The Management of Children's Asthma in Primary Care

Are There Ethnic Differences in Care?

Volume Two: Appendices

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Appendix 1 New Zealand asthma prevalence estimates by ethnicity 1989-2004

Study	Location, age, date data collected	Measure of prevalence	Māori		Non-Māori			
					Pacific		NZE/other	
			n	Prevalence (%)	n	Prevalence (%)	n	Prevalence (%)
Pattemore et al. (1989)	Auckland 7–10 year olds 1985	Wheeze in the last year	509	22.2	460	16.3	1084	16.1
Shaw, Crane, O'Donnell, Porteous, & Coleman (1990)	Hawkes Bay 12–18 years 1975 and 1989	Reported asthma or wheeze			Non-Māori			
	1975 Total N=715 66.8% Māori n ~478 33.2% non-Māori n ~237	1975	~478	27.1	n~ 237	Prevalence=24.2		
	1989 Total N=435 75.4% Māori n ~328 24.6 % non-Māori ~107	1989	~328	36.2	n~107	Prevalence=27.4		
Shaw, Crane, & O'Donnell (1991)	Wairoa 12–18 year olds 1989	Current wheeze (last twelve months)			Non-Māori			
			338	31.1	n=145	Prevalence=22.8		
Barry, Burr, & Limb (1991)	Hastings and Havelock North 12 year olds Date of data collection not stated		Non-NZE Māori 226 Pacific 27 Other/not specified 37		NZE			
		Wheeze in the last 12 months	n=290 Prevalence= 19.3		n=583	Prevalence=17.2		

		Current asthma	n=290 Prevalence= 11.0		n=583 Prevalence=11.1			
Robson et al (1993)	Wellington 12–15 year olds July 1991	Wheeze in the last year (written questionnaire)	375	29	300	20	1170	30
Shaw et al (1994)	Kawerau 8–13 years 1992	Asthma symptoms in previous year	91	21.3			53	21.5
Moyes, Waldon, Ramadas, Crane, & Pearce (1995)	Bay of Plenty 6–7 year olds 13–14 year olds 1992	Wheeze in the last year (written questionnaire) 6–7 year olds 13–14 year olds	 1396 1458	 23* 28*			 1218 1294	 25 31
Pattemore et al. (2004)	6 centres around New Zealand 1992–93	Wheeze in the last twelve months (written questionnaire) 6–7 year olds 13–14 year olds	 3747 3938	 27.6 30.8	 1412 1407	 22.0 21.1	 12190 12387	 24.2 31.7

*Includes Māori and Pacific children. 95% were Māori.

Appendix 2 Critical appraisal of New Zealand literature published between 1988 and 1998 that includes data about ethnic disparities in asthma management

Mitchell, E. A., & Quested, C. (1988). Why are Polynesian children admitted to hospital for asthma more frequently than European children? *New Zealand Medical Journal, 101*(849), 446-448.

Study design	**Participants**	**Exposure (variables) measured and source of information**	**Outcomes measured**
Study not designed to investigate ethnic disparities in management Study was a RCT of an asthma education programme. Results of RCT published in 1986. Time data collected not stated	Children 2–14 years admitted to hospital with diagnosis of asthma Ethnicity classification 'Polynesian' – 156 • 50% or more 'Māori or Pacific Island extractions' NZE – 199 Data obtained during course of a randomised controlled trial of asthma education delivered by community child health nurses	Self-administered questionnaires administered On admission • Referral by GP • Age, gender, parent occupation • Risk factors • Parent history of asthma • Morbidity measures • Number and type of medications 6 months post-discharge (postal) • Morbidity measures • Number and type of medications	Referred to hospital by GP Medications • Number • Type

Mitchell, E. A., & Quested, C. (1988). Why are Polynesian children admitted to hospital for asthma more frequently than European children? *New Zealand Medical Journal, 101*(849), 446-448.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection bias Sample selection from children admitted to hospital Age – Polynesian mean age younger than E **Information bias** Response bias 6 month follow up Polynesian postal return significantly lower than E **Confounders considered** Socioeconomic position (occupation) – adjusted Uncontrolled confounding (data collected but not controlled for) – age, gender, parental history of asthma	**<u>On admission</u>** **Medications** Mean number of drugs Polynesian < E β-agonists Polynesian < E Cromoglycate Polynesian < E Inhaled corticosteroids no difference Theophylline no difference **Referred by GP to hospital** Fewer Polynesian referred by GP **Previous hospital admissions** Polynesian > E **<u>6 month follow up</u>** Mean number of drugs Polynesian < E β-agonists Polynesian < E No ethnic differences for inhaled corticosteroids, cromoglycate, and theophylline	Study not designed for this purpose (i.e. study was designed to trial education programme not to assess ethnic disparities in management) Biological definition of 'Polynesian' (50% of 'blood' Polynesian in order to be classified as 'Polynesian') Incomplete control SEP confounding Other confounders not considered No evidence of difference in severity of asthma at admission No evidence that Polynesian were admitted with less severe asthma (as cause of medication differences on admission)

Garrett, J. E., Mulder, J., & Wong-Toi, H. (1988). Characteristics of asthmatics using an urban accident and emergency department. *New Zealand Medical Journal, 101*(847 Pt 1), 359-361.

Study design	**Participants**	**Exposure (variables) measured and source of information**	**Outcomes measured**
Characteristics of asthmatics using an urban accident and emergency department Cross-sectional survey	Asthmatics attending A&E department 1986 Exclusions • <5 years • >50 years with possible COPD 245 patients • 191 (78%) interviewed 48 –72 hours after visit o 59 (24.9%) Māori o 91 (38.4%) Pacific o 87 (36.7%) E • 54 not contactable o Demographic information for 46 subsequently obtained and included in the study for analysis of these variables. No GP questionnaire o No differences in sex, ethnicity, age and domicile between those interviewed and those not interviewed • GP questionnaire sent to 188/191 interviewed patients. 3 patients had no GP • GP response rate 148/188 (78.7%)	Patient questionnaire Written questionnaire to GP A&E notes Demographics (ethnicity, age, sex, Elley-Irving occupation, domicile) Health service utilisation • GP • Frequency of attendance at A&E	Use of A&E department

Garrett, J. E., Mulder, J., & Wong-Toi, H. (1988). Characteristics of asthmatics using an urban accident and emergency department. *New Zealand Medical Journal, 101*(847 Pt 1), 359-361.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
100% response rate patients 78.7% response rate GP **Confounders considered** Age – stratified for some analyses Do not state how / whether they adjusted for other confounders in logistic regressions	Ethnicity independent predictor of use of A&E P, M>E E, M age specific rates use of A&E higher in younger age groups P age specific rates A&E use higher in older age groups Frequency A&E use M P, E Admission during A&E visit: Frequent attendees more likely to be admitted because had higher number of opportunities (c.f. people attending for first time). Age, ethnicity, domicile, SEP not predictive of admission GP referral to A&E – E, attend during work hours, higher SES, domicile further away from hospital (c.f. those without GP referral) GP use for asthma episode prior to A&E visit No ethnic differences Regular GP 3 patients stated no GP For another 13% GP stated didn't know patient or was only as casual patient. M, P>E no regular GP Low SEP > high SES	Unclear how ethnicity data collected Inadequate control of confounders

Garrett, J., Mulder, J., & Wong-Toi, H. (1989). Reasons for racial differences in A & E attendance rates for asthma. *New Zealand Medical Journal, 102*(864), 121-124.

Study design	**Participants**	**Exposure (variables) measured and source of information**	**Outcomes measured**
Cross-sectional survey	People over 5 years of age attending A&E 74 E 49 Māori 68 Pacific	Questionnaire patient Written questionnaire to GP A&E notes Clinical indices of severity Other measures of severity • Symptoms • Time off work/school • Health service utilisation Self-management skills • Had a peak flow • Had action plan • Had asthma literature Asthma medication knowledge Compliance	Utilisation of • A&E • Urgent medical services (GP after hours services) • GP services • Admitted as result of A&E attendance

Garrett, J., Mulder, J., & Wong-Toi, H. (1989). Reasons for racial differences in A & E attendance rates for asthma. *New Zealand Medical Journal, 102*(864), 121-124.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection 100% response rate patients GP response rate 78.7% **Information bias** 9.7% sample excluded from analysis because did not have all 3 indices of severity recorded. Proportion excluded similar in all 3 ethnic groups **Confounders considered** None Did report that Māori and Pacific had significantly lower SEP but did not state type of measure and no adjustment for this in analyses described	**Morbidity** A&E severity measures ns Asthma symptoms daytime • P<E • M<E ns Asthma symptoms night ns Frequent A&E visits M> E, P Admissions in last year M>E, P Days off work / school M>E, P **Self-management** Has PEFR meter P<M<E • P vs E p<0.005 • M p=0.06 Action plan P<E Information on asthma P<E **Knowledge** Recall medications P<M, E Know preventer • P<E	No multivariable analyses done Māori and Pacific more likely to be on theophylline than inhaled steroids or cromoglycate Concluded that M, P higher A&E use • Possibly due to higher health need (illness and asthma higher in M, P) • Not due to more severe asthma or to earlier use with less severe as severity measures same • Concluded that P asthma less severe as on less medication, less steroids • Could be due to different help seeking behaviour – P, M less regular GP, less referrals, and relatively lower use of urgent services • Compliance in all three groups 'uniformly poor'

Garrett, J., Mulder, J., & Wong-Toi, H. (1989). Reasons for racial differences in A & E attendance rates for asthma. *New Zealand Medical Journal, 102*(864), 121-124.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	• P<M ns **Compliance** – no significant differences in three measures of compliance between ethnic groups **Medication** • Number of meds P<M,E • Inhaled β_2 agonist ns • Preventer P<M, E • Oral theophylline M>P • Continuous steroids P<M, E • Reducing steroids no significant ethnic differences **GP care** Had a regular GP P, M<E Number of GP visits in last year • Patient report P, M>E ns • GP report P, M>E ns • Saw GP prior to A&E visit M<E<P ns GP referral to A&E P, M<E **Urgent GP medical services** • P, M significantly higher number of visits	• Lack of asthma knowledge, lack self-management skills and fewer preventer medications may explain higher P morbidity

Garrett, J., Mulder, J., & Wong-Toi, H. (1989). Reasons for racial differences in A & E attendance rates for asthma. *New Zealand Medical Journal, 102*(864), 121-124.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	• E rates of use of urgent medical services higher than A&E • M, P rates of use of urgent medical services same as rates of use of A&E **A&E use for** • Injury no significant differences • Other illness P, M>E	

Garrett, J., Fenwick, J. M., Taylor, G., Mitchell, E., Stewart, J., & Rea, H. (1994). Prospective controlled evaluation of the effect of a community based asthma education centre in a multiracial working class neighbourhood. *Thorax, 49*(10), 976-983.

Study design	**Participants**	**Exposure (variables) measured and source of information**	**Outcomes measured**
Randomised trial usual care and community asthma education centre vs usual care	Patients aged 2–55 years Attending A&E for asthma English proficiency required Domicile in area served by A&E 980 eligible patients • 747 recruited • Those not recruited younger – mostly 2 year olds • Of the 747 o 102 later refused o 56 not contactable o 45 found to be ineligible o 37 prior contact with centre o 7 unknown	**At recruitment** Patient questionnaire Assessment of PEFR meter technique Scenario based asthma self-management ability Data extraction from hospital records **9 month follow-up** Re-administration patient questionnaire 1 week PEFR and symptom diary after interview Hospital notes abstracted GP questionnaire **Intervention** Clinic run by nurse specialist and 3 trained community health workers (Māori, Samoan, Niuean) Education programme	Asthma severity • Health service utilisation • Symptoms and effect on life • PEFR and diaries Self-management skills Compliance Quality of life Psychological Medication types and number Smoking Health service utilisation

Garrett, J., Fenwick, J. M., Taylor, G., Mitchell, E., Stewart, J., & Rea, H. (1994). Prospective controlled evaluation of the effect of a community based asthma education centre in a multiracial working class neighbourhood. *Thorax, 49*(10), 976-983.

Study design	**Participants**	**Exposure (variables) measured and source of information**	**Outcomes measured**
	• 500 participants • No differences between 500 in study and 247 who did not participate **9 month follow-up done for** 228/251 (91%) intervention group 223/249 (90%) control group	• Pathophysiology • Triggers and avoiding them • Asthma medications • Inhaler use • Self-management – PEFR and symptom diary – and what to if asthma getting worse • How to access care for asthma • If patients medications needed changing or if didn't have action plan – advised to see GP • Smoking cessation advice and support • Discharged once all topics completed	

Garrett, J., Fenwick, J. M., Taylor, G., Mitchell, E., Stewart, J., & Rea, H. (1994). Prospective controlled evaluation of the effect of a community based asthma education centre in a multiracial working class neighbourhood. *Thorax, 49*(10), 976-983.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection bias Collected demographic information about people seen but not asked to be in trial AND those who were asked but declined **Information bias** 191/251 (76%) completed education programme Those who didn't complete • M, P>E • Older > younger ages Used intention to treat analysis At 9 month follow-up Patients • No statistical differences between those assessed and those not able to be assessed in control and intervention	**Pre-intervention** No difference between intervention and control groups for socio-demographic, clinical or psychosocial measures **Follow-up** No difference between intervention and controls for • Admission in the 9 months • A&E visits • Acute attacks GP treated • Days lost at work/school • PEFR variability Intervention group less likely to report nocturnal wakening Children in intervention less likely to report • Cough during day • Running hard causes breathlessness Intervention more likely to report • Improvement in asthma control Māori more likely to report nocturnal wakening **Self-management skills** Intervention group	Ethnicity – no information about how derived Inadequate control of SEP – only Alley-Irving occupation scale used

Garrett, J., Fenwick, J. M., Taylor, G., Mitchell, E., Stewart, J., & Rea, H. (1994). Prospective controlled evaluation of the effect of a community based asthma education centre in a multiracial working class neighbourhood. *Thorax, 49*(10), 976-983.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
groups • PEFR diary returned o 65% intervention o 66% controls • Symptom diary returned o 77% intervention o 81% controls GP response rate for 99% of education and 99% of control group **Confounders** Ethnicity Age Sex SES – Elley-Irving occupation Length of time since asthma diagnosed All treated as independent variables and controlled in multivariable analyses	• Improved inhaler technique pre and post for both adults and children but no between group differences • More likely to have asthma action plan (children and adults) c.f. controls post intervention • Improved knowledge of what to do with worsening asthma both adults and controls c.f. controls Improvements in asthma knowledge E>P, M Had a PFM at recruitment P, M< E **Compliance** Compliance with preventer medicines • No between group differences in the change in proportion compliant Change in attendance at hospital asthma clinic – no difference between intervention and control **Psychological** Caregivers of children in intervention group had greater reduction in anxiety **Medication** Intervention group had greater increase in use of preventive drugs than controls **Health service utilisation** Frequency of routine visits to GP – no differences between intervention and controls Number of GP visits for regular care E>P, M	

Garrett, J., Fenwick, J. M., Taylor, G., Mitchell, E., & Rea, H. (1994). Peak expiratory flow meters (PEFMs)--who uses them and how and does education affect the pattern of utilisation? *Australian & New Zealand Journal of Medicine, 24*(5), 521-529.

