Adult	Child
a. Relative/Friend	78 (14%)	28 (36%)
b. Doctor	460 (77%)	76 (96%)
c. Hospital Staff (Doctors, Nurses	123 (21%)	30 (39%)
d. Community Nurse	13 (2%)	8 (11%)
e. Complementary/alternative practitioner	43 (7%)	7 (9%)
f. Pharmacist/pharmacy assistant	223 (38%)	53 (68%)
g. Asthma Educator	60 (10%)	10 (13%)
h. Other health professional	36 (6%)	4 (5%)
i. Asthma Foundation NSW staff	65 (11%)	14 (18%)
j. Pharmaceutical company	14 (2%)	2 (3%)
k. Asthma Foundation NSW website	54 (9%)	15 (20%)
l. Other internet websites	42 (7%)	13 (17%)
m. Media (TV, newspaper	124 (22%)	27 (36%)
n. Books	66 (11%)	15 (20%)
o. Workplace staff	13 (2%)	10 (13%)
p. Child care staff	3 (1%)	7 (9%)
q. School staff	5 (1%)	8 (10%)
r. Other	40 (8%)	2 (3%)
No. sources/respondent, mean (95% CI)	2.4 (2.3 – 2.6)	4.1 (3.5 – 4.7)
Access to internet in last 4 weeks, n (%)		
Any internet access	401 (66%)	60 (74%)
Internet access at home	371 (61%)	55 (68%)
Internet access at work	180 (30%)	25 (31%)
Internet access elsewhere	72 (12%)	8 (10%)
No. who used internet to access information about health in last 4 weeks, n (% of those with internet access)	136 (34%)	19 (32%)

For adults, the most common sources from which they had received information about asthma in the last 12 months were a doctor (77% of respondents), pharmacist/pharmacy assistant (38%), media (22%) and hospital staff (21%). Parents/carers identified a significantly higher number of sources of information about asthma than did adults, with doctors, pharmacists and hospital staff again being named most commonly. However, for parents/carers, their relatives and friends were also a significant source of information about asthma (36%), as were media such as TV and newspapers (36%).

Sources of information about asthma according to recruitment method

There were significant differences in the number of sources used for information about asthma between participants recruited by different methods (adults and parents/carers combined, n=687). The mean [95% CI] number of sources of information per participant were 4.2 [3.7, 4.7] for respondents recruited through Asthma Foundation NSW, 2.6 [2.3, 2.8] for those recruited from pharmacies, and 2.1 [1.9, 2.3] for respondents from the Woolcock database (p<0.0001, Kruskal-Wallis). The response rate from Asthma Foundation NSW was too low to make any strong assumptions, but the Asthma Foundation NSW respondents may have had a greater interest in seeking information about asthma than did participants from the other two sources. While those recruited through pharmacies were, as expected, more likely to report having obtained information from a pharmacist, respondents living in areas of greater socio-economic disadvantage were also more likely to have obtained information from a pharmacist than those from less disadvantaged areas (p=0.007 Kruskal-Wallis), independent of whether they were recruited through a pharmacy.

Participants who had received information about asthma from Asthma Foundation NSW

Of the 65 adult respondents who reported that they had received information about asthma from staff of Asthma Foundation NSW in the last 12 months, 38 had been recruited from the Asthma Foundation NSW database, 2 from pharmacies, and 25 from the Woolcock. Of the 14 parents/carers respondents who reported that they had received information about asthma from staff of Asthma Foundation NSW, 10 were recruited from the Asthma Foundation NSW database and 4 from pharmacies.

Of the 54 adult respondents who reported that they had received information about asthma from the Asthma Foundation NSW website, 30 had been recruited from the Asthma Foundation NSW database, 4 from pharmacies, and 20 from the Woolcock. Of the 15 parents/carers respondents who reported that they had received information about asthma from the Asthma Foundation NSW website, 8 had been recruited from the Asthma Foundation NSW database and 7 from pharmacies.

Access to internet

Just over two-thirds of all respondents had accessed the internet during the previous 4 weeks, mostly from their homes. For adults, older respondents were less likely to have internet access (p<0.0001, Mann-Whitney test), although 38% of respondents aged ≥65 years had accessed the internet in the previous 4 weeks. Availability of internet access decreased with decreasing SEIFA category (less advantaged) (Chi-square 46.1, p<0.0001), but even for SEIFA categories 1 and 2, about 50% of respondents had accessed the internet in the previous 4 weeks. This increased to about 70% for SEIFA categories 3 and 4, and 84% for respondents in SEIFA category 5 (least disadvantaged).

Although two-thirds of all respondents had accessed the internet in the past 4 weeks, only about one third had accessed the internet for health information during that time.

ISSUES OF IMPORTANCE TO RESPONDENTS

Participants were provided with a list of issues that might be of importance to people with asthma, and asked to score them for their level of importance to themselves on a scale of 1 (Low) to 5 (High).

Table 16. Issues about asthma – how important were they to respondents?

Issue	Adult	Child
Responses: mean (95% CI) [% scoring 5]		
Q89. Being able to cope with my asthma day-to-day	4.3 (4.2, 4.4) [59%]	4.5 (4.3, 4.7) [71%]
Q90. The cost of asthma treatment and medications	3.2 (3.1, 3.3) [29%]	3.2 (2.8, 3.5) [33%]
Q91. Being able to deal with a severe asthma attack	4.3 (4.2, 4.4) [68%]	4.8 (4.7, 4.9) [85%]
Q92. Having the latest information about asthma	4.0 (3.9, 4.1) [47%]	4.5 (4.4, 4.7) [68%]
Q93. Understanding when to use asthma medications	4.4 (4.3, 4.5) [60%]	4.7 (4.6, 4.8) [78%]
Q94. Understanding how asthma medications work	4.2 (4.1, 4.3) [52%]	4.5 (4.4, 4.7) [68%]
Q95. Understanding the side effects of asthma medications	4.2 (4.1, 4.3) [53%]	4.5 (4.3, 4.7) [63%]
Q96. Knowing what triggers my asthma	4.5 (4.4, 4.6) [69%]	4.8 (4.6, 4.9) [88%]
Q97. Knowing how to avoid asthma triggers	4.5 (4.4, 4.6) [67%]	4.8 (4.6, 4.9) [88%]
Q98. Working with my GP to manage my asthma	4.0 (4.0, 4.1) [47%]	4.8 (4.6, 4.9) [85%]
Q99. Having a pharmacist who gives me asthma information	3.6 (3.5, 3.7) [36%]	4.4 (4.2, 4.6) [60%]
Q100. Using natural/herbal medicines, vitamin supplements or alternative therapies to manage my asthma	2.1 (2.0, 2.3) [8%]	2.3 (2.0, 2.6) [8%]
Q101. Being able to exercise without worry or discomfort	4.2 (4.2, 4.3) [57%]	4.6 (4.5, 4.8) [71%]
Q102. Having a workplace, gym, sports club, school or preschool which is knowledgeable about asthma and can help me in an emergency	3.3 (3.1, 3.4) [29%]	4.5 (4.3, 4.7) [70%]
Q103. Having access to support that can help reduce the anxiety of living with asthma	3.2 (3.1, 3.3) [28%]	3.9 (3.6, 4.1) [38%]

	Adult	Parent/carer
Q104. Research into the prevention of and a cure for asthma	4.4 (4.3, 4.5) [68%]	4.7 (4.6, 4.8) [76%]
Q105. Research that will help me in day-to-day living with asthma	4.2 (4.1, 4.3) [57%]	4.5 (4.3, 4.7) [66%]
Q106. Having contact with other people who have asthma to discuss problems and solutions	2.6 (2.5, 2.7) [14%]	3.2 (2.9, 3.4) [19%]
Q107. Participating in online (internet) asthma education programs	2.2 (2.1, 2.3) [7%]	2.40 (2.1, 2.7) [6%]
Q108. Hiding my asthma from other people	1.9 (1.8, 1.9) [4%]	1.3 (1.1, 1.5) [4%]

The highest level of importance was given for issues which related to day-to-day living with asthma, with most respondents giving these issues a score of 4 or 5. Both questions about asthma research (research into prevention and cure, and research to help in day-to-day living with asthma) were also given the highest rank by the majority of respondents, and information to address most of the issues identified as being important would only be able to be obtained through research. Overall, parents/carers scored most issues as higher in importance than did adults. The most striking difference between adult and parent/carer responses was for the question relating to "Having a workplace, gym, sports club, school or preschool which is knowledgeable about asthma and can help me in an emergency", which parents/carers on average scored 1.3 points higher than adults. This may relate to parents recognising the important role of school staff in caring for the child in the event of an asthma emergency during school hours, when the parent/carer is often not immediately to hand.

Q106, about "having contact with other people who have asthma to discuss problems and solutions", was ranked significantly lower by adults than by parents/carers. This issue was also rated significantly lower by adults living in major cities and those in areas of lesser socio-economic disadvantage, compared with those from other areas. City dwellers also gave lower ranks than respondents in inner or outer regional areas for the importance of having a pharmacist who gives information about asthma, and having access to support to reduce the anxiety of living with asthma.

Q107, about "participating in online (internet) asthma education programs" was given low overall rankings. Predictably, the lowest rankings were given by those without internet access in the past 4 weeks (median 1), but low rankings were given even by those respondents who had accessed the internet in the past 4 weeks (median 2). However, participating in online asthma education programs was ranked higher (median 3) by those who had accessed the internet to obtain information about health issues in the last 4 weeks, suggesting that interest in participating in internet programs may have been enhanced by having a previous (presumably positive) experience of accessing health information by this route.

Using natural/herbal medicines or alternative therapies to manage asthma was given low average rankings by both adults and parents/carers, and this did not vary significantly by the source from which the respondent had been recruited (Woolcock, pharmacy or Asthma Foundation NSW). The low ranking given to the importance of complementary and

alternative treatments by respondents in the present survey is in contrast with data obtained from random surveys of people with asthma, as recently reviewed by Slader and colleagues [13]. However, 31% of respondents ranked this issue as 3, 4 or 5, indicating a significant sub-set of asthma consumers for whom this issue would be of interest.

The issue which was ranked lowest by both adults and parents/carers was Q108, "hiding my asthma from other people". In total, 27% of respondents gave this issue a score of 3, 4 or 5. There was no correlation with age, but there was a moderate correlation between responses to this issue and those to Q70, "I dislike using inhalers in public" (rs=0.42, p<0.0001).