Study design	**Participants**	**Exposure (variables) measured and source of information**	**Outcomes measured**
Randomised trial usual care and community asthma education centre vs usual care This article reports whether the socio-demographic and clinical characteristics of people who have a PEFR meter differ from those who don't	Sample drawn from participants in RCT of community asthma education clinic (see critical appraisal of Garrett et al., (1994)) 352 people aged 7–55 years attending A&E for asthma who had agreed to participate in RCT of community based asthma education clinic This age range chosen as considered that children 7 years and over would be capable of doing a PEFR measure	Also see Garrett et al., (1994) **At recruitment into RCT** Patient questionnaire Assessment of PEFR meter technique Scenario based asthma self-management ability Data extraction from hospital records	Also see Garrett et al., (1994) Has a PEFR meter vs does not have a PEFR meter Appropriate use vs inappropriate use by PEFR meter owners Appropriate use – daily use or use when unwell Inappropriate use – rarely or never use

Garrett, J., Fenwick, J. M., Taylor, G., Mitchell, E., & Rea, H. (1994). Peak expiratory flow meters (PEFMs)--who uses them and how and does education affect the pattern of utilisation? *Australian & New Zealand Journal of Medicine, 24*(5), 521-529.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection issues and bias **Information bias** **Confounders considered** Authors noted that design meant they were not able to control confounding by SES, ethnicity, quality of medical care, and asthma severity χ-square analyses comparing those with and without PEFR meters for various categorical variables undertaken. No multivariable analyses	**PEFR meter ownership at recruitment** 191/352 (54%) had PEFR meter at recruitment People with meter more likely to be • 45–55 years • NZE (c.f. Māori and Pacific participants) • High SEP position • Higher morbidity - Severe attacks, A&E visits, admissions in previous 9 months - Higher number visits to GP for regular care in last 9 months - Asthma clinic attendance previous 5 years • Longer duration of asthma • Medication – more likely to - Be on asthma medication - Be on inhaled corticosteroids - Have needed oral steroids - Be on >3 types of medication • In slow onset scenario those with PEFR (c.f. those without) more likely to - Use inhaled β_2 agonists at earliest stage of evolving asthma	Ethnicity – no information about how derived Inadequate assessment of SEP – only Alley-Irving occupation scale used

Garrett, J., Fenwick, J. M., Taylor, G., Mitchell, E., & Rea, H. (1994). Peak expiratory flow meters (PEFMs)--who uses them and how and does education affect the pattern of utilisation? *Australian & New Zealand Journal of Medicine, 24*(5), 521-529.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	- mention inhaled corticosteroids - consider using oral steroids **Appropriate vs inappropriate use** 74% appropriate use 26% inappropriate use Appropriate users more likely to • Have an action plan • Mention PEFR meter in slow onset asthma scenario response • Have been prescribed inhaled steroids • No other clinical or socio-demographic characteristics associated with appropriate use vs inappropriate use - Ethnicity not significant • In slow onset scenario no difference in pattern of inhaled medication use between appropriate and inappropriate users **Effect of asthma education** Repeat assessment at 9 month follow-up Among people who had PEFR meter at entry into trial, those in intervention (asthma education clinic) more likely (c.f. control group) to	

Garrett, J., Fenwick, J. M., Taylor, G., Mitchell, E., & Rea, H. (1994). Peak expiratory flow meters (PEFMs)--who uses them and how and does education affect the pattern of utilisation? *Australian & New Zealand Journal of Medicine, 24*(5), 521-529.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	• Mention PEFR meter in slow onset scenario • Improve PEFR meter technique Among people who acquired a PEFR meter during the course of the study, greater proportion of those in intervention group • Used PEFR meter appropriately • Mention PEFR meter in scenario However, differences not statistically significant as only 19 people in control group who acquired PEFR during the 9 months	

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265.

Wairarapa Māori Executive, & The Wellington Asthma Research Group. (1992). *Te Reo o te Ora: the Wairarapa Māori Asthma Project*.

Study design	**Participants**	**Exposure (variables) measured and source of information**	**Outcomes measured**
Open, prospective trial comparing asthma morbidity, requirement for acute medical treatment, prescribed drug therapy before and after introduction of an individualised asthma self-management programme that included a 'credit card' style action plan. Plan gave step-wise guide to action based on PEFR values and symptoms. Participants could use either PEFR or symptoms parts or both to guide action 1 and 2 year follow-up reported in D'Souza et al., (1998) – see below 6 year follow-up reported in D'Souza et al., (2000) – see below Wairarapa, New Zealand	Non-random sample of Māori aged 14–65 years with asthma Participants excluded if had other uncontrolled medical problems Recruitment through Māori networks resulted in 'a good participation rate of people experiencing significant asthma morbidity' D'Souza et al (1994 p. 1261) Ethnicity – self-identified. Recruitment through local marae 63/66 (91%) attended both clinic appointments • 3 attended 1 clinic • 3 withdrew from study 47/63 (75%) adequately completed more than 60% of daily diaries	8 week before period during which participants • Given PEFR meter if didn't have one • Daily - symptom diaries (nocturnal awakenings, days out of action) - Best morning PEFR before bronchodilator medicine • Monthly recording of - Nebuliser use - Oral steroid use - A&E visits - Hospital admissions After initial 8 week period action plan introduced by doctor at a marae based clinic 16 week follow-up period with clinic	**Asthma morbidity** Best morning PEFR Nocturnal awakenings Days out of action

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265.

Wairarapa Māori Executive, & The Wellington Asthma Research Group. (1992). *Te Reo o te Ora: the Wairarapa Māori Asthma Project*.

Study design	**Participants**	**Exposure (variables) measured and source of information**	**Outcomes measured**
	Analysis restricted to these 47. 55/63 (87%) completed questionnaire on acceptability	appointment at 8 weeks Māori community health workers involved throughout trial	

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265.

Wairarapa Māori Executive, & The Wellington Asthma Research Group. (1992). *Te Reo o te Ora: the Wairarapa Māori Asthma Project*.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection bias Non-random sample 69 participants • 55/69 female • 14/69 male Participants had 'considerable morbidity' 54% no secondary school or tertiary qualifications	**At enrolment** • 54% had a PEFR meter • 13% had a written management plan • 61% had a prescribed ICS Statistical tests compare data from initial 8 week period with pooled data for the two 8 week periods after intervention	Acceptable and effective Generalisability – clinic held on marae by 4 specialists Improvement could be due to specialists clinics independent of plan. But they say careful and thorough explanation is vital

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265.
Wairarapa Māori Executive, & The Wellington Asthma Research Group. (1992). *Te Reo o te Ora: the Wairarapa Māori Asthma Project*.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Information bias See information on completion of diaries adequately. Did 'supplementary analyses' to check for biases due to 'non-completion of sufficient daily diaries' p. 1263 The group who didn't adequately complete diaries did attend both clinics. Not including their data could over-estimate size of effect but analysis with these 16 in showed similar improvements in estimates of morbidity **Confounders considered** None	**Asthma morbidity (n=47)** • Increase in best morning PEFR • Reduction in nocturnal awakenings and days out of action If all 63 participants included in analysis no change in results and all findings remain statistically significant **Health service utilisation (n=47)** • Reduction in A&E visits and admissions but did not reach significance • Significant reduction in use of nebulised medication **Prescribed drug therapy** • No change in oral prednisone initiated by participant or their GP • Fall in oral prednisone given by clinic doctor between first and second clinic (no test of significance as was not pre and post) • Significant increase in participants reporting they were prescribed inhaled corticosteroids and in use of ICS regularly • Significant decrease in prescriptions for oral theophylline **Acceptability (55/63 participants)**	part of introducing plan Non-random High morbidity No control – not possible in close-knit Māori community – would have contaminated control group through discussion and sharing of plan Length of follow-up only 16 weeks

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265.
Wairarapa Māori Executive, & The Wellington Asthma Research Group. (1992). *Te Reo o te Ora: the Wairarapa Māori Asthma Project*.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	• 82% plan had contributed to improvement in asthma • Of the 45 participants who had a 'bad attack' - 48% found both PEFR and symptom sides of plan helpful - 28% PEFR side most helpful - 7% symptom side most helpful • Plan content - 86% disagreed that plan should be bigger - 86% thought had sufficient detail - 94% disagreed with statement that plan instructions were difficult to follow	

D'Souza, W., Te Karu, H., Fox, C., Harper, M., Gemmell, T., Ngatuere, M., et al. (1998). Long-term reduction in asthma morbidity following an asthma self-management programme. *European Respiratory Journal, 11*(3), 611-616

1 and 2 year follow-up of

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265

Design and participant information, in 1 and 2 year follow-up study. Sources of possible bias and confounders considered	**Outcomes measured and source of information**	**Major findings and comments** All findings statistically significant unless stated otherwise
Timeline • Enrolment into study and data collection for 8 week pre-intervention period: Time (t)=0 months • Introduction of programme after 8 weeks: t=2 months • Follow up for further 4 months: t=6 months • 1 year follow-up study: t=18 months • 2 year follow-up study: t=30 months	Outcomes measured were the same as those in original trial Source of information questionnaire Questions about asthma morbidity and use of health services at t=18 and t=30 were same as those used at t=0 However, for question about 'days out of action' at t=30 included an explicit definition	**Follow-up at t=18 (1 year after completion of programme) n=46. Compared with t=0** Significant decrease in % reporting nocturnal awakenings most nights in last year Non-significant decrease in % with >7 days out of action in last year Significant decrease in % with • Non-emergency visits to a doctor • Emergency visits to GP Non-significant decrease in % with • Emergency visits to A&E • Hospital admissions **Follow-up at t=30 (2 years after completion of trial) n=58. Compared with t=0**

D'Souza, W., Te Karu, H., Fox, C., Harper, M., Gemmell, T., Ngatuere, M., et al. (1998). Long-term reduction in asthma morbidity following an asthma self-management programme. *European Respiratory Journal, 11*(3), 611-616

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D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265

Design and participant information, in 1 and 2 year follow-up study. Sources of possible bias and confounders considered	**Outcomes measured and source of information**	**Major findings and comments** All findings statistically significant unless stated otherwise
Follow-up studies at t=18 months and t=30 months After completion of 6 month trial participants discharged to usual care by their GPs. No further educational or therapeutic involvement by research group for 2 years **Participants** 69 participants enrolled at t=0 46/69 at t=18 months 58/69 at t=30 months	of 'out of action'. At t=0 and t=18 the definition had been used as guide for interviewers to classify participant's responses At t=30 additional questions about their 'usual' use of PEFR meter/plan, how they used them if asthma 'getting worse' or they had a 'bad attack'	Significant decrease in % reporting nocturnal awakenings most nights in last year No change in % with >7 days out of action in last year Significant decrease in % with • Nonemergency visits to a doctor • Emergency visits to GP • Emergency visits to A&E • Hospital admissions **Trends for participants completing both follow-up studies (t=18 and t=30) n=41** Significant trend in improvement for • nocturnal awakenings most nights in last year • Nonemergency visits to a doctor • Emergency visits to GP

D'Souza, W., Te Karu, H., Fox, C., Harper, M., Gemmell, T., Ngatuere, M., et al. (1998). Long-term reduction in asthma morbidity following an asthma self-management programme. *European Respiratory Journal, 11*(3), 611-616

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D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265

Design and participant information, in 1 and 2 year follow-up study. Sources of possible bias and confounders considered	**Outcomes measured and source of information**	**Major findings and comments** All findings statistically significant unless stated otherwise
Reasons for non-participation At t=18 information not collected At t=30 • 4 refused • 7 lost to follow-up – moved out of area **Sources of possible bias** Loss to follow up or refusal to participate. Baseline characteristics of participants at t=0, t=18, and t=30 similar		Non-significant trend in improvement for • Emergency visits to A&E • Hospital admissions No trend for % with >7 days out of action **Self-management at t=30** • 24% monitor PEFR at least daily • 73% monitor PEFR during 'bad' attack • 86% had increased inhaled steroids during previous 12 months - 48% had referred to plan to assist with decision - 45% used PEFR value part of plan - 41% used symptom part of plan • 43% had used oral steroids in previous 12 months - 40% had used plan to self-initiate

D'Souza, W., Te Karu, H., Fox, C., Harper, M., Gemmell, T., Ngatuere, M., et al. (1998). Long-term reduction in asthma morbidity following an asthma self-management programme. *European Respiratory Journal, 11*(3), 611-616

1 and 2 year follow-up of

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265

Design and participant information, in 1 and 2 year follow-up study. Sources of possible bias and confounders considered	**Outcomes measured and source of information**	**Major findings and comments** All findings statistically significant unless stated otherwise
Participants in two follow-up studies representative of original study group The two measures of morbidity outcome open to recall and interpretation bias by participants. But this bias shouldn't differ across time periods Change in wording of 'more than 7 days out of action'		**Comments** At t=18 follow-up the most frequent morbidity markers (i.e. less severe) showed statistically significant changes. Less frequent (more severe) markers showed similar improvements but small numbers so not statistically significant In a group with relatively severe asthma improvements in morbidity and acute health service use achieved by credit card self-management plan. Self-assessment and self-management skills learnt through introduction and use credit card self-management plan likely to be maintained in long term by adult people with asthma Māori community – may not be generalisable. Efficacy of plan may be same but process may need to differ in different communities Relatively severe asthma. Would findings be similar with milder asthma? Intensive introduction of self-management plan results in long term reduction in morbidity and acute medical service use. The self-management skills learnt during the introduction of plan are maintained long term

D'Souza, W., Te Karu, H., Fox, C., Harper, M., Gemmell, T., Ngatuere, M., et al. (1998). Long-term reduction in asthma morbidity following an asthma self-management programme. *European Respiratory Journal, 11*(3), 611-616

1 and 2 year follow-up of

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265

Design and participant information, in 1 and 2 year follow-up study. Sources of possible bias and confounders considered	**Outcomes measured and source of information**	**Major findings and comments** All findings statistically significant unless stated otherwise
question may account for lack of continued improvement in this outcome at 2 years		86% of participants increased ICS (half after direct reference to plan) and 40% had taken oral steroids (about 40% of whom self-initiated without medical consultation) in 12 months before 2 year follow-up. This suggests that introduction of plan can translate into increased self-management behaviour

D'Souza, W. J., Slater, T., Fox, C., Fox, B., Te Karu, H., Gemmell, T., et al. (2000). Asthma morbidity 6 yrs after an effective asthma-self-management programme in a Māori community. *European Respiratory Journal, 15*(3), 464-469

6 year follow-up of

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265.

Design and participant information, in 6 year follow-up study **Sources of possible bias and confounders considered**	**Outcomes measured and source of information**	**Major findings and comments** All findings statistically significant unless stated otherwise
Timeline • Enrolment into study: Time (t)=0 months • Data collection for 8 week pre-intervention period • Introduction of programme after 8 weeks: t=2 months • Follow up for further 4 months: t=6 months • 1 year follow-up study: t=18 months • 2 year follow-up study: t=30 months • 6 year follow-up study: t=78	Source of information – questionnaire and medical record review Questions about asthma morbidity and use of health services at t=78 was the same as those used at t=0 However for question about 'days out of action' at t=30 and t=78 included an explicit definition of 'out of action'. At	**Follow-up at t=78 (6 years after completion of trial) n=47. Compared with t=0** No difference in % reporting nocturnal awakenings most nights in last year or % with >7 days out of action in last year Significant decrease in % with • Non-emergency visits to a doctor • Emergency visits to GP Non-significant decrease in % with • Emergency visits to A&E • Hospital admissions **Trends in markers of morbidity and health service utilisation at t=0, t=18, t=30, and t=78. NB: No p values given in the publication.** Earlier trend for improvement not sustained at t=78 and % at t=78 similar to t=0 for

D'Souza, W. J., Slater, T., Fox, C., Fox, B., Te Karu, H., Gemmell, T., et al. (2000). Asthma morbidity 6 yrs after an effective asthma-self-management programme in a Māori community. *European Respiratory Journal, 15*(3), 464-469

6 year follow-up of

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265.

Design and participant information, in 6 year follow-up study **Sources of possible bias and confounders considered**	**Outcomes measured and source of information**	**Major findings and comments** All findings statistically significant unless stated otherwise
months Follow-up study at t=78 months After completion of 6 month trial participants discharged to usual care by their GPs. No further educational or therapeutic involvement by research group for 6 years **Participants** 69 participants enrolled at t=0 46/69 at t=18 months	t=0 and t=18 the definition had been used as guide for interviewers to classify participants responses At t=30 and t=78 there were additional questions about 'usual' use of PEFR meter/plan, and how plans were used if asthma 'getting worse' or they had a 'bad attack' At t=78 hospital records were reviewed to identify hospital	• nocturnal awakenings most nights in last year • Non-emergency visits to a doctor No sustained trend but reduction at t=78 c.f. t=0 in % with • >7 days out of action • Emergency visits to GP • Emergency visits to A&E • Hospital admissions **Asthma management and self-management** ICS use at enrolment (t=0), at end of programme (t=6), and 6 year follow-up (t-78) Baseline vs end of programme significant increase in • % prescribed ICS • % prescribed ICS for regular use

D'Souza, W. J., Slater, T., Fox, C., Fox, B., Te Karu, H., Gemmell, T., et al. (2000). Asthma morbidity 6 yrs after an effective asthma-self-management programme in a Māori community. *European Respiratory Journal, 15*(3), 464-469

6 year follow-up of

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265.

Design and participant information, in 6 year follow-up study **Sources of possible bias and confounders considered**	**Outcomes measured and source of information**	**Major findings and comments** All findings statistically significant unless stated otherwise
58/69 at t=30 months 47/69 at t=78 months (68%) **Reasons for non-participation** At t=18 information not collected At t=30 • 4 refused • 7 lost to follow-up – moved out of area At t=78 • 3 died (all in previous 2 years) o 1 asthma	admissions for asthma Comparison with questionnaire data about hospital admissions done	• Mean daily dose of ICS (among those with ICS for regular use) End of programme vs 6 year follow-up significant decrease in • % prescribed ICS • % prescribed ICS for regular use • Mean daily dose of ICS (among those with ICS for regular use) Self-management at t=78 • 81% still had PEFR meter • 66% had used PEFR meter in previous 12 months • 77% still had their self-management plan Self-management behaviour at t=30 and t=78 months • Non-significant reduction in % using PEFR meter almost daily when asthma 'not bad'

D'Souza, W. J., Slater, T., Fox, C., Fox, B., Te Karu, H., Gemmell, T., et al. (2000). Asthma morbidity 6 yrs after an effective asthma-self-management programme in a Māori community. *European Respiratory Journal, 15*(3), 464-469

6 year follow-up of

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265.

Design and participant information, in 6 year follow-up study **Sources of possible bias and confounders considered**	**Outcomes measured and source of information**	**Major findings and comments** All findings statistically significant unless stated otherwise
○ 1 other cause ○ 1 unknown (overseas) • 19 moved out of area or didn't attend for interview **Sources of possible bias** Loss to follow up or refusal to participate. Baseline characteristics of participants at t=0, t=18, t=30 and t=78 similar. Participants in three follow-up studies representative of original study group. Participants with more severe asthma still		• Significant reduction in % using PEFR meter almost daily when asthma 'getting bad' • Significant reduction in % using plan to increase ICS • Non-significant increase in % who had taken oral steroids in previous 12 months Among those who had taken oral steroids in previous 12 months, similar % had self-initiated **Hospital admissions validation of questionnaire data and hospital records** For each data collection point concordance of participant's recall of number of hospitalisations in previous 12 months with hospital records of asthma admissions in same time period assessed Questionnaire responses and hospital records • Concordant if both positive (or both negative) for admission • Discordant if one positive and other negative High concordance – generally over 90% • Lowest for initial survey

D'Souza, W. J., Slater, T., Fox, C., Fox, B., Te Karu, H., Gemmell, T., et al. (2000). Asthma morbidity 6 yrs after an effective asthma-self-management programme in a Māori community. *European Respiratory Journal, 15*(3), 464-469

6 year follow-up of

D'Souza, W., Crane, J., Burgess, C., Te Karu, H., Fox, C., Harper, N., et al. (1994). Community based asthma care: trial of a 'credit card' asthma self-management plan. *European Respiratory Journal, 7*, 1260-1265.

Design and participant information, in 6 year follow-up study **Sources of possible bias and confounders considered**	**Outcomes measured and source of information**	**Major findings and comments** All findings statistically significant unless stated otherwise
involved at 6 year follow-up		• Remains very high throughout follow-up period Discordance due to admission reported on questionnaire not being found in records. Authors could not search records at hospitals outside of study area **Comments** A&E visits and hospital admissions show decrease at 78 months but not significant. Numbers who report A&E visit or admission are small, so lack of significance should be treated with caution

Gillies, J., Barry, D., Crane, J., Jones, D., Maclennan, L., Pearce, N., et al. (1996). A community trial of a written self-management plan for children with asthma. *New Zealand Medical Journal, 109*, 30-33.

Study design	**Participants**	**Exposure (variables) measured and source of information**	**Outcomes measured**
Open, prospective, 'before and after' trial Whangarei, New Zealand	Eligible children aged 3–11 years with mild – moderate asthma and no previous use of action plans • 110 enrolled • 25% Māori • 102 completed study	Data collected 1993 Provision of a written asthma action plan Pre-intervention 8 weeks data collection • Provision and instruction on use of PEFR meter • Daily symptom diaries, best morning pre-medication PEFR, and inhaler use • Monthly recording of nebuliser and oral steroids use • Monthly recording of GP and hospital visits and hospital admissions Post-intervention 16 weeks data collection • as above for pre-intervention • questionnaire for efficacy and acceptability of plan	Pre and post intervention measures of **Asthma morbidity** • Attacks of wheeze in last 12 months • Nocturnal wheeze or cough • At least one day out of action in last month • Morning PEFR **Acute asthma medical treatment** • GP in last month • Hospital visit in last month • Hospital admission in last month **Prescribed drug treatment in last month** • Oral steroids in last month • Reliever medication in last month • Preventive inhaler in last month • Nebuliser use **Acceptability of plan** Parents Support for plan current and future, benefits of use, acceptability GPs Support, benefits of plan

Gillies, J., Barry, D., Crane, J., Jones, D., Maclennan, L., Pearce, N., et al. (1996). A community trial of a written self-management plan for children with asthma. *New Zealand Medical Journal., 109*, 30-33.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection issues and bias No information about number or characteristics of eligible children who were not enrolled **Information bias** No information about participants who did not complete the intervention or reasons for non-completion 91% of the 102 participants who completed the intervention answered questionnaire about acceptability. No information about participants who did not complete the acceptability questionnaire or reasons for not completing **Confounders considered** None	**Asthma morbidity** Decrease in • Nocturnal awakenings • Days out of action Increase in morning PEFR **Health care utilisation** Decrease in GP visits No significant difference in hospital visit or admission **Medication use** Decrease in • Days on oral steroids • Use of inhaled reliever medicines • Nebuliser use Non-significant increase in inhaled preventer medicines **Acceptability and efficacy** Parents High levels of support, perceived benefit and	No information on classification of ethnicity No reporting by ethnicity Short follow-up period – findings may not be sustained Authors state that improvements may be due to increased family and GP awareness of asthma and communication between them rather than the action plans per se. However, I would expect that increased awareness would also be a result of action plan, information on use of plan, and implementation of the plan

Gillies, J., Barry, D., Crane, J., Jones, D., Maclennan, L., Pearce, N., et al. (1996). A community trial of a written self-management plan for children with asthma. *New Zealand Medical Journal., 109*, 30-33.

Sources of possible bias and confounders considered	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	acceptability for action plan. GPs Supported use of plan, thought plan helped them understand the participants asthma, and made it easier to manage asthma	

Appendix 3 Medical subject heading and keyword search terms

Pharmacological review: search terms used for specific databases

The following databases and search terms were employed:

Medline(R) database and CINAHL

- Asthma: Used as a subject heading term and limited to prevention and control, drug therapy, rehabilitation, and therapy.
- Medications.
- Ethnicity
    - Subject headings: population groups, ethnic groups, minority groups, continental population groups, African Americans, Asian Americans, Hispanic Americans, Inuits.
    - Key words: ethnic$[1], indigenous, aborigin$, Māori$, Pacific, Polynesia$, Pasifica, Pasifika, Pacifika, American India$, Alaska Nativ$, First Natio$.

Medline(R) In-process and other non-indexed citations

- Asthma: Used as a key word.
- Medications
    - Key words: anti-asthmatic agents, bronchodilator agents, anti-inflammatory agents, terbutaline, albuterol, fenoterol, ipratropium, cromolyn sodium, beclomethasone, budesonide, nedocromil, salmeterol, eformoterol, salbutamol, fluticasone.
- Ethnicity
    - Key words: continental population groups, ethnic$, African America$, Asian America$, Hispanic America$, Inui$, American India$, Alaska Nativ$, First Natio$, minorit$, indigenous, aborigin$, Māori$, Pacific, Polynesia$, Pacifica, Pasifika, Pacifika.

EMBASE

- Asthma
    - Subject headings: asthma, nocturnal asthma, mild persistent asthma, moderate persistent asthma, severe persistent asthma, mild intermittent asthma.
- Medications
    - Subject headings: anti-asthmatic agent, beclometasone, cromoglycate disodium, nedocromil or nedocromil sodium, fluticasone or fluticasone propionate or fluticasone propionate plus salmeterol, anti-inflammatory agent, bronchodilating agent, budesonide, ipratropium bromide, terbutaline or terbutaline sulphate, salbutamol, salmeterol, fenoterol, formoterol.
- Ethnicity
    - Subject headings: ethnic difference, ethnic group, minority group, race or race difference.

[1]The $ sign truncates the term and the search engine will identify articles that include all variations of spelling that occur for the word prefacing the $. For example ethnic$ will return ethnic, ethnicity, ethnicities.

- Key words: ethnic$, indigenous, aborigin$, Māori$, Pacific, polynesia$, Pacifica, Pasifika, Pacifika, African America$, Asian America$, Hispanic America$, American India$, Alaska Nativ$, First Natio$.

Asthma self-management review: search terms used for specific databases

The following terms were employed:

Medline(R) database

- Asthma: Used as a subject heading term and limited to prevention and control, psychology, rehabilitation, epidemiology, ethnology, therapy.
- Asthma education and action plans
  - Subject headings: self care, patient education, health education, preventive health services.
  - Key words: action plan.
- Ethnicity
  - Subject headings: ethnic groups, minority groups, population groups.
  - Key words: continental population groups, African Americans, Asian Americans, Hispanic Americans, Inuits, American Indians, Alaska Natives or First Nations, ethnic$, indigenous, aborigin$, Māori$, Pacific, Polynesia$, Pacifica, Pasifica, Pacifika, Pasifika.

CINAHL

- Asthma: Used as a subject heading term and limited to nursing, prevention and control, psychosocial factors, education, rehabilitation, therapy.
- Asthma education and action plans
  - Subject headings: self care, health education, preventive health services, patient education.
  - Key words: asthma education, action plan.
- Ethnicity
  - Subject headings: ethnic groups, minority groups, population groups.
  - Key words: continental population groups, African Americans, Asian Americans, Hispanic Americans, Inuit, American Indians, Alaska Natives or First Nations, ethnic$, indigenous, Aborigin$, Māori$, Pacific, Polynesia$, Pacifica, Pasifica, Pacifika, Pasifika.

Medline(R) In-process and other non-indexed citations

- Asthma: Used as a key word.
- Asthma education and action plans
  - Key words: asthma education, action plan, asthma action plan$, self-management, self care, patient education, health education.
- Ethnicity
  - Key words: continental population group$, ethnic$, African America$, Asian America$, Hispanic America$, Inui$, minorit$, American Indians, Alaska Natives, First Nations, ethnic$, indigenous, Aborigin$, Māori$ or Pacific or Polynesia$, Pacifica, Pasifica, Pacifika, Pasifika.

PsychINFO

- Asthma
  - Subject headings: asthma.
- Asthma education and action plans
  - Subject headings: health education, client education, self-management, client attitudes, health behaviour, self care skills.
  - Key words: patient education, action plan.
- Ethnicity
  - Subject headings: minority groups, Blacks, American Indians, Hispanics, Alaska Native, American Indians, Inuit, Pacific Islanders, racial and ethnic differences, racial and ethnic attitudes, racial and ethnic groups, indigenous populations.
  - Key words: aboriginal, Māori.

ERIC

- Asthma
  - Key word: asthma.
- Asthma education and action plans
  - Subject headings: special health problems, health education, child health, preventive medicine, health services.
  - Key words: asthma education, asthma action plan$.
- Ethnicity
  - Subject headings: ethnic stereotypes, ethnic groups, ethnic studies, minority groups, minority group children, indigenous populations, population groups.
  - Key words: continental population groups, ethnic groups, African Americans, Asian Americans, Hispanic Americans, Inuits, American Indians, Alaska Natives, First Nations, ethnic$, indigenous, aborigin$, Māori$, Pacific, Polynesia$, Pacifica, Pasifica, Pacifika, Pasifika.

Appendix 4 International literature critical appraisal summary tables

Duran-Tauleria, E., Rona, R. J., Chinn, S., & Burney, P. (1996). Influence of ethnic group on asthma treatment in children in 1990–1: national cross sectional study. *BMJ, 313*(7050), 148-152.

Year data collected, study design	**Participants**	**Explanatory variables measured and source of information**	**Outcomes measured**
National cross-sectional survey: National Study of Health and Growth Health surveillance survey of primary school children Data collected - 1990 England - 1990–1991 Scotland - 1991 Inner city	Children 5–11 in primary school in England and Scotland 1990–1. 3 samples - Scotland - England - Inner city Scotland and England ("representative sample") - Stratified random sample of employment exchange areas with proportionally more children from poorer social groups - Distribution of social class in these samples was similar to that of general population Inner city sample selected according to characteristics of deprivation and proportion of ethnic groups 10 628 children in England, Scotland sample 7 049 inner city of which 69% (4 866) ethnic minorities	Self administered questionnaire Questionnaire available in several languages for inner city (English, Urdu, Gujarat, Punjabi) *Information collected about* Respiratory illness - asthma, bronchitis in children and parents Medications - name of drug - how taken - how often taken Socio-demographics - ethnicity of child (language spoken at home and field workers subjective assessment of the child's ethnicity) - paternal social class - single/dual parent household	Prevalence of respiratory symptoms Relationship between prescribed drugs and ethnicity Analysis of management done on sub-sample reporting respiratory symptoms - respiratory symptoms, not wheeze or asthma - occasional wheeze, not persistent, no asthma attacks - persistent wheeze, no attacks - asthma attacks

Duran-Tauleria, E., Rona, R. J., Chinn, S., & Burney, P. (1996). Influence of ethnic group on asthma treatment in children in 1990–1: national cross sectional study. *BMJ, 313*(7050), 148-152.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection issues and bias Response rates - England/Scotland 92.3% - Inner city 85.3% Response rate lowest in Afro-Caribbean (31–33%) ?No information about ethnic distribution in 'representative sample' (England and Scotland) **Recall bias** Information collected from parents. Ethnic differences in prescription patterns varied with ethnicity only in those with asthma attacks (not those with wheeze). Is unlikely that parents memory of treatment varies by ethnicity in those with asthma attacks but doesn't in those with wheeze. So difference unlikely to be due to differences in parent recall **Information bias** More missing data in inner city sample (20–23% c.f. 3–10% in	W, AC, and O more likely to report respiratory symptoms than I, E and S Inner city children, especially AC, probably have under-diagnosed asthma Wheeze only groups less likely to receive asthma treatment and more likely to receive antibiotics and antitussives Children with asthma attacks 75% prescribed β_2 agonist 25% prescribed steroids 14% prescribed other anti-inflammatory drugs Significant proportions of children with wheeze or asthma attack did not receive β_2 agonist or anti-inflammatory	Did not ask about utilisation of health services, having a regular source of care Method of assigning ethnicity same as had been done since 1983 *Ethnic groups* Inner city - Afro-Caribbean (AC) - Indian subcontinent (I) - White (W) - Other (O) England (E) Scotland (S) Children with persistent wheeze under-treated

Duran-Tauleria, E., Rona, R. J., Chinn, S., & Burney, P. (1996). Influence of ethnic group on asthma treatment in children in 1990–1: national cross sectional study. *BMJ, 313*(7050), 148-152.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
England/Scotland samples) 82% children overall had complete data and were included in analyses (so more of inner city children excluded because of missing data) **Confounders considered and method used to deal with them** Social class Bronchitis reported in child Number of asthma attacks in previous 12 months Ethnicity Sex Age 1 parent families Parents reported atopic illness Above factors included as explanatory variables in multiple logistic regression models Morbidity level - stratification	78% with occasional wheeze 79% with persistent wheeze 18% with asthma **Multivariable analyses** *Among children with asthma attack* AC, I, O children less likely to receive β_2 agonist I and O children less likely to receive anti-inflammatory I and O children less likely to receive antibiotics AC and I children more likely to receive antitussive	Ethnicity influenced what drugs children with asthma received. Minority groups more likely to be under-treated Regardless of language spoken at home AC and I children are - less likely to receive β_2 agonist and anti-inflammatory drugs than W - more likely to be treated with antitussive than W children

Inkelas, M., Garro, N., McQuaid, E. L., & Ortega, A. N. (2008). Race/ethnicity, language, and asthma care: findings from a 4-state survey. *Annals of Allergy, Asthma, & Immunology, 100*(2), 120-127.