EXPERIENCE OF ASTHMA FOUNDATION NSW PROGRAMS AND SERVICES

Respondents were asked about their experience of Asthma Foundation NSW services in the previous 12 months, and whether they would use those services again.

Table 17. Use of Asthma Foundation NSW Services in the past 12 months

	Adult	Parent/carer
Q117. In the last 12 months, have you used any Asthma Foundation NSW services?		
Yes	68 (11%)	15 (19%)
No	512 (84%)	58 (72%)
Don't know	23 (4%)	6 (7%)
Missing	5 (1%)	2 (2%)
Q117b. If Yes, would you use these services again in the future?		
Yes*	64 (94%)	14 (93%)
No	1 (1%)	0 (0%)
Missing	3 (4%)	1 (7%)

* In addition, 6 adults and 3 parents/carers answered "Yes" to Q117b despite having answered "No" Q117. These responses may represent people who had previously used Asthma Foundation NSW services but not in the last 12 months.

In total, 11% of adult respondents and 19% of parents/carers reported having used Asthma Foundation NSW services in the past 12 months, and all but one of these said that they would use Asthma Foundation NSW services again in the future. One respondent who had used the Help Line stated that she would not use this service again, but no further details were given. Of the 68 adult respondents who had used Asthma Foundation NSW services in the previous 12 months, 36 had been recruited through the Asthma Foundation NSW database, 28 through the Woolcock, and 4 through pharmacies. Of the 15 parents/carers who had used Asthma

Foundation NSW services in the previous 12 months, 11 had been recruited through Asthma Foundation NSW and 4 through pharmacies.

Respondents were asked to state the Asthma Foundation NSW services which they had used in the previous 12 months. A total of 23 respondents mentioned having received information from Asthma Foundation NSW; of these, 12 referred to information about specific questions, and the remaining 11 referred to general asthma information. Some respondents (n=34) mentioned their mode of contact with Asthma Foundation NSW: of these, 4 referred to email, 18 referred to the website, 14 referred to telephone contact, and one referred to staff contact. A total of 16 respondents mentioned having received print material (newsletter, brochures, information pack).

A full list of the Asthma Foundation NSW services reported as having been used by respondents (adults and parents/carers) is given below in Table 18. It is evident that there was some confusion over who was the provider of some services, particularly the Asthma Clinic at RPAH. Most of this confusion was amongst Woolcock respondents, and may potentially have arisen through the linking of the names of Asthma Foundation NSW, Woolcock Institute and Dr Reddel in the Information for Participants statement.

Table 18. Specific Asthma Foundation NSW services used by participants in the last 12 months

Services mentioned by more than one respondent are indicated in parentheses, e.g. (x3) means that three respondents reported having used this particular service.

- Email (x3)
- Phone (x5)
- Information Line (x5, variously called Help Line, Infoline etc or just a reference to phoning Asthma Foundation NSW for information)
- Website (x15)
- Self-care pharmacist, phone contact
- Booklet, brochure, leaflets (x3)
- Brochures and information pack, e-newsletter
- Print material
- Received information in mail
- Received an information pack
- Asthma card
- Newsletters, Asthma Update, Latest education brochures Asked information
- I am a life member and receive a monthly booklet
- Newsletter (x2)
- Read magazine but no 'services' in a strict sense
- Allergy update
- Asthma Action Plan

- When my doctor told me I had asthma, I rang the Asthma Foundation for information on asthma. I was sent an Asthma Information Pack with letter.

Requests for specific information

- Information on dust mites

- With regards to possible triggers

- Looked at their internet site when buying new pillows + doona for my family to ensure I only bought 'asthma free' bedding

- Enquiry about medication

- Phone Service needing advice because my reaction to bronchodilators is atypical and I was having difficulty convincing my GP that Oxis causes rebound in me.

- Information regarding new heart medication

- Information regarding medications and symptoms -sent information pack. Needed to sort out my confusion and gain some understanding and advice. Very helpful - especially regarding peak flow and pack received

- Latest information on asthma management for daughter who has smoking-induced asthma

- Asked what kind of carpet I should lay and vacuum cleaner to buy.

- Enquiry about air-conditioning and problems of inhaling neighbour's wood fire smoke in air/house.

- I tried to get help to get an asthma peak flow chart to record daily readings & my asthma management plan and I could not get one.

- School project

- Respondent's mother found information on dust mites

Other comments in this section

- Being involved in surveys with pregnant with last child

- I found it very helpful

- Always happy to assist

- St Leonards

- Staff

- Volunteer

Services not provided by Asthma Foundation NSW but attributed to it by respondents

- Asthma Foundation VIC. The nurses were brilliant, mine of information and priceless.

- Asthma Clinic at RPAH (x6).

- Asthma Educator

- Doctors, pharmacists

- Easy walking: Prince of Wales Hospital, Support Group, Therapist

- Woolcock Institute (x5)

PROPOSED ASTHMA FOUNDATION NSW PROGRAMS/SERVICES

Finally, respondents were asked to rate eight proposed programs, services or activities in which Asthma Foundation NSW could be involved, in order to support people with asthma to live well and to manage their asthma better. Respondents were provided with a brief description of Asthma Foundation NSW as being a "not-for-profit organisation providing programs and services to people with asthma and the community in NSW".

Table 19. Proposed programs/services by Asthma Foundation NSW

Proposed Program/Service	Adult	Parent/carer
Responses were for the level of importance that these services would have to the respondent. Results are displayed as median (IQR) [% respondents with score of 5]		
Q109. Representing the needs of people with asthma, e.g. to government	5 (4 - 5) [55%]	4 (3 - 5) [49%]
Q110. Supporting workplaces, gyms, sports clubs, schools and preschools to be knowledgeable about asthma and able to help in an asthma emergency	5 (4 - 5) [54%]	5 (5 - 5) [79%]
Q111. Holding public information and education sessions for people with asthma and their families	4 (3 - 5) [45%]	5 (3 - 5) [51%]
Q112. Providing asthma information on the internet	4 (3 - 5) [46%]	5 (3.5 - 5) [54%]
Q113. Providing opportunities on the internet to connect people with asthma for support or to discuss problems and solutions	4 (2 - 5) [31%]	3 (3 - 5) [30%]
Q114. Providing email or SMS alerts on environmental hazards such as bushfires, high levels of pollution or pollen	4 (3 - 5) [41%]	4 (3 - 5) [39%]
Q115. Providing information on allergies	5 (4 - 5) [55%]	5 (4 - 5) [55%]
Q116. Offering a Membership program that provides regular information updates	4 (3 - 5) [36%]	4 (3 - 5) [41%]

Respondents indicated a high level of interest in all of the proposed programs/services, with a score of 5 (maximum importance) being the modal score for each of the proposed areas. A score of 5 was recorded by more than 50% of adult respondents for Q109 (representing the needs of people with asthma), Q110 (supporting workplaces, schools etc), and Q115 (providing information on allergies). Slightly lower levels of support, with the greatest variations in response, were recorded for Q113 (providing opportunities on the internet to

connect people with asthma for support or to discuss problems and solutions) and Q116 (offering a Membership program that provides regular information updates). However, these two options were still given the maximum level of importance by 31% and 36% of adult respondents respectively, indicating that such programs would be highly valued by a significant proportion of consumers.

For parents/carers, responses were similar to those given by adults, with the exception of the proposal to support workplaces, schools etc [Q110 in adult survey, CQ103 in child survey], to which parents/carers gave significantly more support than adult respondents (p<0.0001). More than 50% of the parents/carers gave the maximum level of importance to CQ104 (holding public information sessions), CQ105 (providing asthma information on the internet), and Q108 (providing information on allergies); for CQ103 (supporting workplaces, schools etc), almost 80% of parents/carers gave the maximum level of importance. The lowest levels of support by parents/carers were recorded for CQ106 (internet support/discussions), CQ107 (email or SMS alerts) and CQ109 (Membership program with regular information updates). However, around one third of parents/carers gave these three options the highest score (30%, 39% and 41% respectively).

There were weak but statistically significant effects of respondents' age and ASGC category (remoteness) on the ratings which they gave for some of the proposed programs/services. There were weak associations between increasing age and higher rankings for all of the proposed programs/services with the exception of Q112 and Q113, both relating to the internet. Respondents living in inner and outer regional areas were more supportive of Q111 (holding public information sessions, p=0.001) and Q113 (providing opportunities on the internet to connect people with asthma, p=0.005) than those living in major cities, and Q116 (Membership program with information updates) was more favoured by respondents living in outer regional areas than in major cities or inner regional (p=0.003). There were no important associations between living in a socially disadvantaged area (low SEIFA category) and the rankings which were given for the proposed programs/services.

DISCUSSION

This project was a collaboration between the Woolcock Institute of Medical Research, the Faculty of Pharmacy at University of Sydney, and staff of the Australian Centre for Asthma Monitoring, to provide Asthma Foundation NSW with quantitative data about the attitudes, behaviours and needs of people with asthma in NSW. The data will be used to assist Asthma Foundation NSW to appropriately represent people with asthma, by being aware of their attitudes, behaviours and needs, and to develop programs and services which will assist consumers to manage their asthma effectively. The project has reached a successful conclusion, with detailed information having been collected from almost 700 people with asthma and the parents/carers of children with asthma.

As outlined in the contract application in November 2007, the methods which could be used for the survey were limited by the available budget. To obtain a truly representative sample would have required use of random telephone dialling, which, even with the known prevalence of current asthma in NSW of approximately 10%, would have needed an approximately 10-fold higher budget. The aim was to obtain a representative sample of approximately 1200 people with asthma from NSW, in order to obtain data about factors with a prevalence of ≥10% with reasonable precision. Using recruitment through pharmacies, the Woolcock database and the Asthma Foundation NSW databases, the final sample size was 689, which was sufficiently large to allow useful conclusions to be reached about factors with a prevalence ≥10%. Recruitment through pharmacies was probably limited by the influenza epidemic in winter 2007, which meant that pharmacists were extremely busy during the recruitment period. Recruitment was also limited by the length of the questionnaire. A single-page questionnaire would have been much more easily completed while customers were waiting for prescriptions to be filled, but this would not have been able to provide sufficient information about the questions of interest to Asthma Foundation NSW. Using an interview-based questionnaire would have allowed access to people with low levels of literacy, but would have substantially increased the cost.