Study author, year of publication, study design	**Participants**	**Explanatory variables measured and source of information**	**Outcomes measured**
Cross-sectional survey Telephone survey 4 States in the USA (California, Texas, Illinois, Alabama) Data collected March 2003–March 2004	Random digit dialling Screening questions to identify people ever diagnosed as having asthma Random selection up to 1 child per household Structured telephone interviews with caregivers of selected children 2 003 children aged 0–18 years with lifetime asthma. Study included - those with current asthma - those with symptoms or asthma medications in previous 12 months Excluded - 117 children with multiple or other race/ethnicity - 53 children with no race/ethnicity data Final sample size 1 517 White 832 African American 296	Race/ethnicity Latino participants stratified into English and Spanish speaking - doesn't specify the question used to determine race/ethnicity Excludes mixed race/ethnicity and other ethnic groups (i.e. excludes if not White, African American, Latino) Caregiver of child with asthma Retrospective report	6 process of care variables (Ever experienced) - given asthma management plan - taught to recognise early signs - taught what to do during an attack - taught how to use PEFR meter (if aged 5–17 years) - had taken a course on how to manage asthma - advised to change things in environment Medication use in previous 3 months - restricted to children with persistent asthma - any controller - inhaled corticosteroid - β_2 agonist - any reliever (β_2 agonist, oral steroids, inhaled anti-cholinergic)

Inkelas, M., Garro, N., McQuaid, E. L., & Ortega, A. N. (2008). Race/ethnicity, language, and asthma care: findings from a 4-state survey. *Annals of Allergy, Asthma, & Immunology, 100*(2), 120-127.

Study author, year of publication, study design	**Participants**	**Explanatory variables measured and source of information**	**Outcomes measured**
	Latino (English interview) 272 Latino (Spanish interview) 117		Health care use in previous 12 months - had planned encounters and number of these - had visits for asthma episodes and number of these - had urgent care or ED visits and number of these

Inkelas, M., Garro, N., McQuaid, E. L., & Ortega, A. N. (2008). Race/ethnicity, language, and asthma care: findings from a 4-state survey. *Annals of Allergy, Asthma, & Immunology, 100*(2), 120-127.

Possible sources of bias, confounding and method used to minimise effect	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection issues and bias Response rate 52.2% Random digit dialling – excludes those without phone. Adjusted for non-response for households with no phone or multiple phones	**Descriptive analysis** 41.4% total had been given an action plan (race/ethnicity ns) 82.4% taught to recognise early signs (lower in both	Response rate similar to other National Center for Health Statistics surveys

Inkelas, M., Garro, N., McQuaid, E. L., & Ortega, A. N. (2008). Race/ethnicity, language, and asthma care: findings from a 4-state survey. *Annals of Allergy, Asthma, & Immunology, 100*(2), 120-127.

Possible sources of bias, confounding and method used to minimise effect	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Recall bias Retrospective report. No validation. No discussion of possible impacts of this **Information bias** Non-English speaking participants – questionnaire translated into Spanish and Spanish language interviewers 90.6% of interviews in English; 9.4% in Spanish Adjusted for multiple eligible children, unit non-response, and 'over-sampling' No direct measure of English-language proficiency Didn't include unused filled prescriptions or unfilled prescriptions in medication measures (i.e. only medications given to child measured) Wasn't able to analyses outcomes by asthma severity level. Did restrict medications to those with persistent asthma (who may differ systematically from those using medications who, therefore, have controlled asthma) Didn't include measure of clinician communication or other assessment of doctor – patient relationship	Latino subgroups p=0.03) Taught what to do in attack overall 85.0% White 89.1%; AA 85.1% Latino (English) 83.9% Latino (Spanish) 67.7% Taking a class 17.4% overall. Race/ethnicity ns Advised to change environment 48.5% overall. p=0.03 White 50.4%; AA 53.6% Latino (English) 45.7% Latino (Spanish) 34.3% *Health service utilisation* Planned encounters (p=0.01) White 65.5%; AA 80.1% Latino (English) 71.4% Latino (Spanish) 68.0% Visits for asthma episodes 47.3% overall. Race/ethnicity ns	No ethnic differences in planned asthma encounter visits Use of controller medications lower for AA and Latino children than Whites Process of care differences associated with language (Spanish speaking) rather than race/ethnicity. Implies less effective communication between physicians and subgroups of patients Need to increase use of controller medications, increase environmental advice, increase use of action plans

Inkelas, M., Garro, N., McQuaid, E. L., & Ortega, A. N. (2008). Race/ethnicity, language, and asthma care: findings from a 4-state survey. *Annals of Allergy, Asthma, & Immunology, 100*(2), 120-127.

Possible sources of bias, confounding and method used to minimise effect	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Missing data – information not provided **Confounders considered and method used to deal with them** Age – adjusted in multivariable modelling Health insurance status (insurance yes/no) – adjusted in multivariable modelling Income (4 bands) – adjusted in multivariable modelling Parental education – didn't include measure of this. Asthma severity – NAEPP scoring - medication use restricted to children with persistent asthma as children with mild intermittent not expected to receive controller medications	Urgent/ED visits (p<0.001) White 15.8%; AA 36.3% Latino (English) 18.3% Latino (Spanish) 25.9% **Multivariable analyses** Adjusted for design effects, age, insurance status, and income *Process of care* Given management plan (Race/ethnicity=0.73) White OR 1.0 AA OR 1.2 (0.8–1.8) Latino (English) 1.0 (0.7–1.4) Latino (Spanish) 1.0 (0.6–1.6) Taught to recognise early symptoms (p=0.20) White OR 1.0 AA OR 1.1 (0.7–2.0) Latino (English) 0.8 (0.5–1.3) Latino (Spanish) 0.6 (0.4–1.0)	

Inkelas, M., Garro, N., McQuaid, E. L., & Ortega, A. N. (2008). Race/ethnicity, language, and asthma care: findings from a 4-state survey. *Annals of Allergy, Asthma, & Immunology, 100*(2), 120-127.

Possible sources of bias, confounding and method used to minimise effect	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	Taught what to do in an attack (p=0.004) White OR 1.0 AA OR 0.9 (0.5–1.7) Latino (English) 0.8 (0.4–1.3) Latino (Spanish) 0.4 (0.2–0.6) Taught how to use PEFR (p=0.21) White OR 1.0 AA OR 1.1 (0.7–1.7) Latino (English) 0.7 (0.5–1.1) Latino (Spanish) 0.7 (0.4–1.2) Taken a class (p=0.12) White OR 1.0 AA OR 1.7 (1.0–2.9) Latino (English) 1.0 (0.6–1.7) Latino (Spanish) 1.5 (0.8–3.1) Advised to change home environment (p=0.03) White OR 1.0 AA OR 1.1 (0.7–1.6)	

Inkelas, M., Garro, N., McQuaid, E. L., & Ortega, A. N. (2008). Race/ethnicity, language, and asthma care: findings from a 4-state survey. *Annals of Allergy, Asthma, & Immunology, 100*(2), 120-127.

Possible sources of bias, confounding and method used to minimise effect	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	Latino (English) 0.8 (0.5–1.1) Latino (Spanish) 0.5 (0.3–0.8) *Medication* Inhaled corticosteroids (p=0.08) White OR 1.0 AA OR 0.5 (0.2–1.0) Latino (English) 0.5 (0.2–1.0) Latino (Spanish) 0.4 (0.1–1.4) Any controller (p=0.005) White OR 1.0 AA OR 0.4 (0.2–0.8) Latino (English) 0.4 (0.2–0.8) Latino (Spanish) 0.2 (0.1–0.8) β_2 agonist (p=0.34) White OR 1.0 AA OR 1.7 (0.8–3.8) Latino (English) 0.9 (0. –1.8)	

Inkelas, M., Garro, N., McQuaid, E. L., & Ortega, A. N. (2008). Race/ethnicity, language, and asthma care: findings from a 4-state survey. *Annals of Allergy, Asthma, & Immunology, 100*(2), 120-127.

Possible sources of bias, confounding and method used to minimise effect	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	Latino (Spanish) 0.7 (0.2–2.3) Any reliever (p=0.06) White OR 1.0 AA OR 2.5 (1.1–5.5) Latino (English) 0.9 (0.4–1.8) Latino (Spanish) 1.2 (0.3–4.5)	

Krishnan, J. A., Diette, G. B., Skinner, E. A., Clark, B. D., Steinwachs, D., & Wu, A. W. (2001). Race and sex differences in consistency of care with national asthma guidelines in managed care organizations. *Archives of Internal Medicine, 161*(13), 1660-1668.

Year data collected, study design	**Participants**	**Explanatory variables measured and source of information**	**Outcomes measured**
Cross-sectional survey Postal questionnaire Data collected Sept–Dec 1993	Patients were workers in 11 employment sites that were enrolled in managed care organisations Inclusion criteria - 18 years of age or older - Enrolled in managed care organisation at time of data collection - 2 or more medical encounters for asthma (outpatient, ED, admission) over time period. 300 participants with inpatient visits (ED, admission) and 300 with outpatient visits randomly selected from each MCO. Minimum of 600 per organisation	Data provided by patient Race (restricted to AA and White as sample too small in other ethnic groups) Sex Age College education Employment status Smoking status Age at onset and duration of asthma Frequency of asthma symptoms in past 4 weeks Frequency of attacks in past 4 weeks Interval symptoms between attacks Asthma symptoms responses combined into Asthma Symptom Index score Health service utilisation in previous year Multivariable models – stratified by inpatient	Indicators of consistency of care with NAEPP guidelines - medication (has ICS; daily use of ICS) - self-management education - control of factors related to asthma severity - periodic assessment - asthma specialist care (no didn't need to, no but would have liked to, yes)

Krishnan, J. A., Diette, G. B., Skinner, E. A., Clark, B. D., Steinwachs, D., & Wu, A. W. (2001). Race and sex differences in consistency of care with national asthma guidelines in managed care organizations. *Archives of Internal Medicine, 161*(13), 1660-1668.

Year data collected, study design	Participants	Explanatory variables measured and source of information	Outcomes measured
	August 1993 10 539 patients randomly sampled 8 640 eligible for study - ineligible – disenrolled, didn't have asthma, 'other reason' 6 612 (77%) completed the questionnaire Data in this paper comes from 5 062 (77%) with incomplete asthma control and 1991 NAEPP guideline defined moderate or severe asthma	and outpatient care - race, sex, age, education level, employment status, race x sex - same models by each MCO site	

Krishnan, J. A., Diette, G. B., Skinner, E. A., Clark, B. D., Steinwachs, D., & Wu, A. W. (2001). Race and sex differences in consistency of care with national asthma guidelines in managed care organizations. *Archives of Internal Medicine, 161*(13), 1660-1668.

Possible sources of bias, confounding and method used to minimise effect	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection issues and bias No upper age limit – confusion between asthma and CORD in older age groups **Information bias** Patient recall of medications. Concordance between patient and physician report 93.7% Patients may have over-reported actual use of medicines. If over-reporting varied by race or sex would bias data **Confounders considered and method used to deal with them** Age, education level, employment status included in multivariable analyses Asthma Symptom Index also included to account for reporting bias related to symptom frequency. Level of asthma control – sample limited to moderate and severe asthma Insurance status/SES – sample limited to people enrolled in employer based managed care	5 062 patients - 14% AA - 72% women **Demographics** Whites older than AA Males and females no difference in age Whites > college education Males and females no difference in college education Onset asthma earlier in AA and in males Duration of asthma no ethnic differences Duration of asthma longer in males than females **Self-report asthma symptoms and health service utilisation** Respiratory symptoms AA>W (p=0.06) Asthma attacks W>AA ED visits AA>W Admissions AA>W Respiratory symptoms F>M Asthma attacks M>F	Generalisability – large study but in insured managed care population. May be generalisable to managed care populations but not to uninsured, other types of care, lower SES Generalisability Didn't examine effect of specialist care vs primary care physician Exclusion of people with well controlled asthma may mask ethnic differences – may be more ethnic differences in proportion of well controlled asthma and this is excluded from analysis because have no/mild symptoms Differences in management by race in bivariate analyses were largely unchanged after adjusting for age, education, employment status, and symptom

Krishnan, J. A., Diette, G. B., Skinner, E. A., Clark, B. D., Steinwachs, D., & Wu, A. W. (2001). Race and sex differences in consistency of care with national asthma guidelines in managed care organizations. *Archives of Internal Medicine, 161*(13), 1660-1668.

Possible sources of bias, confounding and method used to minimise effect	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	ED visits F>M Admissions F>M **Domains of asthma care** Ethnic and sex differences did not differ by MCO so combined results from MCO reported *Medication* Has an ICS AA<W Daily use ICS AA<W Medication regimen consistent with guideline AA men (65.8%) significantly less likely to have medication consistent with guideline recommendations (AA female 78.9%, W male 76.5%, W female 78.2%). *Self-management education* Action plan AA<W Adjusting medication AA<W *Control of factors relating to severity* Trigger avoidance AA<W *Periodic assessment* Has PEFR AA<W	frequency and suggest that among people with insurance differences in medical management may contribute to ethnic disparities in outcomes

Krishnan, J. A., Diette, G. B., Skinner, E. A., Clark, B. D., Steinwachs, D., & Wu, A. W. (2001). Race and sex differences in consistency of care with national asthma guidelines in managed care organizations. *Archives of Internal Medicine, 161*(13), 1660-1668.