Surveys about asthma which are based only on self-report are limited by a lack of objective confirmation of the diagnosis of asthma, and by the lack of any objective measurement of the level of asthma control, such as spirometry. Nevertheless, populations reached in this way represent people who *believe* that they have asthma; such people are therefore targets for the programs and activities of consumer organisations such as Asthma Foundation NSW.

Obtaining information about asthma in children is typically limited by the literacy and recall of the children themselves, and using data from parents or carers is accepted as being more appropriate for this age-group. In the questions about attitudes and beliefs, we asked about the parent/carers attitudes/beliefs, rather than the child's. It would have been preferable for us to find out which parent responded to the questionnaire (mother or father), and whether they were the usual carer for that child. It would also have been interesting to find out whether the parent/carers themselves had asthma, as this could have affected their attitudes and beliefs about asthma.

No allowance has been made for multiple comparisons in the present analyses, so some of the positive findings would have been expected to be found by chance.

REPRESENTATIVENESS OF THE STUDY POPULATION

Given the planned recruitment methods, we expected at the outset that any bias in the study population would be towards people whose asthma was more troublesome, and towards those who had greater contact with health care professionals.

The study population largely (88%) comprised people with "current asthma", defined as those having symptoms of asthma or taking treatment for asthma within the previous 12 months. By contrast, in national surveys, only about 50% of people with diagnosed asthma have had current asthma (using the same definition) [3]. The predominance of respondents with current asthma is a strength rather than a limitation of the present survey (for the objectives specified by Asthma Foundation NSW), because people who have current asthma are more likely to seek or benefit from the services of Asthma Foundation NSW than those who have had a diagnosis of asthma at some time in the past but have no active problem. Many previous surveys about asthma have been restricted to people with current asthma.

The proportion of responses about children aged 5-13 (11%) was similar to the proportion of this age group in the whole Australian population, but the absolute numbers of children were too small for analysis of sub-groups.

The proportion of respondents who were of Aboriginal or Torres Strait Island origin (2%) was similar to Australian census data [4], but the absolute numbers of such respondents were too few for the responses to be considered representative. As expected, because the questionnaire was only available in English, the study population only included respondents who were fluent in English; hence, the proportion of respondents who spoke a language other than English at home (8%) was lower than in the Australian population (21%), as reported from the 2001 Census. The proportion of respondents born overseas (15%) was somewhat lower than the Australian average (22%) [4]. When respondents were classified by geographical remoteness, the proportions were similar to those reported in the 2006 NSW Population Health Survey; however, the absolute number of respondents for outer regional areas in the present survey was small.

More than 50% of respondents had completed TAFE or University. This is higher than the level of 35% recorded in the 2001 Australian census [4]. The length of the present questionnaire would be likely to have discouraged respondents who had low levels of literacy.

The study population provided a representative balance of gender, geographical remoteness and level of socio-economic advantage, apart from an over-representation of those living in less disadvantaged locations. The population groups which would be considered to be not well represented by the present survey were: those of non-English-speaking background, those with low literacy, teenagers, and those living in outer regional and remote areas of NSW.

AREAS OF NEED RELEVANT TO AIMS OF ASTHMA FOUNDATION NSW

Following are brief comments about survey findings relevant to areas of need for people with asthma in NSW, which could be considered by Asthma Foundation NSW for further investigation or for intervention. These comments are in addition to those found within the Results section.

- Pharmacies provide an established route for contact with people with asthma in lower socio-economic areas, whose other options for education about asthma may be limited.

- Pharmacies are used by many patients to access advice and health care about their asthma (as about other medical conditions). Pharmacies provide the potential to access some patients at the time that their asthma is poorly-controlled (e.g. during a viral infection); this may represent a window of opportunity to provide information at a time when it may be accepted by the patient, because of current discomfort or disturbance to their lifestyle due to their asthma, and to obtain access to some patients who may not be able to afford (or prefer pharmacist advice) to conventional general practitioner-based care.

- The higher proportion of poorly-controlled asthma in younger people with asthma indicates an area of particular need, particularly as these were the respondents who indicated that the cost of medications was an issue for them.

- The proportion of current smokers in the pharmacy-based population is as high as that in the general NSW population; this is of concern, in view of the known relationship between smoking and decline of lung function, and between smoking and lack of effectiveness of inhaled corticosteroid-containing medications. In the present survey, current smoking was a significant independent risk factor for poor asthma control.

- The high prevalence of obesity in this population of people with current asthma suggests several areas for investigation or intervention. This includes the need for accurate diagnosis, so that a person who is overweight and breathless is not just assumed to have asthma, and provision of advice about exercise for people with asthma in order to assist in weight loss. Several research institutes currently have programs investigating the potential causative or contributory relationship between obesity and asthma.

- This study, like many other population surveys, revealed that adults with asthma had a high level of urgent health care utilisation due to asthma, and a high level of poor asthma control (based on a questionnaire which has been validated against physician judgement). From previous surveys about asthma control (e.g. the AIRE series of surveys[5]), investigators have concluded that there needs to be a greater effort to ensure that people with poorly-controlled asthma are treated with ICS-containing medications. However, unlike most of the previous surveys, the great majority of the present study population were currently prescribed an ICS-containing medication, and, at least according to self-report, were taking it regularly (although self-report is known to over-estimate ICS use). This implies that important factors other than just under-prescribing of ICS are likely to be contributing to poor asthma control in the NSW community. There is a need to identify these factors amongst ICS users, such as poor inhaler technique, lack of routine review, smoking etc which may contribute to the burden of poor asthma control. Although few respondents in the present survey admitted to poor adherence, it still appeared to be a problem for at least one quarter of respondents. There appears to be scope for reinforcing the message about routine visits for review of asthma, in conjunction with the Asthma Cycle of Care.

- The survey revealed a very high level of urgent health care utilisation and activity limitation due to asthma in children. This is of particular concern, because of the burden to the child and family, the known association with impaired lung function in adult life, and the social and economic impact. More research is needed, e.g. with focus groups or brief interviews at the time of urgent doctor or ED attendance, about the factors that contribute to parents' use of urgent doctor visits and ED visits, in order to develop strategies to reduce the need for such visits. In the present dataset, almost ¾ of children had a non-urgent visit for asthma in the previous 12 months. Those that did were no less likely to have an urgent visit for asthma in the previous 12 months than those who did not have a routine visit. The level of ownership of written asthma action plans by children is reassuring, but research is needed to establish that the strategies which are advised in these action plans are effective.

- If the high proportions of children in this survey who were using potent ICS and particularly ICS/LABA combinations were found to be representative of regular treatment of the general population of children with asthma, it would be of great concern, in view of current paediatric guidelines, and the potential for systemic side-effects. In the present survey, the appropriateness of this treatment in individual children cannot be established because of confounding by severity, and lack of information about dosage. In addition, recruitment through pharmacies would tend to over-select for children taking regular rather than intermittent treatment. However, the survey findings support information from other sources about apparent over-prescribing for children in Australia, and mechanisms to deal with this need to be addressed by major asthma stakeholders. In addition, it may be helpful to prompt parents to discuss with their child's doctor the pros and cons of various treatment options, to ensure that the minimum effective treatment is being used.

- The finding that poor asthma control and urgent health care utilisation were more common in the small proportion of respondents who had only completed primary education, independent of their level of socio-economic disadvantage, suggests that low levels of literacy may be a contributory factor. Educational qualifications were also a significant factor for urgent health care utilisation in a recent publication from a large US database [14]. Further investigation is needed within this subgroup of people with asthma in order for Asthma Foundation NSW to be able to provide programs and services which can reach people with this particular need.

- There were some particularly interesting findings in the survey about attitudes to asthma and to asthma medications. Further work about the impact of such attitudes on adherence with medications will be carried out in 2008 with Project Grant funding provided by Asthma Foundation NSW. The differences in responses in the present survey about being symptomatic in public and about using medications in public suggest the need for further investigation of the factors involved in these attitudes. If there is a perception by some patients that regular use of such medications implies dependency or if there is a perceived stigma for some patients from using asthma medications in public, there may be a need for education campaigns about these issues, addressed not just at asthma consumers but at the general public.

- We had originally intended to look at the relationship between the Beliefs and Behaviours Questionnaire and outcomes such as poor asthma control and urgent health care utilisation, but the initial analysis indicated that the sub-scores of the BBQ would need to be re-established for asthma, before reliable results could be obtained on the multiple logistic regression analysis.

- There appears to be scope for further work with interested pharmacists to investigate ways of improving practical inhaler management by patients (renewal of prescriptions, checking of expiry date, counting of doses, storage conditions etc).

- Overall, respondents appeared to be satisfied with the management and information that their current doctor was offering, despite the fact that many of them were assessed as having poorly-controlled asthma. There is scope for increasing patients' awareness of what they should expect from good asthma management.

- The survey found that relatives and friends were a common source of information for parents/carers of children with asthma. Asthma Foundation NSW should perhaps regard such social or family contacts as important consumers, to ensure that potentially erroneous lay beliefs about asthma can be identified and overcome, so that relatives/friends do not provide advice to the parent/carer which conflicts with evidence-based messages from doctors, nurses, Asthma Foundation NSW etc.

- This survey showed a greater burden of poor asthma control and urgent health care utilisation, and more problems interfering with asthma management in younger compared with older adults, independent of their socioeconomic status. Asthma-related quality of life was worse in older compared with younger participants, but we were not able to adjust for co-morbidities.

- The majority of respondents had access to the internet. This is only likely to increase in future years, and provides an excellent potential route for delivery of Asthma Foundation NSW services to many of its consumers, even in socio-economically disadvantaged areas. This would not be as useful a strategy in the elderly ($\geq$65 years), as fewer than 40% had accessed the internet in the last month. It is useful to note that only few of the respondents with internet access had accessed it for health information in the previous four weeks; there perhaps needs to be more education about how consumers can use the internet wisely, and which sites are reliable, i.e. essentially training consumers to expect to benefit from health sites such as that provided by Asthma Foundation NSW.

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APPENDIX 1

Final questionnaire for people with asthma, aged 14 years and over

NEW SOUTH WALES ASTHMA SURVEY

(for people with asthma aged 14 years and over)

Name: _____

Contact number: _____

For more information about this survey, please see the separate Information Page

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Instructions

- This survey should take you about 20 minutes to finish.