Possible sources of bias, confounding and method used to minimise effect	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	Daily PEFR meter use AA=W PEFR meter instructions given AA=W No race x sex interaction for other domains of care *Medication* Has an ICS M<F Daily use ICS F<M *Self-management education* Action plan F=M Adjusting medication F=M *Control of factors relating to severity* Trigger avoidance M<F *Periodic assessment* Has PEFR M<F Daily PEFR meter use F=M PEFR meter instructions given F=M **Specialist care** Saw specialist AA<W and F<M No specialist but wanted to AA>W and M=F No race x sex interaction	

Krishnan, J. A., Diette, G. B., Skinner, E. A., Clark, B. D., Steinwachs, D., & Wu, A. W. (2001). Race and sex differences in consistency of care with national asthma guidelines in managed care organizations. *Archives of Internal Medicine, 161*(13), 1660-1668.

Possible sources of bias, confounding and method used to minimise effect	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	Multivariable analyses Inpatient and outpatient stratified analyses – no differences in results of multivariable modelling so report combined results No race x sex interactions in multivariable models White vs AA odds ratio and 95% CI *Medication* Has an ICS 1.49 (1.25, 1.77) Daily use ICS 2.16 (1.78, 2.62) Medication regimen consistent with guideline 1.00 (0.83, 1.21) ns *Self-management education* Action plan 1.60 (1.36, 1.88) Adjusting medication 1.60 (1.36, 1.89) *Control of factors relating to severity* Trigger avoidance 1.94 (1.64, 2.29) *Periodic assessment* Has PEFR 1.27 (1.06, 1.53) Daily PEFR meter use 1.06 (0.71, 1.59) ns	

Krishnan, J. A., Diette, G. B., Skinner, E. A., Clark, B. D., Steinwachs, D., & Wu, A. W. (2001). Race and sex differences in consistency of care with national asthma guidelines in managed care organizations. *Archives of Internal Medicine, 161*(13), 1660-1668.

Possible sources of bias, confounding and method used to minimise effect	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	PEFR meter instructions given 0.97 (0.66, 1.44) ns *Asthma specialist care* 1.25 (1.06, 1.48) Male vs female odds ratio and 95% CI *Medication* Has an ICS 0.83 (0.72, 0.95) Daily use ICS 1.17 (1.02, 1.34) Medication regimen consistent with guideline 0.88 (0.76, 1.02) ns *Self-management education* Action plan 0.93 (0.82, 1.06) ns Adjusting medication 0.98 (0.86, 1.11) ns *Control of factors relating to severity* Trigger avoidance 0.85 (0.75, 0.97) *Periodic assessment* Has PEFR 0.76 (0.66, 0.88) Daily PEFR meter use 1.04 (0.77, 1.42) ns PEFR meter instructions given 0.73 (0.55, 0.97) *Asthma specialist care* 1.17 (1.03, 1.33)	

Lieu, T. A., Lozano, P., Finkelstein, J. A., Chi, F. W., Jensvold, N. G., Capra, A. M., et al. (2002). Racial/ethnic variation in asthma status and management practices among children in managed Medicaid. *Pediatrics, 109*(5), 857-865.

Year data collected, study design	**Participants**	**Explanatory variables measured and source of information**	**Outcomes measured**
Asthma Care Quality Assessment Study Cross-sectional survey Data collected 1999	Medicaid-insured children enrolled in 5 managed care organisations in Massachusetts, Washington, California Identified potentially eligible through health plan data (registration information and claims forms). Children aged 2-16 years who met at least two health service utilisation or pharmaceutical inclusion criteria. 4094 children identified - 15% (603) no longer plan members	Telephone interview - letter sent asking to participate, card to send back if did not want to participate - phone call to interview - questionnaire sent out to people they couldn't contact by phone Demographic factors (age, race, parental age, parental education, income, language spoken at home, some asthma risk factors) Current asthma severity – standardised instrument Current asthma symptoms to establish asthma phenotype – intermittent and persistent asthma (NAEPP [2] criteria) Types of managed care within Medicaid programme and practice site type Access to care – having a primary care physician Health service utilisation Specific practices and tools for home management of asthma	Asthma status Processes of asthma care/asthma management processes - β-agonist use - anti-inflammatory use -

[2] NAEPP National Asthma Education and Prevention Programme

Lieu, T. A., Lozano, P., Finkelstein, J. A., Chi, F. W., Jensvold, N. G., Capra, A. M., et al. (2002). Racial/ethnic variation in asthma status and management practices among children in managed Medicaid. *Pediatrics, 109*(5), 857-865.

Year data collected, study design	Participants	Explanatory variables measured and source of information	Outcomes measured
	- 3% (141) refused to participate - were able to contact 2568/3350 - 628 ineligible - 1663 completed survey Overall response rate 63% (1663/2642)	- action plan - having a follow-up visit to doctor for asthma - having seen an asthma specialist Computerised data collection about asthma-related health care from electronic medical records and claim data for those who completed the survey	

Lieu, T. A., Lozano, P., Finkelstein, J. A., Chi, F. W., Jensvold, N. G., Capra, A. M., et al. (2002). Racial/ethnic variation in asthma status and management practices among children in managed Medicaid. *Pediatrics, 109*(5), 857-865.

Possible sources of bias, confounding and method used to minimise effect.	Major findings All findings statistically significant unless stated otherwise	Comments
Selection issues and bias Excludes 'other' ethnic groups. 63% is very good response rate for a survey of this sort in a Medicaid population.	Ethnicity of participants - 38% Black - 19% Latino - 31% White Excluded 12% who were of other ethnic groups	**Generalisability and representative** Excludes other ethnic groups Medicaid-insured children 5 managed care health plans 3 states

Lieu, T. A., Lozano, P., Finkelstein, J. A., Chi, F. W., Jensvold, N. G., Capra, A. M., et al. (2002). Racial/ethnic variation in asthma status and management practices among children in managed Medicaid. *Pediatrics, 109*(5), 857-865.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	Asthma status	
Non-respondents and those who didn't participate because no longer covered by Medicaid – study may under-estimate the problems faced by these groups	Black children worse than White and Latino across several different measures. Black – White disparities persisted after multivariable modelling. **Asthma health care use** *Hospitalisations* Black children more hospitalisations than White, Latino. Differences did not persist after multivariable modelling	Recall bias – no evidence of differential recall bias by ethnic group Lower anti-inflammatory use NOT due to financial barriers in this group as all participants had full medicine coverage under Medicaid.
Children who had not had healthcare for asthma in last 12 months – not included	*ED use* No ethnic differences in ED use after multivariable modelling. *Outpatient visit (to Primary care provider in past 6 months* – multivariable modelling - no ethnic differences	Racial/ethnic disparities similar across different MCO types – so not due to different methods of support for asthma care across different MCOs.
Undiagnosed asthma – not included. Black children have more undiagnosed asthma than other ethnic groups.	*Specialist visit in past 6 months* – multivariable modelling – Latino children more likely to have made a visit. No ethnic differences for Black (Black – White) **Anti-inflammatory medication use** Black and Latino less likely to be using anti-inflammatory drugs. Differences persisted after multivariable modelling.	Recommended that increasing use of preventive medications important. Recommended work in area of
Information bias Parent recall – possible recall bias.	Black OR 0.64; CI 0.45, 0.90 Latino OR 0.52; CI 0.33, 0.82	Culturally competent health care provision, quality of care, doctor-patient interactions,

Lieu, T. A., Lozano, P., Finkelstein, J. A., Chi, F. W., Jensvold, N. G., Capra, A. M., et al. (2002). Racial/ethnic variation in asthma status and management practices among children in managed Medicaid. *Pediatrics, 109*(5), 857-865.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Parent report may underestimate symptom frequency of child's asthma Children with asthma may over-estimate their medication use. Was good concordance between parent report of medication use and computerised medical record of medication dispensing Incomplete adjustment for SES **Confounders considered and method used to deal with them** SES – adjust Asthma status – adjust Family structure – adjust Type of MCO – adjust	Repeat analysis including health plan type – no change to ethnic differences. Repeat analysis including practice site - significant difference persisted for black children but Latino children was diminished and CI included 1.0. **Other asthma management practices** *B-agonist use*- Multivariable model – no ethnic differences Other self-management practices more common in Black and Latino participants (ethnicity significant in multivariable models) – action plan, has a nebuliser, no smoking in household, no pets in house *Has a written action plan* Black OR 1.80; CI 1.33, 2.43 Latino OR 1.50, CI 1.04, 2.15 Use of action plans and specialist visits was low in ALL children	family health beliefs and practices

Lieu, T. A., Lozano, P., Finkelstein, J. A., Chi, F. W., Jensvold, N. G., Capra, A. M., et al. (2002). Racial/ethnic variation in asthma status and management practices among children in managed Medicaid. *Pediatrics, 109*(5), 857-865.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Practice site – adjust		

Moudgil, H., & Honeybourne, D. (1998). Differences in asthma management between white European and Indian subcontinent ethnic groups living in socioeconomically deprived areas in the Birmingham (UK) conurbation. *Thorax, 53*(6), 490-494.

Year data collected, study design	**Participants**	**Explanatory variables measured and source of information**	**Outcomes measured**
Cross-sectional survey GP based sampling Data collected August 1995 – August 1996	Children and adults 11-59 years who were Indian subcontinent (ISC) or White European (WE) ethnicity with diagnosed asthma. Identified through GP registers in inner-city suburbs. 12 of 14 practices in area participated. All eligible patients were sent a letter asking them to attend for review by one of the researchers. Response rates Overall 57% (689/1217) 43% (n=154) WE men 58% (n=191) WE women 67% (n=183) ISC men 71% (n=161) ISC women	Face-to-face interview with participant Self-defined ethnicity. Do not report what question(s) were used to determine this. *Collected information about* Demographic factors Socio-economic status Lifestyle factors Illness profile Objective measures of airflow obstruction (PEFR meter and hand held spirometry) Current levels of drug prescription were assessed against the 1993 British Thoracic Society guidelines.	Asthma education and self-management practices

Moudgil, H., & Honeybourne, D. (1998). Differences in asthma management between white European and Indian subcontinent ethnic groups living in socioeconomically deprived areas in the Birmingham (UK) conurbation. *Thorax, 53*(6), 490-494.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection bias Minimised by asking all to attend for consultation with researcher. i.e. GP didn't have to nominate/recruit. 'Small number' (not specified) of ISC participants who could not speak English, Punjabi, Urdu or Hindi were excluded. Sample limited to people living in medium and high deprivation areas Excluded older people who may have CORD **Response bias** Response rate varied significantly by ethnicity, gender and age. Response rate higher among - ISC than WE - females Stratified by gender for outcomes. Responders significantly older (mean age 34.5 y vs 29.8y for non-responders). **Information bias** Participants interviewed in language of choice (English, Punjabi, Urdu, Hindi).	Report proportions for SEP and demographics but do not report statistical tests. ISC participants - 42% non-UK born (8% WE) - 34% spoke no/little English (WE 100% spoke English) - 9% had never attended school **On anti-inflammatory for asthma** *Males* WE 76% ISC 70% Adj OR 1.31 (0.77 - 2.28) ns *Females* WE 81% ISC 80% Adj OR 1.12 (0.62 - 2.01) ns **Carries β-agonist** *Male* WE 73% ISC 57% Adj OR 1.69 (1.03 - 2.87) *Females* WE 84% ISC 73% Adj OR 2.18 (1.22 - 3.97) **Previous asthma education** *Males* WE 68% ISC 62% Adj OR 1.31 (0.80 - 2.15) ns	Only adjusted for gender and age. Geographic level restriction to account for SES Generalisability? – inner-city Birmingham Report that 95% of both ethnic groups were on steps 1-3 of BTS guidelines treatment recommendations but does not appear to have considered adequacy of treatment participants were receiving. *For both males and females* WE significantly more likely to

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Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Single interviewer used. For most aspects of information about asthma knowledge objective confirmation of responses obtained (e.g. able to say what medicine was reliever or treater rather than talking non-specifically about these types of medicines). Weren't able to verify self-reported compliance. **Confounding** *Sex* For some demographic data and functional measures an interaction between ethnicity and gender was observed i.e. size/significance of ethnic differences varied by gender group. Analyses of outcomes between the two ethnic groups were stratified by gender. *Age* Mantel-Haenszel summary chi-square stratified by 6 year age groups *Socio-economic status* All participants lived in same area – socio-economically deprived inner city (i.e. restricted sample to deprived area)	*Females* WE 70% ISC 67% Adj OR 1.22 (0.75 - 2.01) ns **Advised on trigger factors** *Males* WE 52% ISC 42% Adj OR 1.69 (1.05 - 2.75) *Females* WE 56% ISC 42% Adj OR 1.99 (1.27 - 3.26) **Symptoms/mechanisms explained** *Males* WE 51% ISC 43% Adj OR 2.46 (1.58 - 4.21) *Females* WE 53% ISC 33% Adj OR 2.47 (1.57 - 4.03) **Had role of medications explained** *Males* WE 53% ISC 44% Adj OR 1.51 (0.95 – 2.43) ns *Females* WE 51% ISC 48% Adj OR 1.22 (0.77 – 1.93) ns **Understands role of medications** *Males*	- carry a β-agonist - have been told about triggers - to have symptoms mechanisms explained *Among females* WE significantly more likely to - understand the role of medication - carry out self-management *Among males* WE significantly more likely to - report full drug compliance Information about previous medications prescribed very limited (and therefore of very limited use). Don't provide results of analysis about medication use

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Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	WE 55% ISC 44% Adj OR 1.41 (0.88 – 2.28) ns *Females* WE 59% ISC 39% Adj OR 2.27 (1.44 – 3.64) **Report full drug compliance** *Males* WE 73% ISC 62% Adj OR 1.66 (1.01 – 2.80) *Females* WE 74% ISC 67% Adj OR 1.48 (0.90 – 2.47) ns **Carry out self-management** *Males* WE 18% ISC 11% Adj OR 1.41 (0.70 – 2.76) ns *Females* WE 23% ISC 12% Adj OR 2.17 (1.16 – 4.09) No ethnic differences in whether the participant had had drug delivery technique assessed **Previous health service utilisation** *Males*	and guideline 'step' level. Don't appear to have assessed level of control of asthma symptoms, or analysed prescription data by level of control.

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Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	WE males significantly less likely to have previous asthma follow-up by hospital No differences in follow up by GP/nurse, admission, A&E attendance *Females* WE less likely to have follow-up by hospital, admission No difference in follow-up by GP, A&E attendance	

Ortega, A. N., Gergen, P. J., Paltiel, A. D., Bauchner, H., Belanger, K. D., & Leaderer, B. P. (2002). Impact of site of care, race, and Hispanic ethnicity on medication use for childhood asthma. *Pediatrics, 109*(1), E1.

Year data collected, study design	**Participants**	**Explanatory variables measured and source of information**	**Outcomes measured**
Childhood asthma severity study (CHAS) - community-based prospective study to investigate environmental, familial and health service related factors related to asthma severity. This article reports data about the sibling (child under 12 y) collected from the mother at time of enrolment into study Data collection period for this article 1996-1998.	Eligibility Families with a new-born and a child <12 years who had been diagnosed with asthma. Recruited from 5 Massachusetts and 1 Connecticut hospitals between 1996 and 1998. 1002 families recruited. 24 siblings exclude because did not have at least 9 months of data. Sample size 978.	Data about sibling's asthma collected from mother at time of enrolment into study. Retrospective data collection about - health service use - asthma symptoms - medication use Time period: Mothers asked to report the data for each month for the 12 months prior to interview. Unit of analysis is the sibling (not patient-month). Data for each month aggregated to give information over the 12 month period. Child excluded from this analysis if mother couldn't provide information for at least 9 of the previous 12 months. Data collected was about these Data collected for Socio-demographics – race/ethnicity, age,	Do differences in medication use by provider site and race/ethnicity persist after adjusting for previous patterns of health service use, insurance status and asthma severity? Outcome measures B-agonists Inhaled steroids Cromoglycate Systemic steroids Anticholinergics Theophylline Analysis Descriptive analysis of explanatory variables and of site of care by race/ethnicity. All multivariable models included race/ethnicity, age, gender, insurance status,

Ortega, A. N., Gergen, P. J., Paltiel, A. D., Bauchner, H., Belanger, K. D., & Leaderer, B. P. (2002). Impact of site of care, race, and Hispanic ethnicity on medication use for childhood asthma. *Pediatrics, 109*(1), E1.