- Most of the answers are Yes/No or multiple choice, so please tick the most appropriate answer for each question.

- Some questions might seem to be similar, but we would like you to complete all of them.

- Post the questionnaire back to us in the reply-paid envelope

If you would like to complete the survey by telephone, please call Dr Helen Reddel on 02 9515 7026, and keep this booklet for reference when you are contacted by phone.

If you have any questions or problems with the survey, please contact Dr Helen Reddel, Woolcock Institute of Medical Research, phone 02 9515 7026, email: hkr@med.usyd.edu.au

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Would you like to receive a copy of the survey results?   Yes ☐   No ☐

   If yes, please write your mailing address below:

Name Mr/Mrs/Ms/Miss   _____   _____
                              Family name   **Other names**

Address _____

Suburb _____   **Postcode** _____

1. Please write in today's date	☐☐ ☐☐ /2007 Day / Month
2. Have you ever been told by a doctor or nurse that you have asthma? **If the answer is 'No', please skip to Question 3** 2a. If Yes, have you had symptoms of asthma or taken treatment for asthma in the last 12 months?	Yes ☐1 No ☐0 Yes ☐1 No ☐0
3. How old were you when you first had symptoms of asthma?	_____ years old
4. In general, how would you rate your health? (tick one box only)	Excellent ☐4 Very good ☐3 Good ☐2 Fair ☐1 Poor ☐0
5. Do you have a written asthma action plan, that is, written instructions for what to do if your asthma is worse or out of control?	Yes ☐1 No ☐0 Don't know ☐99

THE NEXT 6 QUESTIONS ASK ABOUT HOW YOUR ASTHMA HAS BEEN
IN THE LAST **ONE WEEK**

6. On average, in the last week, how often were you woken by your asthma during the night? (Tick one box only)	Not at all ☐0 Hardly ever ☐1 A few times ☐2 Several times ☐3 Many times ☐4 A great many times ☐5 Unable to sleep because of asthma ☐6
7. On average, in the last week, how were your asthma symptoms when you woke up in the morning? (Tick one box only)	No symptoms ☐0 Very mild symptoms ☐1 Mild symptoms ☐2 Moderate symptoms ☐3 Quite severe symptoms ☐4 Severe symptoms ☐5 Very severe symptoms ☐6

8. In general, in the last week, how limited were you in your day-to-day activities because of your asthma?

    (Tick one box only)

Not at all limited	☐	0
Very slightly limited	☐	1
Slightly limited	☐	2
Moderately limited	☐	3
Very limited	☐	4
Extremely limited	☐	5
Totally limited	☐	6

9. In general, in the last week, how much shortness of breath did you experience because of your asthma?

    (Tick one box only)

None	☐	0
Very little	☐	1
A little	☐	2
A moderate amount	☐	3
Quite a lot	☐	4
A great deal	☐	5
An extreme amount	☐	6

10. In general, in the last week, how often did you wheeze?

    (Tick one box only)

None of the time	☐	0
Hardly any of the time	☐	1
A little of the time	☐	2
A moderate amount of the time	☐	3
A lot of the time	☐	4
Most of the time	☐	5
All the time	☐	6

11. On average, in the last week, how many puffs of relief medication (short-acting bronchodilator such as Ventolin, Bricanyl etc) have you used each day? (If you are not sure how to answer this question, please ask for help)

    (Tick one box only)

None	☐	0
1–2 puffs per day	☐	1
3–4 puffs per day	☐	2
5–8 puffs per day	☐	3
9–12 puffs per day	☐	4
13–16 puffs per day	☐	5
More than 16 puffs per day	☐	6

In the last 4 weeks, what medications have you taken for your asthma? Fill in the columns below, with one medication in each column. Include inhalers, tablets, natural/herbal medicines or vitamin supplements that you take for asthma. The extra page contains names and photographs of inhalers to help you identify the one(s) you are taking.

	MEDICATION 1	MEDICATION 2	MEDICATION 3	MEDICATION 4	MEDICATION 5
12. Write the name of each medication, e.g. Ventolin					
13. Description of medication, e.g. blue inhaler, white tablet					
14. In the last 4 weeks, did you take this medication most days, or just when you had symptoms, or both?	Most days ☐1 Symptoms ☐2 Both ☐3	Most days ☐1 Symptoms ☐2 Both ☐3	Most days ☐1 Symptoms ☐2 Both ☐3	Most days ☐1 Symptoms ☐2 Both ☐3	Most days ☐1 Symptoms ☐2 Both ☐3
15. In the last 4 weeks, how many days a week (on average) did you take this medication?	____ days/week	____ days/week	____ days/week	____ days/week	____ days/week

The next 4 questions are FOR INHALERS ONLY (leave these questions blank in the columns for other medications)
    Where do you keep each type of inhaler? (*In the boxes, write how many of each type of inhaler are in each place*)

	MEDICATION 1	MEDICATION 2	MEDICATION 3	MEDICATION 4	MEDICATION 5
16. How many inhalers are kept **at home** in a fixed location e.g. bedroom, bathroom?	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____
17. How many inhalers are kept **at home** but not in any particular place?	☐inhalers	☐inhalers	☐inhalers	☐inhalers	☐inhalers
18. How many inhalers are kept in **another location** e.g. work, gym bag?	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____
19. How many inhalers do you **carry around** with you?	☐inhalers	☐inhalers	☐inhalers	☐inhalers	☐inhalers

IF YOU HAVE ONLY USED A BLUE RELIEVER INHALER OR NEBULISER IN THE LAST 4 WEEKS, **SKIP TO QUESTION 24**

Questions 20 to 23:If you used <u>any</u> of the medications on the list below in the last 4 weeks, circle the medication name, and answer the next 4 questions about that medication.

If you used more than one medication on the list, circle each of their names, but answer the next 4 questions only about the medication that is <u>highest</u> on the list.

1. Seretide
2. Symbicort
3. Alvesco
4. Flixotide
5. Pulmicort
6. Qvar
7. Singulair tablets
8. Intal
9. Tilade
10. Nuelin
11. Prednisone

Write the name of the medication that you are answering these 4 questions about:

_____ (medication name)

20. In the last 4 weeks, have you at times been careless about using this medication?	Yes	$_0$	No	$_1$
21. In the last 4 weeks, have you ever forgotten to use this medication?	Yes	$_0$	No	$_1$
22. In the last 4 weeks, have you ever stopped using this medication because you felt better?	Yes	$_0$	No	$_1$
23. In the last 4 weeks, have you ever used this inhaler less than the doctor prescribed because you felt better?	Yes	$_0$	No	$_1$

THE NEXT TWO PAGES CONTAIN A SERIES OF STATEMENTS DESCRIBING THE WAY IN WHICH ASTHMA (OR ITS TREATMENT) AFFECTS SOME PEOPLE.

PLEASE TICK THE RESPONSE TO EACH STATEMENT WHICH MOST CLOSELY APPLIES TO YOU OVER THE LAST FOUR WEEKS.

	Not at all	Mildly	Moderately	Severely	Very severely
24. I have been troubled by episodes of shortness of breath.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
25. I have been troubled by wheezing attacks	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
26. I have been troubled by tightness in the chest	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
27. I have been restricted in walking down the street on level ground or doing light housework because of asthma	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
28. I have been restricted in walking up hills or doing heavy housework because of asthma	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
29. I have felt tired or a general lack of energy	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
30. I have been unable to sleep at night	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
31. I have felt sad or depressed	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
32. I have felt frustrated with myself	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
33. I have felt anxious, under tension or stressed	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
34. I have felt that asthma is preventing me from achieving what I want from life	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
35. Asthma has interfered with my social life	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

	Not at all	Mildly	Moderately	Severely	Very severely
36. I have been limited in going to certain places because they are bad for my asthma	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
37. I have been limited in going to certain places because I have been afraid of getting an asthma attack and not being able to get help	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
38. I have been restricted in the sports, hobbies or other recreations I can engage in because of my asthma.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
39. I have felt generally restricted.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
40. I have felt that asthma is controlling my life.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
41. I have been worried about my present or future health because of asthma.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
42. I have worried about asthma shortening my life.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
43. I have felt dependent on my asthma inhalers.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

THE NEXT FEW QUESTIONS ASK ABOUT THE LAST **FOUR WEEKS**

44. During the last 4 weeks, how often did your asthma interfere with your daily activities? (tick one box only)

All of the time ☐ 3
Most of the time ☐ 2
Some of the time ☐ 1
None of the time ☐ 0

45. In the last 4 weeks, did you access the internet?

At home   Yes ☐ 1   No ☐ 0
At work   Yes ☐ 1   No ☐ 0
Other locations   Yes ☐ 1   No ☐ 0

46. In the last 4 weeks, did you use the internet to access information about health issues?   Yes ☐ 1   No ☐ 0

THE NEXT SET OF QUESTIONS ARE ABOUT THE LAST 4 WEEKS <u>AND</u> THE LAST 12 MONTHS. **ANSWER <u>BOTH</u> COLUMNS**.

Have you taken any of the following actions <u>for asthma</u> in the last 4 weeks or the last 12 months?

Action taken for asthma	In the last 4 weeks	In the last 12 months
47. Admitted to hospital as an inpatient for asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0 If Yes, how often in the last 12 months? _____ times
48. Visited emergency/ casualty for asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0 If Yes, how often in the last 12 months? _____ times
49. Consulted a doctor urgently about asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0 If Yes, how often in the last 12 months? _____ times
50. Had a non-urgent visit with a GP or clinic about your asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0 If Yes, how often in the last 12 months? _____ times
51. Had days away from study/work because of asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0
52. Had other days of reduced activities because of asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0
53. Used natural/herbal medicines, vitamin supplements or alternative therapies for your asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0

THE NEXT FEW QUESTIONS ARE ABOUT THE **LAST 12 MONTHS**

54. **In the last 12 months**, where have you obtained information about asthma?

a. Relative/Friend	Yes ☐ 1....No ☐ 0
b. Doctor	Yes ☐ 1....No ☐ 0
c. Hospital Staff (Doctors, Nurses	Yes ☐ 1....No ☐ 0
d. Community Nurse	Yes ☐ 1....No ☐ 0
e. Complementary/alternative practitioner	Yes ☐ 1....No ☐ 0
f. Pharmacist/pharmacy assistant	Yes ☐ 1....No ☐ 0
g. Asthma Educator	Yes ☐ 1....No ☐ 0
h. Other health professional	Yes ☐ 1....No ☐ 0
i. Asthma Foundation NSW staff	Yes ☐ 1....No ☐ 0
j. Pharmaceutical company	Yes ☐ 1....No ☐ 0
k. Asthma Foundation NSW website	Yes ☐ 1....No ☐ 0
l. Other internet websites	Yes ☐ 1....No ☐ 0
m. Media (TV, newspaper	Yes ☐ 1....No ☐ 0
n. Books	Yes ☐ 1....No ☐ 0
o. Workplace staff	Yes ☐ 1....No ☐ 0
p. Child care staff	Yes ☐ 1....No ☐ 0
q. School staff	Yes ☐ 1....No ☐ 0
r. Other (please specify) _____ _____	Yes ☐ 1....No ☐ 0

FOR EACH OF THE FOLLOWING STATEMENTS, PLEASE MARK YOUR RESPONSE BY A TICK IN THE APPROPRIATE BOX.

	Definitely true	Mostly true	Do not know	Mostly false	Definitely false
55. I have sufficient understanding about my asthma	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
56. I know what to expect from my asthma management	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
57. I dislike being wheezy, short of breath or coughing in public	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
58. My current management will keep my asthma at bay	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
59. I am receiving the best possible management	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
60. The management of my asthma is a mystery for me (reverse scored)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
61. It is helpful to know the experiences of others with asthma	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
62. Natural remedies are safer than medicines	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
63. My doctors have limited management options to offer me	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
64. My medications are working	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
65. Using any medication involves some risk	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
66. I am on too many medications	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
67. I have a say in the way my asthma is managed	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
68. I have sufficient understanding about the options for managing my asthma	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
69. My doctors are very knowledgeable	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
70. I dislike using inhalers in public	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
71. My pharmacist is very knowledgeable	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

FOR EACH OF THE FOLLOWING STATEMENTS, PLEASE MARK YOUR RESPONSE BY A TICK IN THE APPROPRIATE BOX.

	Extremely	Quite a bit	Moderately	Slightly	Not at all
72. I am concerned about the side effects from my medications	☐5	☐4	☐3	☐2	☐1
73. It is unpleasant (e.g. taste, smell) to use some of my medications	☐5	☐4	☐3	☐2	☐1
74. It is physically difficult to handle some of my medications	☐5	☐4	☐3	☐2	☐1
75. I am satisfied with the information my doctors share with me	☐5	☐4	☐3	☐2	☐1
76. My doctors are compassionate	☐5	☐4	☐3	☐2	☐1
77. Financial difficulties limit my access to the best healthcare	☐5	☐4	☐3	☐2	☐1
78. My doctors spend adequate time with me	☐5	☐4	☐3	☐2	☐1
79. The management of my asthma disrupts my life	☐5	☐4	☐3	☐2	☐1
80. My pharmacist spends adequate time with me	☐5	☐4	☐3	☐2	☐1

FOR EACH OF THE FOLLOWING STATEMENTS, PLEASE MARK YOUR RESPONSE BY A TICK IN THE APPROPRIATE BOX.

	Always	Often	Sometimes	Rarely	Never
81. I get confused about my medications	☐5	☐4	☐3	☐2	☐1
82. I have strict routines for using my regular medications	☐5	☐4	☐3	☐2	☐1
83. I keep my medications close to where I need to use them	☐5	☐4	☐3	☐2	☐1
84. I ensure I have enough medications so I do not run out	☐5	☐4	☐3	☐2	☐1
85. I strive to follow the instructions of my doctors	☐5	☐4	☐3	☐2	☐1
86. I make changes in the recommended asthma management to suit my lifestyle	☐5	☐4	☐3	☐2	☐1
87. I vary my recommended asthma management based on how I am feeling	☐5	☐4	☐3	☐2	☐1
88. I put up with my asthma before taking any action	☐5	☐4	☐3	☐2	☐1

THESE QUESTIONS ARE ABOUT ISSUES THAT MIGHT BE IMPORTANT TO YOU.
Please circle the number of the rating score that corresponds with your opinion

Issue	Level of Importance				
89. Being able to cope with my asthma day-to-day	1 Low	2	3	4	5 High
90. The cost of asthma treatment and medications	1 Low	2	3	4	5 High
91. Being able to deal with a severe asthma attack	1 Low	2	3	4	5 High
92. Having the latest information about asthma	1 Low	2	3	4	5 High
93. Understanding when to use asthma medications	1 Low	2	3	4	5 High
94. Understanding how asthma medications work	1 Low	2	3	4	5 High
95. Understanding the side effects of asthma medications	1 Low	2	3	4	5 High
96. Knowing what triggers my asthma	1 Low	2	3	4	5 High
97. Knowing how to avoid asthma triggers	1 Low	2	3	4	5 High
98. Working with my GP to manage my asthma	1 Low	2	3	4	5 High
99. Having a pharmacist who gives me asthma information	1 Low	2	3	4	5 High
100.Using natural/herbal medicines, vitamin supplements or alternative therapies to manage my asthma	1 Low	2	3	4	5 High
101.Being able to exercise without worry or discomfort	1 Low	2	3	4	5 High
102.Having a workplace, gym, sports club, school or preschool which is knowledgeable about asthma and can help me in an emergency	1 Low	2	3	4	5 High
103.Having access to support that can help reduce the anxiety of living with asthma	1 Low	2	3	4	5 High
104.Research into the prevention of and a cure for asthma	1 Low	2	3	4	5 High
105.Research that will help me in day-to-day living with asthma	1 Low	2	3	4	5 High
106.Having contact with other people who have asthma to discuss problems and solutions	1 Low	2	3	4	5 High

Issue	Level of Importance				
107. Participating in online (internet) asthma education programs	1 Low	2	3	4	5 High
108. Hiding my asthma from other people	1 Low	2	3	4	5 High

THE NEXT QUESTIONS ARE ABOUT THE ASTHMA FOUNDATION OF NSW

Asthma Foundation NSW is a not-for-profit organisation providing programmes and services to people with asthma and the community in NSW.

What programs, services and activities should Asthma Foundation NSW be involved in to support people with asthma to live well and manage their asthma better?

Please circle the number of the score that corresponds with your opinion

Program, service or activity from Asthma Foundation NSW	Level of Importance that these services would have to you				
109. Representing the needs of people with asthma, e.g. to government	1 Low	2	3	4	5 High
110. Supporting workplaces, gyms, sports clubs, schools and preschools to be knowledgeable about asthma and able to help in an asthma emergency	1 Low	2	3	4	5 High
111. Holding public information and education sessions for people with asthma and their families	1 Low	2	3	4	5 High
112. Providing asthma information on the internet	1 Low	2	3	4	5 High
113. Providing opportunities on the internet to connect people with asthma for support or to discuss problems and solutions	1 Low	2	3	4	5 High
114. Providing email or SMS alerts on environmental hazards such as bushfires, high levels of pollution or pollen	1 Low	2	3	4	5 High
115. Providing information on allergies	1 Low	2	3	4	5 High
116. Offering a Membership program that provides regular information updates	1 Low	2	3	4	5 High

117.	In the last 12 months, have you used any Asthma Foundation NSW services?	Yes ☐ 1
		No ☐ 0
		Don't know ☐ 99

a. If Yes, please list the services that you have used

_____

_____

_____

_____

b. If Yes, would you use these service(s) again in the future?	Yes ☐ 1
	No ☐ 0

THE NEXT FEW QUESTIONS ARE ABOUT THE LAST 12 MONTHS

Have any of the following problems interfered with managing your asthma in the **last 12 months**?

118.	Difficulty getting an appointment with a GP about my asthma?	Yes ☐ 1 No ☐ 0
		Not applicable ☐ 98
119.	Difficulty getting a referral to a specialist for my asthma if I think I need one?	Yes ☐ 1 No ☐ 0
		Not applicable ☐ 98
120.	Cost of seeing a GP or specialist?	Yes ☐ 1 No ☐ 0
		Not applicable ☐ 98
121.	Cost or difficulty of transport to doctor or pharmacist?	Yes ☐ 1 No ☐ 0
		Not applicable ☐ 98
122.	Cost of medications?	Yes ☐ 1 No ☐ 0
		Not applicable ☐ 98

GENERAL QUESTIONS

123. How old are you today?	_____ years
124. Are you male or female?	Male ☐ 0 Female ☐ 1
125. What is your height without shoes?	_____ cm OR _____ ft _____ inches
126. What is your weight (in normal daytime clothing)?	_____ Kg OR _____ stone _____ lb
127. Do you currently smoke?	Yes ☐ 1 No ☐ 0
a. If yes, Do you smoke at least once a week?	Yes ☐ 1 No ☐ 0
128. Apart from Medicare, are you currently covered by private health insurance?	Yes ☐ 1 No ☐ 0 Don't know ☐ 99
129. In the last 4 weeks, which of the following best describes your employment status: (tick one) Employed full-time ☐ 5 Employed part-time ☐ 4 Employed casual ☐ 3 Unpaid work ☐ 2 Retired ☐ 1 Not currently working ☐ 0	
130. Do you currently receive a government pension, allowance or benefit?	Yes ☐ 1 No ☐ 0 Don't know ☐ 99
131. Did you qualify for the medication Safety Net card last year (2006)?	Yes ☐ 1 No ☐ 0 Don't know ☐ 99

132. Are you covered by any of the following concession cards?		
a. Health care card	Yes ☐ 1 No ☐ 0	Don't know ☐ 99
b. Pensioner concession card	Yes ☐ 1 No ☐ 0	Don't know ☐ 99
c. Commonwealth seniors health card	Yes ☐ 1 No ☐ 0	Don't know ☐ 99
d. Veterans' Affairs treatment entitlement card	Yes ☐ 1 No ☐ 0	Don't know ☐ 99

133. What is the highest level of education you have completed? (tick one)

Still at school or not yet at school	☐ 4
Completed primary school	☐ 3
Completed year _____ of secondary school	☐ 2
Completed tertiary studies (TAFE, Uni etc)	☐ 1

134. What is your postcode?   ☐ ☐ ☐ ☐

135. In which country were you born? _____

136. Are you of Aboriginal origin or Torres Strait Islander origin or both?

Aboriginal	Yes ☐ 1 No ☐ 0
Torres Strait Islander	Yes ☐ 1 No ☐ 0

137. Do you usually speak a language other than English at home?   Yes ☐ 1   No ☐ 0

b. If yes, which language(s)?