Year data collected, study design	**Participants**	**Explanatory variables measured and source of information**	**Outcomes measured**
		family yearly income, maternal education, Insurance status – Medicaid, private, (excluded 4 participants without insurance) Symptom severity – validated symptom severity score Primary care contact – regular source of care, number of routine and acute visits to regular provider, Provider practice types	symptom severity, number of routine visits to routine source of care in last year, number of urgent visits to routine source of care, practice type.

Ortega, A. N., Gergen, P. J., Paltiel, A. D., Bauchner, H., Belanger, K. D., & Leaderer, B. P. (2002). Impact of site of care, race, and Hispanic ethnicity on medication use for childhood asthma. *Pediatrics, 109*(1), E1.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection issues and bias **Information bias** Parent recall.	Ethnicity of participants - 15% Black - 27% Latino - 58% White	Ethnic disparity persists when control for previous health service use, SES, symptomatology, insurance status and other familial factors.

Ortega, A. N., Gergen, P. J., Paltiel, A. D., Bauchner, H., Belanger, K. D., & Leaderer, B. P. (2002). Impact of site of care, race, and Hispanic ethnicity on medication use for childhood asthma. *Pediatrics, 109*(1), E1.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Excluded data from children if mother couldn't provide data for at least 9 of the previous 12 months. **Confounders considered and method used to deal with them** Age Gender Insurance status Symptom severity Number of routine visits to routine source of care in last year Number of urgent visits to routine source of care Family income Maternal education Practice type All the above were included in the multivariable model	Practice type Private practice commonest. 72% overall Blacks and Hispanics used ambulatory care centre, hospital based clinic or information not found **Descriptive analysis** *β-agonists* Overall 20% had not used β-agonists in the last year Higher proportion of Black and Hispanic had not used in last year. Higher proportion of Whites had used on more than 30 days in last year *Inhaled steroids* Overall 79% had not used ICS in last year Higher proportion of Black and Hispanic had not used in last year H8igher proportion of White had used on more than 30 days in last year *Systemic steroids* Overall 74% had not used in the last year Higher proportion of Black and Hispanic had not used in last year	Stratification by practice type – sample size to low for precise estimates for β-agonists. Ethnic disparities found for ICS. Limited to medications. Doesn't look at other aspects of asthma management or examine the effect of these on medication use. Recommend - improve quality of asthma care, cultural competency - examine Dr-patient, Dr-family interaction - more work on how asthma and its management is perceived, treatment accepted Don't know if children did not take medicine

Ortega, A. N., Gergen, P. J., Paltiel, A. D., Bauchner, H., Belanger, K. D., & Leaderer, B. P. (2002). Impact of site of care, race, and Hispanic ethnicity on medication use for childhood asthma. *Pediatrics, 109*(1), E1.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Did not look for interactions between ethnicity and income or maternal education for each of the outcome variables.	Site of care – private practices associated with better quality of care (higher proportions of participants having used various types of drugs) **Multivariable analyses** *β-agonists* Black less likely to have used *Inhaled steroids* Black and Hispanic less likely to have used *Systemic steroids* No ethnic differences Stratification by practice type Limited to private practices as numbers in other types too low. *β-agonists* Point estimates for both Black and Hispanic (compared with White) low but confidence intervals include 1.0 *Inhaled steroids* Hispanic less likely to have ICS than White Blacks point estimate still low but CI includes 1.0 for ICS	because they were not prescribed or because prescription wasn't filled. No measure of whether participants had needed care but did not / were not able to access it.

Ortega, A. N., Gergen, P. J., Paltiel, A. D., Bauchner, H., Belanger, K. D., & Leaderer, B. P. (2002). Impact of site of care, race, and Hispanic ethnicity on medication use for childhood asthma. *Pediatrics, 109*(1), E1.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	Point estimates essentially the same but confidence intervals widened. Ethnic sub-samples too small, lower precision and wider estimates of CI	

Shields, A. E., Comstock, C., & Weiss, K. B. (2004). Variations in asthma care by race/ethnicity among children enrolled in a state Medicaid program. *Pediatrics, 113*(3 Pt 1), 496-504.

Year data collected, study design	**Participants**	**Explanatory variables measured and source of information**	**Outcomes measured**
Retrospective cohort study Data from 12 month period over 1993 - 1994	5773 children aged 2 – 18 years with asthma in non-HMO portion of Massachusetts Medicaid programme Eligibility criteria - continuous enrolment - at least 2 visits, 1 Ed, 1 hospitalisation or 2 prescription fills for asthma - enrolled in non-HMO parts of Medicaid programme (76% of Medicaid population) i.e. enrolled in fee-for-service or primary care case manager parts of Medicaid. - White, Hispanic, Black	Data derived from Massachusetts Medicaid service and drug claims, demographic and managed care enrolment files. Morbidity and health care needs measured by Johns Hopkins Case Mix System Burden of asthma assessed using NCQA claims-based algorithm for likely persistent asthma. Morbidity and health care needs (case-mix variables) were based on 1993 data and process of care variables on 1994 data.	Performance on 6 claims based process of care measures that reflect aspects of car recommended by NAEPP guidelines. - Minimum of 2 asthma visits per year - Access to asthma specialist - Patient that was given ≥ 3 months supply of β-agonist within a six month period should also have anti-inflammatory - follow-up physician visit within 5 days of ED visit - follow-up physician visit within 5 days of discharge from hospital - receiving more than 6 months supply of β-agonist within a 6 month period.

Shields, A. E., Comstock, C., & Weiss, K. B. (2004). Variations in asthma care by race/ethnicity among children enrolled in a state Medicaid program. *Pediatrics, 113*(3 Pt 1), 496-504.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Selection issues and bias **Information bias** No information about incomplete records or quality of databases information No information on how ethnicity data collected, potential inaccuracies Morbidity assessment limited to use of electronic algorithm to estimate morbidity **Confounders considered and method used to deal with them** SES – limited to poor (Medicaid recipients) Case mix, age, sex, provider type and region - adjusted	Sample – 5773 children - 3199 White - 1649 Hispanic - 925 Black **Bivariate analyses** No differences in age, sex across ethnic groups. Health service utilisation - primary care visits no ethnic differences - specialist visits H<B<W - ED visits W<H<B - Hospitalisations W=H<B Prescriptions - Anticholinergics No ethnic differences - β-agonist H<B<W - Cromolyn H<B<W - ICS H<B<W - systemic steroids no differences - theophylline H<B<W - total asthma prescriptions H<B<W	Children in all ethnic groups received less than optimal care. - <28% received a minimum of 2 visits for asthma during the year - Among children with persistent asthma, only 12% saw an asthma specialist during the year. - Only 65% of children regularly using β-agonist also received an anti-inflammatory <15% of children seen in the ED had follow-up physician visit within 5 days - only 30% of those hospitalized for asthma received saw Dr within 5 days of discharge Black and Hispanic children received comparable or better care for some processes - anti-inflammatory medication - timely follow-up after hospitalisation - excessive use of β-agonists - similar number of primary care visits

Shields, A. E., Comstock, C., & Weiss, K. B. (2004). Variations in asthma care by race/ethnicity among children enrolled in a state Medicaid program. *Pediatrics, 113*(3 Pt 1), 496-504.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	NCQA persistent asthma W=H<B **Processes of care bivariate** *Minimum of 2 asthma visits per year* Total 27.5% W 27.3% H 28.7% B 26.5% *Access to asthma specialist* Total 12.0% W 14.7% H 7.3% B 11.1% *Prescribed anti-inflammatory medication* Total 65.1% W 66.8% H 60.3% B 65.7% *Timely follow-up after ED visit* Total 14.7% W 19.7% H 13.4% B 6.7% *Timely follow-up after hospitalisation* Total 30.4% W 33.8% H 29.1% B 25.0% *Over-reliance on β-agonist* Total 7.9% W 9.1% H 6.1% B 6.9% **Processes of care multivariable (reference is White children)**. Controlling for case mix, age, sex, provider type and region *Minimum of 2 asthma visits per year* Hispanic OR 1.16; 95%CI 1.01, 1.34	Ethnic disparities in - access to specialists - timely follow-up after ED visit Didn't examine other aspects of quality care – e.g. action plans, peak flow meter Generalisability- only Medicaid recipients. Didn't include 20% of Medicaid people who were in HMOs

Shields, A. E., Comstock, C., & Weiss, K. B. (2004). Variations in asthma care by race/ethnicity among children enrolled in a state Medicaid program. *Pediatrics, 113*(3 Pt 1), 496-504.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	Black:White no difference *Access to asthma specialist* Hispanic OR 0.61; 95%CI 1.46, 0.81 Black:White no difference *Prescribed anti-inflammatory medications* No ethnic differences *Timely follow-up after ED visit* Hispanic OR 0.59; 95%CI 0.36, 0.95 Black OR 0.36; 95%CI 0.18, 0.73 *Timely follow-up after hospitalisation* No ethnic differences *Over-reliance on β-agonist* Hispanic OR 0.73; 95%CI 0.54, 0.99 No black – white differences	

Zoratti, E. M., Havstad, S., Rodriguez, J., Robens-Paradise, Y., Lafata, J. E., & McCarthy, B. (1998). Health service use by African Americans and Caucasians with asthma in a managed care setting. *American Journal of Respiratory & Critical Care Medicine, 158*(2), 371-377.

Year data collected, study design	**Participants**	**Explanatory variables measured and source of information**	**Outcomes measured**
Cross-sectional survey Participants in a managed care setting Data collected 1993	Aged 15 -45 years Continuous enrolment in HMO for calendar year 2003 Self-identified Caucasian or African American ethnicity - 464 AA - 1609 C Low income sub-group - 270 AA - 187 C At least one outpatient visit with physician where asthma diagnosis code was primary reason for visit.	HMO electronic database information collection - ethnicity, DOB, address, sex, marital status, number and location of asthma visits Data from HMO billing records to identify "out of plan" health care for urgent asthma episodes e.g. ED and admissions SES – average income per occupant by using census block data about median household income and average household size. Arbitrary cut point for 'low income' (<$10450 per occupant). All regression analyses adjusted for age, gender, marital status and income	Mean number of visits Visit type – ED, primary care clinic, asthma specialist clinic, hospital inpatient. Physician type – primary care, asthma specialists (17). Access to specialist required referral from primary care doctor Data about prescriptions filled – HMO billing data. Each prescription fill represents one months supply for drug that should be used continuously.

Zoratti, E. M., Havstad, S., Rodriguez, J., Robens-Paradise, Y., Lafata, J. E., & McCarthy, B. (1998). Health service use by African Americans and Caucasians with asthma in a managed care setting. *American Journal of Respiratory & Critical Care Medicine, 158*(2), 371-377.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
Sampling bias Doesn't include people who had no asthma related visit in the 12 months or people who had partial / discontinuous enrolment *Information bias* Prescriptions data – only those filled. Didn't collected data on prescriptions written. Physicians could also have given people samples. Filling a prescription doesn't necessarily mean it is used. Cross-sectional – can't determine cause and effect Confounding SES – small area measure for income. AA lower use of ICS primarily a function of SEP and lower specialist referral.	No ethnic difference in "out of plan" ED visits. Only 1 "out of plan" hospitalisation. **Demographics** *All sample* No significant difference in age. AA sample significantly more female, fewer married, lower median family income, lower median income per occupant. *Low income sub-sample* No significant difference in age, gender. AA sample significantly fewer married, lower median income per occupant. **Physician visits** *Mean number all sample* ED AA>C Primary care physician – no significant differences Asthma specialist physician AA<C Hospital inpatient AA>C *Mean number low income sub-sample* ED AA>C	Managed care environment – minimises financial barriers to accessing care, but is still a co-payment for some services. No assessment of morbidity No assessment of appropriateness of medications used vs morbidity Despite similar primary care use AA still have higher ED, admissions. Differences in SEP don't fully explain ethnic differences in health service utilisation Barriers to specialist referral for low income groups and for AA

Zoratti, E. M., Havstad, S., Rodriguez, J., Robens-Paradise, Y., Lafata, J. E., & McCarthy, B. (1998). Health service use by African Americans and Caucasians with asthma in a managed care setting. *American Journal of Respiratory & Critical Care Medicine, 158*(2), 371-377.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	Primary care physician – no significant differences Asthma specialist physician – no significant differences Hospital inpatient AA>C *Adjusted analyses all sample* Ethnicity significant association with - higher ED and admissions - For ED visits was interaction between ethnicity and gender – the association between ED and ethnicity stronger for males than females. *Adjusted analyses low income sub-sample* ED visits and ethnicity still associated but association with speciality visits and hospitalisations were no longer significant **Prescription medications - average number of prescriptions filled per participant** *All sample* Inhaled corticosteroids C>AA Inhaled cromolyn/nedocromil Ethnicity ns Inhaled anticholinergics Ethnicity ns Inhaled β-agonist Ethnicity ns	Higher ED and admissions for AA suggest less well controlled asthma. Specialists more vigorous in management of asthma. Populations with highest Ed and hospitalisations have lower rates of specialist referral Lower use of inhaled steroids for AA and low income groups. But have higher use of oral steroids. Use of oral steroids and higher inhaled β-agonist suggest asthma less well controlled and that physicians underutilise ICS in this group.

Zoratti, E. M., Havstad, S., Rodriguez, J., Robens-Paradise, Y., Lafata, J. E., & McCarthy, B. (1998). Health service use by African Americans and Caucasians with asthma in a managed care setting. *American Journal of Respiratory & Critical Care Medicine, 158*(2), 371-377.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	Oral β-agonist Ethnicity ns Theophylline Ethnicity ns Oral corticosteroids AA>C *Low income sub-sample* Inhaled corticosteroids Ethnicity ns Inhaled cromolyn/nedocromil Ethnicity ns Inhaled anticholinergics C>AA Inhaled β-agonist Ethnicity ns Oral β-agonist Ethnicity ns Theophylline Ethnicity ns Oral corticosteroids Ethnicity ns *Adjusted analyses all sample* Inhaled corticosteroids marginally more used in C (p=0.055) Oral corticosteroids higher in AA *Adjusted analyses low income sub-sample* No association between ICS and ethnicity No association between oral corticosteroids and ethnicity Asthma specialists and average number of prescriptions filled per participant	

Zoratti, E. M., Havstad, S., Rodriguez, J., Robens-Paradise, Y., Lafata, J. E., & McCarthy, B. (1998). Health service use by African Americans and Caucasians with asthma in a managed care setting. *American Journal of Respiratory & Critical Care Medicine, 158*(2), 371-377.

Possible sources of bias, confounding and method used to minimise effect.	**Major findings** All findings statistically significant unless stated otherwise	**Comments**
	Filling of all types of prescription medications higher in participants who had at least one visit to asthma specialist than those who did not. Among those who had seen a specialist use - oral corticosteroids significantly higher in AA - no other ethnic differences in prescription medications filled Participants who were not seen by specialists - oral corticosteroids AA>C - inhaled β-agonist AA>C - all other medications types no ethnic differences **Prescription co-payments and average number of prescriptions filled per participant** (low $2-3 versus high $5-10) Low co-payment AA>C Average number of fills higher in low co-pay group for all medication types but only statistically significant for oral corticosteroids and oral β-agonist	

Appendix 5 Training manual

The Primary Care Management of Childhood Asthma

Department of Maori and Pacific Health, University of Auckland,
Department of Paediatrics, University of Auckland

TRAINING MANUAL FOR RECRUITERS AND INTERVIEWERS

Recruiter and Interviewer Name :

_____

If found please return to :

The Primary Care Management of Childhood Asthma
C/- Mrs. Mavis Roberts,
Department of Paediatrics,
School of Medicine,
University of Auckland,
Private Bag 92019,
Auckland.