_____

_____

THANK YOU VERY MUCH FOR COMPLETING THIS SURVEY

Please post the survey back to the Woolcock Institute of Medical Research in the reply-paid envelope

APPENDIX 2

Final questionnaire for parents/carers of children with asthma aged 5-13 years

The University of Sydney WOOLCOCK
INSTITUTE of MEDICAL RESEARCH

☐ ☐ ☐ ☐
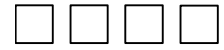
NEW SOUTH WALES ASTHMA SURVEY

(for parents of children with asthma aged 5-13 years)

Name: _____

Contact number: _____

For more information about this survey, please see the separate Information Page

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Instructions

- This survey should take you about 20 minutes to finish.

- Most of the answers are Yes/No or multiple choice, so please tick the most appropriate answer for each question.

- Some questions might seem to be similar, but we would like you to complete all of them.

- Post the questionnaire back to us in the reply-paid envelope

If you would like to complete the survey by telephone, please call Dr Helen Reddel on 02 9515 7026, and keep this booklet for reference when you are contacted by phone.

If you have any questions or problems with the survey, please contact Dr Helen Reddel, Woolcock Institute of Medical Research, phone 02 9515 7026, email: hkr@med.usyd.edu.au

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1. Please write in today's date	☐☐ ☐☐ /2007 Day / Month
2. Have you ever been told by a doctor or nurse that your child has asthma?	Yes ☐1 No ☐0
If the answer is 'No', please skip to Question 3	
2a. If Yes, has your child had symptoms of asthma or taken treatment for asthma in the last 12 months?	Yes ☐1 No ☐0
3. How old was your child when he/she first had symptoms of asthma?	_____ years old
4. In general, how would you rate your child's health? (tick one box only)	Excellent ☐4 Very good ☐3 Good ☐2 Fair ☐1 Poor ☐0
5. Does your child have a written asthma action plan, that is, written instructions for what to do if his/her asthma is worse or out of control?	Yes ☐1 No ☐0 Don't know ☐99

THE NEXT 6 QUESTIONS ASK ABOUT HOW YOUR CHILD'S ASTHMA HAS BEEN IN THE LAST **ONE WEEK**. TICK ONE BOX ONLY FOR EACH QUESTION.

6. On average, in the last week, how often was your child woken by asthma during the night?	Not at all ☐7 Hardly ever ☐6 A few times ☐5 Several times ☐4 Many times ☐3 A great many times ☐2 Unable to sleep because of asthma ☐1
7. On average, in the last week, how were your child's asthma symptoms when he/she woke up in the morning?	No symptoms ☐7 Very mild symptoms ☐6 Mild symptoms ☐5 Moderate symptoms ☐4 Quite severe symptoms ☐3 Severe symptoms ☐2 Very severe symptoms ☐1

8. In general, in the last week, how limited was your child in his/her day-to-day activities because of asthma?

Not at all limited	☐	7
Very slightly limited	☐	6
Slightly limited	☐	5
Moderately limited	☐	4
Very limited	☐	3
Extremely limited	☐	2
Totally limited	☐	1

9. In general, in the last week, how much shortness of breath did your child experience because of asthma?

None	☐	7
Very little	☐	6
A little	☐	5
A moderate amount	☐	4
Quite a lot	☐	3
A great deal	☐	2
An extreme amount	☐	1

10. In general, in the last week, how often did your child wheeze?

None of the time	☐	7
Hardly any of the time	☐	6
A little of the time	☐	5
A moderate amount of the time	☐	4
A lot of the time	☐	3
Most of the time	☐	2
All the time	☐	1

11. On average, in the last week, how many puffs of relief medication (short-acting bronchodilator such as Ventolin, Bricanyl etc) has your child used each day? (If you are not sure how to answer this question, please ask for help)

None	☐	7
1–2 puffs per day	☐	6
3–4 puffs per day	☐	5
5–8 puffs per day	☐	4
9–12 puffs per day	☐	3
13–16 puffs per day	☐	2
More than 16 puffs per day	☐	1

THE NEXT SET OF QUESTIONS ARE DESIGNED TO FIND OUT HOW YOU HAVE BEEN **DURING THE LAST WEEK**.

WE WANT TO KNOW ABOUT THE WAYS IN WHICH YOUR CHILD'S ASTHMA HAS INTERFERED WITH YOUR NORMAL DAILY ACTIVITIES AND HOW THIS HAS MADE YOU FEEL.

Please answer each question by placing a tick in the appropriate box. Tick one box only for each question

12. In the last week, how often did you feel helpless or frightened when your child experienced bouts of coughing, wheezing, or breathlessness?	
All of the time	☐ 7
Most of the time	☐ 6
Quite often	☐ 5
Some of the time	☐ 4
Once in a while	☐ 3
Hardly any of the time	☐ 2
None of the time	☐ 1
13. In the past week, how often did your family need to change plans because of your child's asthma?	
All of the time	☐ 7
Most of the time	☐ 6
Quite often	☐ 5
Some of the time	☐ 4
Once in a while	☐ 3
Hardly any of the time	☐ 2
None of the time	☐ 1
14. In the past week, how often did you feel frustrated or impatient because your child was irritable due to asthma?	
All of the time	☐ 7
Most of the time	☐ 6
Quite often	☐ 5
Some of the time	☐ 4
Once in a while	☐ 3
Hardly any of the time	☐ 2
None of the time	☐ 1
15. In the past week, how often did your child's asthma interfere with your job or work around the house?	
All of the time	☐ 7
Most of the time	☐ 6
Quite often	☐ 5
Some of the time	☐ 4
Once in a while	☐ 3
Hardly any of the time	☐ 2
None of the time	☐ 1

16. In the past week, how often did you feel upset because of your child's cough, wheeze or breathlessness?

All of the time	☐	7
Most of the time	☐	6
Quite often	☐	5
Some of the time	☐	4
Once in a while	☐	3
Hardly any of the time	☐	2
None of the time	☐	1

17. In the past week, how often did you have sleepless nights because of your child's asthma?

All of the time	☐	7
Most of the time	☐	6
Quite often	☐	5
Some of the time	☐	4
Once in a while	☐	3
Hardly any of the time	☐	2
None of the time	☐	1

18. In the past week, how often were you bothered because your child's asthma interfered with family relationships?

All of the time	☐	7
Most of the time	☐	6
Quite often	☐	5
Some of the time	☐	4
Once in a while	☐	3
Hardly any of the time	☐	2
None of the time	☐	1

19. In the past week, how often were you awakened during the night because of your child's asthma?

All of the time	☐	7
Most of the time	☐	6
Quite often	☐	5
Some of the time	☐	4
Once in a while	☐	3
Hardly any of the time	☐	2
None of the time	☐	1

20. In the past week, how often did you feel distressed that your child has asthma?

All of the time	☐	7
Most of the time	☐	6
Quite often	☐	5
Some of the time	☐	4
Once in a while	☐	3
Hardly any of the time	☐	2
None of the time	☐	1

21. In the past week, how worried or concerned were you about your child's performance of normal daily activities?

Very, very worried or concerned	☐	7
Very worried or concerned	☐	6
Fairly worried or concerned	☐	5
Somewhat worried or concerned	☐	4
A little worried or concerned	☐	3
Hardly worried or concerned	☐	2
Not worried or concerned	☐	1

22. In the past week, how worried or concerned were you about your child's asthma medications and side effects?

Very, very worried or concerned	☐	7
Very worried or concerned	☐	6
Fairly worried or concerned	☐	5
Somewhat worried or concerned	☐	4
A little worried or concerned	☐	3
Hardly worried or concerned	☐	2
Not worried or concerned	☐	1

23. In the past week, how worried or concerned were you about being overprotective of your child?

Very, very worried or concerned	☐	7
Very worried or concerned	☐	6
Fairly worried or concerned	☐	5
Somewhat worried or concerned	☐	4
A little worried or concerned	☐	3
Hardly worried or concerned	☐	2
Not worried or concerned	☐	1

24. In the past week, how worried or concerned were you about your child being able to lead a normal life?

Very, very worried or concerned	☐	7
Very worried or concerned	☐	6
Fairly worried or concerned	☐	5
Somewhat worried or concerned	☐	4
A little worried or concerned	☐	3
Hardly worried or concerned	☐	2
Not worried or concerned	☐	1

THE NEXT FEW QUESTIONS ASK ABOUT THE LAST **FOUR WEEKS**

25. During the last 4 weeks, how often did your child's asthma interfere with his/her daily activities? *(tick one box only)*

All of the time	☐	3
Most of the time	☐	2
Some of the time	☐	1
None of the time	☐	0

26. In the last 4 weeks, did <u>you</u> access the internet?

At home	Yes ☐ 1	No ☐ 0
At work	Yes ☐ 1	No ☐ 0
Other locations	Yes ☐ 1	No ☐ 0

27. In the last 4 weeks, did <u>you</u> use the internet to access information about health issues? ....   Yes ☐ 1   No ☐ 0

In the last 4 weeks, what medications has your child taken for asthma? Fill in the columns below, with one medication in each column. Include inhalers, tablets, natural/herbal medicines or vitamin supplements that your child takes for asthma. The extra page contains names and photographs of inhalers to help you identify the one(s) you are taking.