TABLE OF CONTENTS

INTRODUCTION to the STUDY

The project aims to find out how childhood asthma is managed by doctors and other health professionals in the community in the Auckland area. It will look at areas such as

- the types of medicines and medicine delivery devices used
- the amount of asthma education provided
- the provision of asthma action plans
- asthma knowledge levels
- health service utilisation
- parental confidence in managing asthma
- family information relating to asthma
- and the socio-demographic characteristics of families involved in the study.

This study will involve the different ethnic communities in Auckland, and will seek to gather information that is relevant to children from the Maori, Pacific and European/others communities.

There will be 510 subjects.

This project is a collaborative project involving the Department's of Paediatrics and Maori and Pacific Health at the University of Auckland.

The data collection of these infants will involve :
Socio-demographic data
Information about the child's asthma
Information about the severity of the child's asthma
Information about parental confidence in managing the child's asthma
Family information relating to asthma and other related illnesses
Questions which assess asthma knowledge
Questions about how health services (for asthma) have been used in the preceding 12 months
Information about asthma action plans: whether they have been offered a plan, who by, who explained the plan, how useful it was, etc. etc.
Information about asthma education: whether they have been offered any information / education about asthma, who by, what information they were given, how useful it was, etc. etc.

All this information will be collected during a single interview with the main care-giver of the child.

KEY PEOPLE INVOLVED IN THIS STUDY

Dr. Sue Crengle
Dr. Crengle is the principal investigator for this study.

Department of Maori and Pacific Health, School of Medicine,
Phone: 373 7599 ex 6470

Dr. Cameron Grant
Department of Paediatrics, School of Medicine,
Phone: 373 7599 ext 6192

Dr. Colin Tukuitonga
Department of Maori and Pacific Health, School of Medicine,
Phone: 373 7599 ext 6951

Mrs. Mavis Roberts
Department of Paediatrics, School of Medicine
Phone : 373 7599 ext 6192

Ms. Binky Taua ,
Department of Paediatrics, School of Medicine,
Phone 3737599 ext 6434

Mrs. Iritana Hankins,
Department of Maori and Pacific Health, School of Medicine,
Phone: 373 7599 ex 2529

TIMETABLE OF DATA COLLECTION

The timeline for enrolment for each enrolled infant from identification to completion of data collection is three to four weeks.

Week 1 : Identification of eligibility by recruiter, application of sampling ratio based on ethnicity.

Week 2 : Family invited to enrol in study

- Subject Information sheet handed out
- An appointment is made for interview

Week 3 - 4 : Interviewer visit

- Informed consent obtained
- Interview undertaken

SAMPLING PROTOCOL FOR INTERVIEWERS

SELECTION OF THE STUDY SAMPLE

The sampling method that will be used is cluster sampling using random addresses as start points in Auckland. The sample will be stratified by ethnicity (Maori, Pacific Islander, Other). In Auckland equal numbers of each of the 3 ethnic groups (Maori, Pacific and European/other) will be enrolled. 612 children will be included in the study. The ages of the children involved in the study are 2 years to 14 years.

Coding of ethnicity
Children will be assigned to an ethnic group based on the ethnicity identified for them by their caregiver. When caregivers indicate multiple ethnicities then ethnicity will be assigned based on the ethnicity that the parent states the child identifies with the most.

Stratification of sample
We are aiming to have 510 children finish the study. We are also assuming that only 80% of those who agree to participate will actually finish the study. Therefore we will need to enrol 612 children in order to have 510 finish. We will be enrolling equal numbers of Maori, Pacific Island and European/Other children so we will be aiming to enrol 204 children of each ethnic group with the expectation that only 170 of each ethnic group will complete the study.

There are differences between each ethnic group (Maori, Pacific and European/other) for the number of children in the age group 2 – 14 years, the prevalence of asthma in children in this age group, and the number of children per family. Therefore a different proportion of each ethnic group identified will be enrolled. Based on these differences each eligible Pacific child identified will have a 100% chance of being enrolled, each eligible Maori child will have a 60% chance of being enrolled and each eligible European/other child will have a 20% chance of being enrolled.

Therefore we will need to identify 204 eligible Pacific children to enrol 204, 340 Maori children to enrol 204 and 1020 European/Other children to enrol 204. Therefore 1564 eligible children need to be identified to enrol 612.

The process of identifying children to be enrolled is by door knocking using a series of random start points. Ten houses will be visited per start point. Each child identified as eligible from these houses must have a chance of being enrolled. ie it is not appropriate to simply enrol the first 204 children of each ethnic group that are identified. If we did this then we would enrol the European/other part of the sample before the other 2 ethnic groups and then would be approaching houses and indicating at each household that we are only interested in enrolling children from these households if the children were Maori or Pacific Islander.

All eligible children will be identified from each start point. To apply these proportions a table of random numbers is used. This will be done by Sue or Colin and Mavis or Binki. The last 2 digits of the random number are selected and expressed as a proportion. This number is then compared to the proportion for the identified

child's ethnic group. If the random number is less than or equal to the proportion, then the child is eligible for the study.

Cluster sampling using random addresses as start points was the sampling method used during a recent pilot study conducted in Auckland to identify risk factors for meningococcal disease. In this study 118 children aged < 6 years of age were identified by visiting 62 start points and 10 houses from each start point. Therefore we expect it will require approximately 370 start points to identify our sample of 612 children aged 2 – 14 years. However, this is only a very approximate guide. It may need more start points as we will only be using one child from each family.

DETAILS OF SAMPLING METHODOLOGY

Study subject identification from each start point

The study recruiter will always move in the same direction from each start point. This direction has been arbitrarily set at **Right**. After visiting the start point, the recruiter will return to the street. S/he will then move to the right, based on the direction when facing the dwelling. The recruiter will continue from dwelling to dwelling in this fashion until a full series of households has been visited.

Town houses, flats, retirement villages and caravan parks will be treated in the same way, except that the common drive will be treated as the street.

A slight variation will be required for apartment blocks and buildings that are arranged vertically. Here the recruiter will move through them in ascending order, based on their number or letter.

Should the starting point be a block of houses, or a set of apartments, the middle number of the houses or apartments will be the starting point to begin.

If the recruiter gets to the start or end of a street, then they will simply continue around the corner staying on the same side of the road. The same rule applies if the recruiter hits the end of a dead end street.

In rare circumstances this process could bring the recruiter back to a household that had already been visited. In this situation, the recruiter should go to the household immediately behind him/herself, when facing the last household visited.

Documentation of household visits

1. Timing of visits

The timing of visits is designed to maximise efficiency, by visiting at times when people are most likely to be at home. It is also designed to reach people who have a range of work and recreational routines.

The initial visits to each starting point should occur on a Saturday between 9.00 am and 6.00 pm or a Sunday between 1.00 pm and 6.00 pm (to avoid church time).

A second visit should occur during the day, Monday through Friday between 9.00 am and 6.00 pm. The ideal time during the week may be between 10.00 am and 12.00 pm when the caregivers are at home.

A third visit should occur on any day different to the previous two visits. If the third visit is on a Monday through Friday, it must be at a different time of day to the previous mid-week visit. eg. if the previous weekday visit was in the morning, the next weekday visit should be either in the afternoon or early evening.

2. Making return visits

Households where there is no access or no one home MUST be visited again. This step is essential to avoid selecting a sample of children who spend more time than average at home. Up to two subsequent visits must be carried out for each of these households before the attempt is abandoned. All of these visits must be on different days and different times of the day than the initial visit. Households where the caregiver was not home also require a return visit. Ideally, the timing for the visit would have been arranged with someone else in the household.

1. Opportunity to discuss with household, resulting in one or more of the following outcomes:

- Record number of children in household aged 2 – 14 years of age
    - none → no need to return
    - one or more → attempt to recruit as potential subject
- child present but caregiver out → make appointment for return visit
- caregiver present and study discussed with them
    - agree → record, fill in details about child on Study Log form
    - decline → record, no need to return
- No English spoken by people in the household when visited → record language spoken and either treat as if out and return with person who speaks that language, or treat as decline if they are clearly not interested.

4. No opportunity to discuss with householder

The following strategies should be used when there is no opportunity to discuss with householder, because:

- No access → record reason, and return at a later visit
    - because of a refusal to communicate
    - because of a dog
    - because of another reason → record reason in comments field
- Out → return at a later visit

5. No one home at one address, so information obtained from people at next address

- no child at preceding address → record and return to address at later visit
- one or more children at preceding address → record and return to address at later visit

Recruiters should not take the word of neighbours regarding the question of whether an eligible child resides at a particular address. However if no one is home during a visit, then the next house visited should be asked if there are children living at the previous house. The house in question should still receive return visits regardless of the answer to this question. This information will be used to assess whether many

potentially eligible children are being missed by the recruitment process because they are not at home.

6. Starting points in non-residential areas

A small number of starting points that are selected may be in mostly non-residential areas eg. commercial, retail, and industrial areas. These starting points should be rejected from the recruitment process after ensuring that there are no residential properties in the immediate area. To do this the recruiter should first establish that the property at the starting point is non-residential. The recruiter should then proceed from the starting point in the manner described above. If the next 10 addresses visited are also non-residential then this starting point can be rejected. However, if even one property among the 10 visited is residential, then the starting point should be used. Recruiters should make efforts to include households that are attached to commercial premises. eg. people living above shops.

INTERVIEW GUIDELINES (Recruitment Phase)

RECRUITMENT (A)

1) Interviewer introducing themselves
2) Telling the caregivers what the study is about, give subject info letter
3) Inquire if they are interested in being involved in the study
4) If yes, explain the possibility that they may not be in the study but if they are

ENROLLING THE FAMILY

1) Invite family to participate in the study
2) Arrange a date and time that would suit the participant
3) Ask for the name, address, phone number or an alternative phone number.

DATA COLLECTION (B)

1) An interview will be undertaken at the time arranged with the caregiver.
2) At the time of the interview the study will be explained again, using the participant information sheet as an explanatory resource
3) Ask the caregiver if they have any comments or questions
4) Obtain written consent to participate
5) Undertake the interview
6) Thank the family for participating in the study.

THE QUESTIONNAIRE

The interviewers will administer the questionnaire. The interviewers will be responsible for writing the responses of the caregivers on the questionnaire forms.

Some questions have a number of possible responses for the caregiver to choose from. These questions will have flashcards that accompany the question. Show the flashcard to the caregiver and ask them which number response is the correct response for them and their child. Record the response on the questionnaire form.

Flashcards are used with Questions 9, 11, 15 – 21, 23, 25b, 26 – 29, 34 – 36, 45, 48 – 52, 54, 55, 59, 61 – 64, 66, 67, 69, 72, 74, 76, 79, 81 and 84.

(Questionnaire removed as it is presented in Appendix 10 of this thesis).

Sample of Participant Information Sheet and Consent Form

Participant information sheet and consent forms removed as they are presented in Appendix 6 (participant information sheet) and Appendix 8 (consent form) of this thesis.

CHECK LIST FOR INTERVIEWERS

Interview visit:

1. Reintroduce yourself and the study
2. Check that it is all right to spend 1 – 11/2 hour of their time
3. Informed Consent obtained
4. Questionnaire administered
5. Check all paperwork has an ID number for the child before leaving
6. Questions that need answered?
7. Giving out of information about asthma
8. Gift for the family

NOTES :

Appendix 6 Participant information sheet

Participant Information Sheet

Research Project : The Primary Care Management of Childhood Asthma (How childhood asthma is managed by doctors, nurses and other health professionals in the community)

Principal Investigator: Dr. Sue Crengle,
Senior Lecturer and Researcher,
Department of Maori and Pacific Health,
Auckland Medical School
University of Auckland,
Private Bag 92019,
Auckland.
Phone 3737599 Ext. 6470

About the study

Asthma is a significant health problem for many children in New Zealand. Some children are admitted to hospital for asthma, but most children who have asthma are looked after in the community (out of hospital) by doctors, nurses and other health professionals. We have very little information about the way asthma is managed in the community. This study will provide this information by describing what types of management (from doctors, nurses and other health professionals in the community) has been offered to, and used by children with asthma.

Who is in the study

The study is being done all over Auckland during 1999 and 2001. We have used a door knocking technique to find children aged 2 - 14 years. Your child has been randomly chosen to be involved in the study because they have had asthma or episodes of wheezing in the past 12 months.

What will happen during the study?

Firstly, you need to decide if you would like to be involved in the study. We will be asking a selected number of people who agree to be involved in the study to answer the questionnaire. This means that even though you have agreed to participate in the study, you may not be one of the people selected to answer the questionnaire. Selection of people to answer the questionnaire is done by one of the researchers who does not know who you are. If you are selected to answer a questionnaire an interviewer will contact you and arrange a time to come and talk to you. You can choose the day, time and where the interview takes place.

When the interviewer comes to talk to you, she / he will talk to you about the study and answer any questions you have. The interviewer will ask you to sign a form that confirms your agreement to be in the study. You will be given a copy of the consent form. The interview will then start. The interview will consist of you answering a questionnaire about your child's asthma. We expect the interview to take about 90 minutes.

For most participants, answering the questionnaire is all that they will be needed to do. A small number (10%) of participants will be asked if they would repeat some of

the interview at a later date. Repeating the questionnaire allows the researchers to check that your answers are being recorded correctly.

Do I have to take part in the study?
Your participation is **entirely voluntary** (your choice). If you do agree to take part you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your child's future health care. You do not have to answer all the questions in the questionnaire. You may stop the interview at any time.

Confidentiality
All the information about your child and your family is completely confidential. No material which could personally identify you will be used in any reports on this study.

The consent form. The consent form you sign will have your name on it. The consent forms will be stored separately from the questionnaires and other information about the study.

The questionnaire. The only people who will have access to the completed questionnaires are the researchers. The questionnaire will NOT contain any information that allows people to identify who you are.

All the consent forms and questionnaires will be kept in locked places during the study and for 6 years after the study finishes. After 6 years they will be destroyed by shredding. Dr. Sue Crengle will be responsible for the storage of the questionnaires.

What will happen to the results of the study?
A report of the results of the study will be written and made available to interested groups and people. The results of the study will also be published in medical journals. A summary of the results of the study will be sent to all participants. You can also ask for a copy of the report once the study is finished. The report and the summary of the findings will not be available until after the study is finished (in 2001)

Where can I get more information about the study?
You can get more information about the study from Dr. Sue Crengle, Dr. Colin Tukuitonga or Dr. Cameron Grant. Information about how to contact them is at the end of this information sheet.

If I need an interpreter, can one be provided?
Yes. Please tell us if you would like an interpreter.

Who can I contact if I have questions or concerns about the study?
If you have any questions or concerns about the study you can contact

Dr. Sue Crengle or Dr. Colin Tukuitonga Department of Maori and Pacific Health

School of Medicine
University of Auckland
Private Bag 92019
Auckland
Phone 3737599 Ext. 6470

If you have any queries or concerns about your rights as a participant in this study you may wish to contact
Dr. Dennis Moore who is the Chair of the University of Auckland Human Subjects Ethics Committee. His address is Chair, The University of Auckland Human Subjects Ethics Committee, Private Bag 92019, Auckland. His phone number is 3737599, ext. 8939.