	MEDICATION 1	MEDICATION 2	MEDICATION 3	MEDICATION 4	MEDICATION 5
28. Write the name of each medication, e.g. Ventolin					
29. Description of medication, e.g. blue inhaler, white tablet					
30. In the last 4 weeks, did your child take this medication most days, or just when he/she had symptoms, or both?	Most days ☐1 Symptoms ☐2 Both ☐3	Most days ☐1 Symptoms ☐2 Both ☐3	Most days ☐1 Symptoms ☐2 Both ☐3	Most days ☐1 Symptoms ☐2 Both ☐3	Most days ☐1 Symptoms ☐2 Both ☐3
31. In the last 4 weeks, how many days a week (on average) did your child take this medication?	____ days/week	____ days/week	____ days/week	____ days/week	____ days/week
The next 4 questions are FOR INHALERS ONLY (leave these questions blank in the columns for other medications) Where does your child keep each type of inhaler? (*In the boxes, write how many of each type of inhaler are in each place*)					
32. How many inhalers are kept **at home** in a fixed location e.g. bedroom, bathroom?	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____
33. How many inhalers are kept **at home** but not in any particular place?	☐inhalers	☐inhalers	☐inhalers	☐inhalers	☐inhalers
34. How many inhalers are kept in **another location** e.g. school office, gym bag?	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____	☐inhalers Where are they? _____ _____
35. How many inhalers does your child **carry around** with him/her?	☐inhalers	☐inhalers	☐inhalers	☐inhalers	☐inhalers

IF YOUR CHILD HAS ONLY USED A BLUE RELIEVER INHALER OR NEBULISER IN THE LAST 4 WEEKS, **SKIP TO QUESTION 40**

THE NEXT 4 QUESTIONS ARE ABOUT **ANY ASTHMA MEDICATIONS OTHER THAN A BLUE RELIEVER INHALER OR NEBULISER** THAT YOUR CHILD TOOK IN THE **LAST 4 WEEKS**. These medications might include:

1. Seretide
2. Symbicort
3. Alvesco
4. Flixotide
5. Pulmicort
6. Qvar
7. Singulair tablets
8. Intal
9. Tilade
10. Nuelin
11. Prednisone

If your child used a medication on this list in the last 4 weeks, **circle** the medication name, and answer the next 4 questions about that medication. If your child used more than one medication on the list, answer the questions about the one that is highest on the list.

Write the name of the medication that you are answering these 4 questions about:

_____ (medication name)

36. In the last 4 weeks, has your child at times been careless about using this medication?	Yes	☐ 0	No	☐ 1	
37. In the last 4 weeks, has your child ever forgotten to use this medication?	Yes	☐ 0	No	☐ 1	
38. In the last 4 weeks, has your child ever stopped using this medication because he/she felt better?	Yes	☐ 0	No	☐ 1	
39. In the last 4 weeks, has your child ever used this inhaler less than the doctor prescribed because he/she felt better?	Yes	☐ 0	No	☐ 1	

THE NEXT SET OF QUESTIONS ARE ABOUT THE LAST 4 WEEKS <u>AND</u> THE LAST 12 MONTHS. **ANSWER <u>BOTH</u> COLUMNS**.

Have you taken any of the following actions <u>for your child's asthma</u> in the last 4 weeks or the last 12 months?

Action taken for asthma	In the last 4 weeks	In the last 12 months
40. Admitted to hospital as an inpatient for asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0 If Yes, how often in the last 12 months? _____ times
41. Visited emergency/ casualty for asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0 If Yes, how often in the last 12 months? _____ times
42. Consulted a doctor urgently about asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0 If Yes, how often in the last 12 months? _____ times
43. Had a non-urgent visit with a GP or clinic about your asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0 If Yes, how often in the last 12 months? _____ times
44. Had days away from study/work because of asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0
45. Had other days of reduced activities because of asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0
46. Used natural/herbal medicines, vitamin supplements or alternative therapies for your asthma	Yes ☐ 1 No ☐ 0	Yes ☐ 1 No ☐ 0

THE NEXT SET OF QUESTIONS IS ABOUT THE **LAST 12 MONTHS**

47. **In the last 12 months**, where have you obtained information about asthma?

a. Relative/Friend	Yes ☐ 1....No ☐ 0
b. Doctor	Yes ☐ 1....No ☐ 0
c. Hospital Staff (Doctors, Nurses	Yes ☐ 1....No ☐ 0
d. Community Nurse	Yes ☐ 1....No ☐ 0
e. Complementary/alternative practitioner	Yes ☐ 1....No ☐ 0
f. Pharmacist/pharmacy assistant	Yes ☐ 1....No ☐ 0
g. Asthma Educator	Yes ☐ 1....No ☐ 0
h. Other health professional	Yes ☐ 1....No ☐ 0
i. Asthma Foundation NSW staff	Yes ☐ 1....No ☐ 0
j. Pharmaceutical company	Yes ☐ 1....No ☐ 0
k. Asthma Foundation NSW website	Yes ☐ 1....No ☐ 0
l. Other internet websites	Yes ☐ 1....No ☐ 0
m. Media (TV, newspaper	Yes ☐ 1....No ☐ 0
n. Books	Yes ☐ 1....No ☐ 0
o. Workplace staff	Yes ☐ 1....No ☐ 0
p. Child care staff	Yes ☐ 1....No ☐ 0
q. School staff	Yes ☐ 1....No ☐ 0
r. Other (please specify) _____ _____	Yes ☐ 1....No ☐ 0

FOR EACH OF THE FOLLOWING STATEMENTS, PLEASE MARK YOUR RESPONSE
BY A TICK IN THE APPROPRIATE BOX.

	Definitely true	Mostly true	Do not know	Mostly false	Definitely false
48. I have sufficient understanding about my child's asthma	☐5	☐4	☐3	☐2	☐1
49. I know what to expect from my child's asthma management	☐5	☐4	☐3	☐2	☐1
50. I dislike my child being wheezy, short of breath or coughing in public	☐5	☐4	☐3	☐2	☐1
51. My child's current management will keep their asthma at bay	☐5	☐4	☐3	☐2	☐1
52. My child is receiving the best possible management	☐5	☐4	☐3	☐2	☐1
53. The management of my child's asthma is a mystery for me	☐1	☐2	☐3	☐4	☐5
54. My child's medications are working	☐5	☐4	☐3	☐2	☐1
55. I have a say in the way my child's asthma is managed	☐5	☐4	☐3	☐2	☐1
56. I have sufficient understanding about the options for managing my child's asthma	☐5	☐4	☐3	☐2	☐1
57. My child's doctors are very knowledgeable	☐5	☐4	☐3	☐2	☐1
58. It is helpful to know the experiences of others with similar illness as my child's	☐5	☐4	☐3	☐2	☐1
59. Natural remedies are safer than medicines	☐5	☐4	☐3	☐2	☐1
60. My child's doctors have limited management options to offer us	☐5	☐4	☐3	☐2	☐1
61. Using any medication involves some risk	☐5	☐4	☐3	☐2	☐1
62. My child is on too many medications	☐5	☐4	☐3	☐2	☐1
63. My pharmacist is very knowledgeable	☐5	☐4	☐3	☐2	☐1
64. I dislike my child using inhalers in public	☐5	☐4	☐3	☐2	☐1

FOR EACH OF THE FOLLOWING STATEMENTS, PLEASE MARK YOUR RESPONSE BY A TICK IN THE APPROPRIATE BOX.

	Extremely	Quite a bit	Moderately	Slightly	Not at all
65. My child's doctors are compassionate	☐5	☐4	☐3	☐2	☐1
66. I am satisfied with the information my child's doctors share with me	☐5	☐4	☐3	☐2	☐1
67. My child's doctors spend adequate time with me/my child	☐5	☐4	☐3	☐2	☐1
68. I am concerned about the side effects from my child's medications	☐5	☐4	☐3	☐2	☐1
69. It is unpleasant (e.g. taste, smell) for my child to use some of their medications	☐5	☐4	☐3	☐2	☐1
70. It is physically difficult for my child to handle some of their medications	☐5	☐4	☐3	☐2	☐1
71. Financial difficulties limit my child's access to the best healthcare	☐5	☐4	☐3	☐2	☐1
72. The management of my child's asthma disrupts our life	☐5	☐4	☐3	☐2	☐1
73. My pharmacist spends adequate time with me/my child	☐5	☐4	☐3	☐2	☐1

FOR EACH OF THE FOLLOWING STATEMENTS, PLEASE MARK YOUR RESPONSE BY A TICK IN THE APPROPRIATE BOX.

	Always	Often	Sometimes	Rarely	Never
74. I (or my child) have strict routines for using their regular medications	☐5	☐4	☐3	☐2	☐1
75. I (or my child) keep their medications close to where they need to use them	☐5	☐4	☐3	☐2	☐1
76. I (or my child) ensure they have enough medications so they do not run out	☐5	☐4	☐3	☐2	☐1
77. I (or my child) strive to follow the instructions of their doctors	☐5	☐4	☐3	☐2	☐1
78. I (or my child) get confused about their medications	☐5	☐4	☐3	☐2	☐1
79. I (or my child) make changes in the recommended management to suit their lifestyle	☐5	☐4	☐3	☐2	☐1
80. I (or my child) vary their recommended management based on how they are feeling	☐5	☐4	☐3	☐2	☐1
81. I (or my child) put up with their asthma before taking any action	☐5	☐4	☐3	☐2	☐1

THESE QUESTIONS ARE ABOUT ISSUES THAT MIGHT BE IMPORTANT TO YOU WITH REGARD TO YOUR CHILD'S ASTHMA

Please circle the number of the rating score that corresponds with your opinion

Issue	Level of Importance				
82. Being able to cope with my child's asthma day-to-day	1 Low	2	3	4	5 High
83. The cost of asthma treatment and medications	1 Low	2	3	4	5 High
84. Being able to cope with a severe asthma attack	1 Low	2	3	4	5 High
85. Having the latest information on the treatment and management of asthma	1 Low	2	3	4	5 High
86. Understanding when my child should use asthma medications	1 Low	2	3	4	5 High
87. Understanding how asthma medications work	1 Low	2	3	4	5 High
88. Understanding the side effects of asthma medications	1 Low	2	3	4	5 High
89. Knowing what triggers my child's asthma	1 Low	2	3	4	5 High
90. Knowing how my child can avoid asthma triggers	1 Low	2	3	4	5 High
91. Having a GP that helps me manage my child's asthma	1 Low	2	3	4	5 High
92. Having a pharmacist who gives me asthma information	1 Low	2	3	4	5 High
93. Using natural/herbal medicines or alternative therapies to manage my child's asthma	1 Low	2	3	4	5 High
94. Being able to manage my child's asthma so he/she can exercise without worry or discomfort	1 Low	2	3	4	5 High
95. Having a workplace, gym, sports club, school or preschool which is knowledgeable about asthma and can help me or my child in an emergency	1 Low	2	3	4	5 High
96. Having access to support that can help reduce the anxiety of living with asthma	1 Low	2	3	4	5 High
97. Research into the prevention of and a cure for asthma	1 Low	2	3	4	5 High
98. Research that will help me in day-to-day living with a child with asthma	1 Low	2	3	4	5 High
99. Having contact with other people who have asthma to discuss problems and solutions	1 Low	2	3	4	5 High

Issue	Level of Importance				
100. Participating in online (internet) asthma education programs	1 Low	2	3	4	5 High
101. Hiding my child's asthma from other people	1 Low	2	3	4	5 High

THE NEXT QUESTIONS ARE ABOUT THE ASTHMA FOUNDATION OF NSW

Asthma Foundation NSW is a not-for-profit organisation providing programmes and services to people with asthma and the community in NSW.

What programs, services and activities should Asthma Foundation NSW be involved in to support people with asthma to live well and manage their asthma better?

Please circle the number of the score that corresponds with your opinion

Program, service or activity from Asthma Foundation NSW	Level of Importance that these services would have to you				
102. Representing the needs of people with asthma, e.g. to government	1 Low	2	3	4	5 High
103. Supporting workplaces, gyms, sports clubs, schools and preschools to be knowledgeable about asthma and able to help in an asthma emergency	1 Low	2	3	4	5 High
104. Holding public information and education sessions for people with asthma and their families	1 Low	2	3	4	5 High
105. Providing asthma information on the internet	1 Low	2	3	4	5 High
106. Providing opportunities on the internet to connect people with asthma for support or to discuss problems and solutions	1 Low	2	3	4	5 High
107. Providing email or SMS alerts on environmental hazards such as bushfires, high levels of pollution or pollen	1 Low	2	3	4	5 High
108. Providing information on allergies	1 Low	2	3	4	5 High
109. Offering a Membership program that provides regular information updates	1 Low	2	3	4	5 High

110.	In the last 12 months, have you used any Asthma Foundation NSW services?	Yes ☐ 1
		No ☐ 0
		Don't know ☐ 99

a. If Yes, please list the services that you have used

_____

_____

_____

_____

b. If Yes, would you use these service(s) again in the future?	Yes ☐ 1
	No ☐ 0

THE NEXT FEW QUESTIONS ARE ABOUT THE LAST 12 MONTHS

Have any of the following problems interfered with managing your child's asthma in the **last 12 months**?

111. Difficulty getting an appointment with a GP about my child's asthma?	Yes ☐ 1 No ☐ 0
	Not applicable ☐ 98
112. Difficulty getting a referral to a specialist for my child's asthma if I think he/she needs one?	Yes ☐ 1 No ☐ 0
	Not applicable ☐ 98
113. Cost of seeing a GP or specialist?	Yes ☐ 1 No ☐ 0
	Not applicable ☐ 98
114. Cost or difficulty of transport to doctor or pharmacist?	Yes ☐ 1 No ☐ 0
	Not applicable ☐ 98
115. Cost of medications?	Yes ☐ 1 No ☐ 0
	Not applicable ☐ 98

GENERAL QUESTIONS

| 116. How old is your child today?	_____ years
117. Is your child male or female?	Male ☐ 0 Female ☐ 1
118. What is your child's height without shoes?	_____ cm OR _____ ft _____ inches
119. What is your child's weight (in normal daytime clothing)?	_____ Kg OR _____ stone _____ lb
120. Does your child currently smoke?	Yes ☐ 1 No ☐ 0
a. If yes, does your child smoke at least once a week?	Yes ☐ 1 No ☐ 0
121. Apart from Medicare, is your child currently covered by private health insurance?	Yes ☐ 1 No ☐ 0 Don't know ☐ 99
122. In the last 4 weeks, which of the following best describes your employment status: (tick one) Employed full-time ☐ 5 Employed part-time ☐ 4 Employed casual ☐ 3 Unpaid work ☐ 2 Retired ☐ 1 Not currently working ☐ 0	
123. Do you currently receive a government pension, allowance or benefit?	Yes ☐ 1 No ☐ 0 Don't know ☐ 99
124. Did your family qualify for the medication Safety Net card last year (2006)?	Yes ☐ 1 No ☐ 0 Don't know ☐ 99

125. Is your child covered by any of the following concession cards?

a. Health care card

Yes ☐ 1   No ☐ 0
Don't know ☐ 99

b. Pensioner concession card

Yes ☐ 1   No ☐ 0
Don't know ☐ 99

c. Commonwealth seniors health card

Yes ☐ 1   No ☐ 0
Don't know ☐ 99

d. Veterans' Affairs treatment entitlement card

Yes ☐ 1   No ☐ 0
Don't know ☐ 99

126. What is the highest level of education your child has completed? (tick one)

Not yet in school ☐ 4

Still in primary school ☐ 3

Completed primary school ☐ 2

Completed year _____ of secondary school ☐ 1

127. What is your postcode? ☐ ☐ ☐ ☐

128. In which country was your child born? _____

129. Is your child of Aboriginal origin or Torres Strait Islander origin or both?

Aboriginal   Yes ☐ 1   No ☐ 0

Torres Strait Islander   Yes ☐ 1   No ☐ 0

130. Do you usually speak a language other than English at home?   Yes ☐ 1   No ☐ 0

b. If yes, which language(s)?

_____

_____

THANK YOU VERY MUCH FOR COMPLETING THIS SURVEY

Please post the survey back to the Woolcock Institute of Medical Research in the reply-paid envelope

APPENDIX 3

Figure A1. Questionnaire returns in the NSW Asthma Survey
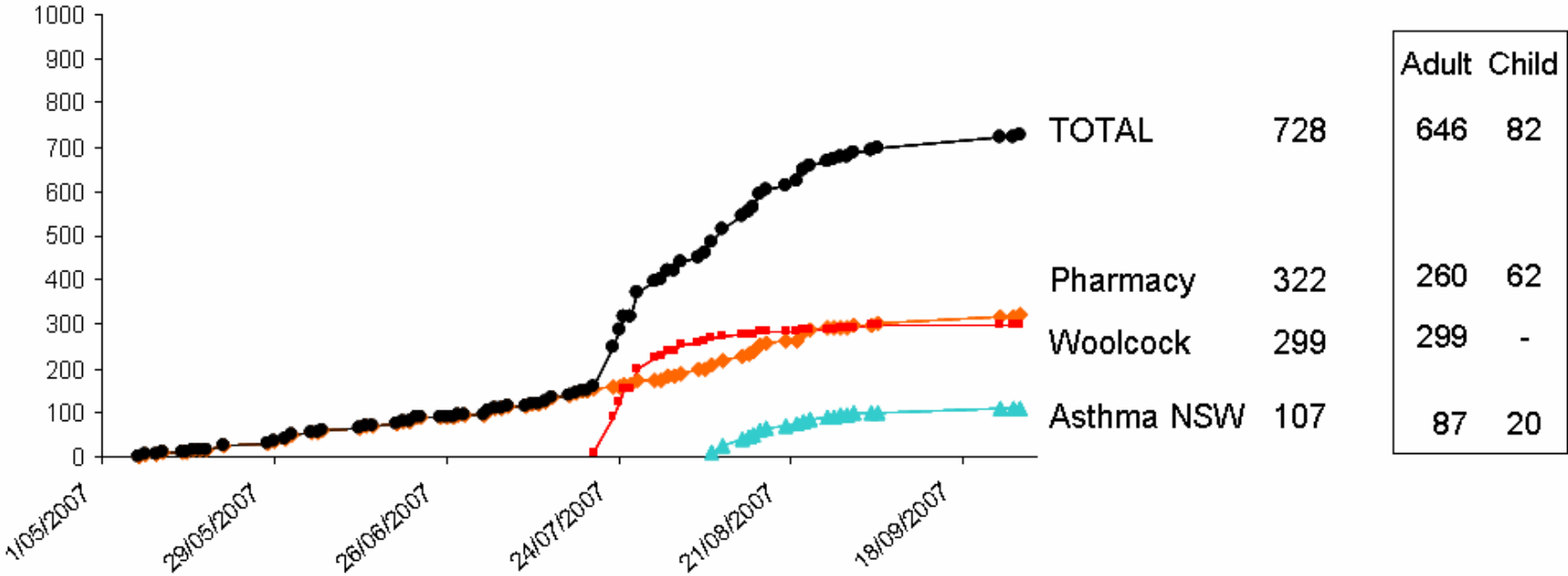
ABSTRACT

To be presented at the Annual Scientific Meeting of the Thoracic Society of Australia and New Zealand, Melbourne, March 2008

Title: Predictors of Poor Asthma Control and Urgent Health Care for Asthma

H.K. Reddel, MBBS PhD[1], S.Z. Bosnic-Anticevich, BPharm PhD[2], P. Correll, BN MPH[1], B.G. Toelle, BA PhD[1], C.R. Jenkins, MBBS MD[1], V. Kritikos, BPharm MPharm PhD[2], R.D. Ampon, MAppStat[1], M. Dephoff, B Health Sci (OT)[3], J. Thomson, BA Communications[3] and G.B. Marks, MBBS PhD[1]. [1]Woolcock Institute of Medical Research, Australia; [2]University of Sydney, Australia and [3]Asthma Foundation NSW, Australia.

Rationale: When direct clinical assessment is not possible, urgent health care utilisation (HCU) is often used as an indirect measure of asthma control. This study aimed to identify factors predicting urgent HCU and asthma control. **Methods**: Patients with doctor-diagnosed asthma were recruited from community pharmacies, a research volunteer database, and Asthma Foundation databases, to complete a questionnaire about asthma. Poor asthma control was defined as Asthma Control Questionnaire (ACQ) score ≥ 1.5. Urgent HCU was defined as hospitalization, ER visit, or urgent doctor visit due to asthma. Multiple logistic regression was used to identify predictors of poor control and urgent HCU. **Results**: Questionnaires were completed by 608 adults (61% female, median age 56 yrs). 87% were using inhaled corticosteroid (ICS) ±long-acting $\beta_2$agonist. 9% were current smokers. Mean ACQ score was 1.4 (95% CI 1.3-1.5), with 40% of participants having poor asthma control (ACQ≥ 1.5). 28% had urgent HCU for asthma in the previous year. Significant independent predictors for poor asthma control were younger age, current smoking, living in more disadvantaged areas, being retired, only primary education, and holding a concession card. Predictors for urgent HCU were younger age, being in full-time employment, only primary education, and non-English speaking background. Neither ICS use nor possession of a written asthma action plan was associated with lower risk for either poor asthma control or HCU. **Conclusions**: Poor asthma control is common even in patients using ICS. Although urgent HCU is often used as an indirect measure of poor asthma control, it is affected by different factors, perhaps because health care utilisation represents a more complex balance between need and access.