This study received ethical approval from the University of Auckland Human Subjects Ethics Committee on 10/2/99 for a period of two years, from 10/2/99 to 10/2/2001. Reference 1999/018.

Appendix 7 Recruiters form

STARTING POINT (SP) ADDRESS LOG

Starting point number ________ Starting point address ________________ Recruiter ________

Address	Timing of visit						Outcome									
Street name and number	Visit No.	Date	Time	resin?	No access dog	No access other	Out	refuse to discuss	No Engl	0-24m Number	2-14yrs Number	Caregiver sui-appt	Participate Agree	Participate Decline	Neighbour None	Comments
	1	/ / 99	am pm													
	2	/ / 99	am pm													
	3	/ / 99	am pm													
	1	/ / 99	am pm													
	2	/ / 99	am pm													
	3	/ / 99	am pm													
	1	/ / 99	am pm													
	2	/ / 99	am pm													
	3	/ / 99	am pm													
	1	/ / 99	am pm													
	2	/ / 99	am pm													
	3	/ / 99	am pm													
	1	/ / 99	am pm													
	2	/ / 99	am pm													
	3	/ / 99	am pm													

CONTROL LOG A

RECRUITER'S SECTION Recruiters Name

CHILD'S NAME

DOB ___ /___ /____ Age ____ Ethnicity ☐ Maori ☐ Pacific Island ☐ European/Other
Ethnic group

Address

Start point no. Next dwelling no.

CAREGIVER NAME 1. 2.

ADDRESS (if different from child)

Relationship to child

PHONE Home Home

Work Work

Other Other

Specify where Specify where

COMMENT (when is it best to contact them)

COORDINATOR'S SECTION

CHECK LIST	yes	no
Age 6 - 24 months	☐	☐
Age 2 –14 years		
Usually resident in Auckland urban area	☐	☐
Ethnic group	☐ Maori	
	☐ Pacific Island	
	☐ European/Other	

SELECTION PROCESS Weighting assigned _____ Random number _____

NOT SELECTED FOR INTERVIEW ☐ /___/199__

Thank-you letter sent ☐ /___/199__

SELECTED FOR INTERVIEW ☐ __ / __/199__ STUDY ID NUMBER _____

Interviewer assigned __ _____ / ___/199__

Appendix 8 Consent form

CONSENT TO PARTICIPATE IN RESEARCH

Project title: The Primary Care Management of Childhood Asthma (How childhood asthma is treated by doctors, nurses and other health professionals in the community)e

Researchers: Dr Sue Crengle and Dr. Colin Tukuitionga (Department of Maori and Pacific Island Health) Dr. Cameron Grant (Department of Paediatrics).

I have been given and understood an explanation of this study. I have read and I understand the information sheet dated 8th April 1999 for volunteers taking part in the study designed to describe how childhood asthma is managed by health professionals in the community.

I have had an opportunity to ask questions and discuss this study. I am satisfied with the answers I have been given.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect the future health care my child receives for their asthma.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

I have had time to consider whether to take part.

I know whom to contact if I have any concerns about the study. I know whom to contact if I have any questions about the medication or the study.

I would like to receive a summary of the results of the study ☐ Yes ☐ No

I, (full name) hereby consent to take part in this study.

Date

Signature

Names of Researchers : Dr. Sue Crengle, Dr. Colin Tukuitonga and Dr. Cameron Grant.
Contact Phone Number for researchers: Dr. Sue Crengle: 3737599 Ext. 6470
Dr. Colin Tukuitonga: 3737599 Ext. 6951
Dr. Cameron Grant: 3737599 Ext. 6192

Project explained by

Project role

Signature

Date

This study received ethical approval from the University of Auckland Human Subjects Ethics Committee on 10/2/99 for a period of two years, from 10/2/99 to 10/2/2001. Reference 1999/018.

Note: A copy of the consent form to be retained by participant

Appendix 9 Coding manual

The Primary Care Management of Childhood Asthma

Coding Manual

Questionnaire question	Questionnaire Office Use only column	Coding Instructions	Field Name	Area investigated and source if from other study
1. The child who is participating in the study is a *(Tick the appropriate box)* Boy ☐ (1) Girl ☐ (2)	☐ 1	1 = male 2 = female	sex	demographics
2 S/he was born on ☐☐ ☐☐ ☐☐ (dd/mm/yy)	☐☐☐☐☐☐ 2	ddmmyy	dob	demographics
3 S/he has had asthma or wheeziness for (Coding: convert years and months to months and code as number of months 1 – 999) Parents opinion ☐☐ *(years)* ☐☐ *(months)* GP / Doctor diagnosis ☐☐ *(years)* ☐☐ *(months)*	☐☐☐ 3 ☐☐☐	Convert years and months to total months (years X 12 plus number of months). Record total months 0 - 999	dasp dasd	History asthma child

4	What symptoms of asthma does your child get? ***Ask parent to volunteer symptoms first. Then specifically ask about any symptoms not mentioned by the caregiver.***				All ticked boxes are a Yes. Code yes =1 no =2 Don't know = 9	History asthma child
		Yes (1)	No			
	(2)			☐	asywhd	
	4.1. Wheeziness or tight chest during the day	☐	☐	☐	asywhn	
	4.2. Wheeziness or tight chest at night	☐	☐	☐	asywhx	
	4.3. Wheeziness or tight chest during exercise	☐	☐	☐	coud	
	4.4. Asthma type cough during the day	☐	☐	☐	coun	
	4.5. Asthma type cough during the night	☐	☐	☐	coux	
	4.6. Asthma type cough during exercise	☐	☐	☐	asysob	
	4.7. Shortness of breath	☐	☐			

5	What things bring CHILDS NAME asthma on or make it worse? ***Ask parent to volunteer symptoms first. Then specifically ask about any symptoms not mentioned by the caregiver***.			Question 5 yes = 1 no = 2 don't know = 9	Question 5	History asthma child
		Yes (1)	No (2)			
	Colds and flu's	☐	☐		exurti	
	Emotions	☐	☐		exemot	
	Changes in the weather	☐	☐		exweat	
	Dusty places	☐	☐		exdust	
	Exercise	☐	☐		exexer	
	Closed in spaces	☐	☐		exclos	
	Eating some sorts of food	☐	☐		exfood	
	Being close to pets	☐	☐		expet	
	Wearing damp clothes	☐	☐		exdamp	
	Being around smokers	☐	☐		exsmok	
	Asthma / wheeziness just comes by itself	☐	☐		exnil	
	Other *Specify* _____		☐		exoth	
	☐			☐ 6	Question 6	Question 6	diet
6	Have you ever changed CHILD'S NAME diet because you thought some foods seemed to make asthma worse?			yes = 1 no = 2 don't know = 9	chdiet	
	Yes	☐	(1)			
	No	☐	(2)			
				☐ 7a	Question 7a	Question 7a	risk factors
7	(a) Is your house carpeted?			yes = 1 no = 2 don't know = 9	carpeth	
	Yes	☐	(1)			

	No ☐ (2)					
		☐ 7b	Question 7b yes = 1 no = 2 don't know = 9	Question 7b carpetr	risk factors
	(b) Is CHILD'S NAME bedroom carpeted?					
	Yes ☐ (1) No ☐ (2)					
		☐ 8	Question 8 yes = 1 no = 2 don't know = 9	Question 8 matcov	risk factors
8	Have you put a special asthma mattress cover on CHILD'S NAME mattress?					
	Yes ☐ (1) No ☐ (2)					

9	What medicines does your child CURRENTLY have for their asthma (using the medicines every day OR only occasionally)? Are there any <u>other</u> medicines that s/he has used for asthma in the last three or twelve months? ***Show Card***								YES = 1 NO = 2 Don't know = 9		current medications and medication used in previous 3 and 12 months
	months	Currently		Last 3 months		Last 12					
		Yes (1)	No (2)	Yes (1)	No (2)	Yes (1)	No (2)	9			
	<u>Ventolin / Aeromir</u>	☐	☐	☐	☐	☐	☐	☐☐☐		ventcurr vent3m vent12m	
	<u>Bricanyl</u>	☐	☐	☐	☐	☐	☐	☐☐☐		briccurr bric3m bric12m	
	<u>Atrovent</u>	☐	☐	☐	☐	☐	☐	☐☐☐		atrocurr atro3m atro12m	
	<u>Respolin</u>	☐	☐	☐	☐	☐	☐	☐☐☐		respcurr resp3m resp12m	
	Intal / Vicrom	☐	☐	☐	☐	☐	☐	☐☐☐		intalcurr intal3m intal12m	
	Becotide	☐	☐	☐	☐	☐	☐	☐☐☐		becocurr beco3m beco12m	
	Pulmicort	☐	☐	☐	☐	☐	☐	☐☐☐		pulmcurr pulm3m pulm12m	
	Respocort	☐	☐	☐	☐	☐	☐	☐☐☐		spoccurr spoc3m spoc12m	
	Flixotide	☐	☐	☐	☐	☐	☐	☐☐☐		flixcurr flix3m flix12m	
	Oral Steroids (Betnesol or Prednisone)	☐	☐	☐	☐	☐	☐	☐☐☐		orstcurr orst3m orst12m	

Becloforte ☐☐ ☐☐ ☐☐ Zasten (Ketotifen) ☐☐ ☐☐ ☐☐ Serovent ☐☐ ☐☐ ☐☐ Combivent ☐☐ ☐☐ ☐☐ Tilade ☐☐ ☐☐ ☐☐ Floridil ☐☐ ☐☐ ☐☐	☐☐☐ ☐☐☐ ☐☐☐ ☐☐☐ ☐☐☐ ☐☐☐		bclfcurr bclf3m bclf12m ketocurr keto3m keto12m serocurr sero3m sero12m singcurr sing3m sing12m combcurr comb3m comb12m tilacurr tila3m tila12m florcurr flor3m flor12m	
10 Which of your child's current medicines will relieve wheezing straight away? ***Record the names of ALL the medicines the caregiver states are relievers.*** Drugs _____ _____ _____	☐ 10 ☐ ☐	Can have up to THREE different reliever medicines. Score 1 if unable to correctly name the reliever	relmed1 relmed2 relmed3	asthma knowledge	

	medicine(s). Score 2 if correctly names some but not all of reliever medicines Score 3 if correctly identifies all reliever medicines		

11 How does CHILDS NAME take their medicines at the moment? ***(Can have up to 3 responses) Show card.*** Uses a nebuliser all the time ☐ (1) Uses a nebuliser sometimes ☐ (2) Uses an inhaler ☐ (3) Uses an inhaler with a spacer ☐ (4) Uses an inhaler with a spacer and mask ☐ (5) Has syrup medicines ☐ (6) *Specify which medicines are given in syrup form:* _____ _____ _____ _____ _____	☐ 11 ☐ ☐	Can have up to THREE different ways of taking medicines. Write number 1 – 6 in coding box Don't know = 9	howmed1 howmed2 howmed3	current medication delivery devices
12 ***Ask this question if the child is NOT using a nebuliser currently (all the time or sometimes). Otherwise go to question 13.*** In the past TWELVE months has CHILD'S NAME ever needed a nebuliser? Yes ☐ (1) No ☐ (2)	☐ 12	yes = 1 No = 2 Don't know = 9	12mneb	nebuliser use in past 12 months

13 ***Ask this question if the child is NOT using a spacer +/- mask currently. Otherwise go to question 14.*** In the Past TWELVE months has CHILDS NAME ever used a spacer +/- mask to take their medicine? Yes ☐ (1) ***Go to Question 14*** No ☐ (2) ***Go to Question 15***	☐ 13	yes = 1 no = 2 Don't know = 9	12mspacer	spacer use in past 12 months

14 ***Answer this question if the child has used a spacer in the last twelve months*** Which of the following comments about spacers are TRUE and which are FALSE?		Code each part of the question true = 1 false = 2 Don't know = 9		spacer use knowledge (asthma knowledge)
You should only put one puff of inhaler into the spacer at the same time: True (1) False (2) ☐ ☐	☐ 14		spacuse1	
You should wash the spacer with warm water and detergent and dry it in the air: True (1) False (2) ☐ ☐	☐		spacuse2	
You should never rinse out your mouth after using the spacer: True (1) False (2) ☐ ☐	☐		spacuse3	
You should hold the spacer in or over the mouth until the child has taken FIVE breaths: True (1) False (2) ☐ ☐	☐		spacuse4	

15 In general over the last TWELVE MONTHS, would you say that CHILDS NAME asthma has been ***Show card*** Very mild ☐ (1) Mild ☐ (2) Moderate ☐ (3) Severe ☐ (4) Very severe ☐ (5)	☐ 15	very mild = 1 mild = 2 moderate = 3 severe = 4 very severe = 5	severity	Asthma severity scale (Asher et al)
16 How often has CHILDS NAME asthma prevented him/her from participating in activities ***Show card*** Never ☐ (1) Very occasionally ☐ (2) Sometimes ☐ (3) Often ☐ (4) Very often ☐ (5)	☐ 16	never = 1 very occasionally =2 sometimes = 3 often = 4 very often = 5	prevact	Asthma severity scale (Asher et al)

17 How often has CHILDS NAME asthma stopped family activities ***Show card*** Never ☐ (1) Very occasionally ☐ (2) Sometimes ☐ (3) Often ☐ (4) Very often ☐ (5)	☐ 17	never = 1 very occasionally =2 sometimes = 3 often = 4 very often = 5	prevfac	Asthma severity scale (Asher et al)
18 How often do you feel frightened because of CHILDS NAME asthma? ***Show card*** Never ☐ (1) Sometimes ☐ (2) Often ☐ (3)	☐ 18	never = 1 sometimes = 2 often = 3	fright	Asthma severity scale (Asher et al)

Questions 19 - 21 have a 5 point visual analogue scale which is shown to parent/caregiver and their response is scored 19 How certain are you that you can recognise the signs of an asthma attack? ☐ 20 How certain are you that you can prevent your child from having an asthma attack? ☐ 21 How certain are you that you can manage (or control) your child's asthma? ☐	19 ☐ 20 ☐ 21 ☐	For each question the care giver indicates a number 1 – 5 on the visual analogue scale which the interviewer then records	recas prevas conas	parental confidence modified from towns
22 Does anyone in your family have asthma, get wheezy or use asthma type medicines? Yes ☐ (1) No ☐ (2) ***Go to Question 24***	☐ 22	yes = 1 no = 2 Don't know = 9	fhas	family history of asthma Demographics

23 What is this person's relationship to the child? ***Show card Can have more than one answer (up to four)*** Brother or sister ☐ (1) Parent ☐ (2) Grandparent ☐ (3) Auntie or Uncle ☐ (4) Cousin ☐ (5) Other *Specify relationship:* _____ ☐ (6-9)	☐ 23 ☐ ☐ ☐	Can have up to FOUR 'types' of relatives with asthma No relation = 1 Brother / sister = 2 Parent = 3 Grandparent = 4 Auntie / Uncle = 5 Cousin = 6 Other 7, 8 or 9 – will be specified during coding and included in manual as time goes on	fhasr1 fhasr2 fhasr3 fhasr4	family history of asthma Demographics
24 Did CHILD'S NAME mother or father have asthma, wheeziness or need asthma type medicines when they were a child? Yes ☐ (1) No ☐ (2)	☐ 24	yes = 1 no = 2 Don't know = 9	pahas	parental history of asthma Demographics

25 Does anyone in your family have eczema or hayfever? (a) Yes ☐ (1) No ☐ (2) ***Go to Question 26***	☐ 25a	Question 25a yes = 1 no = 2 Don't know = 9	fhec	family history of atopy Demographics
(b) What is this persons relationship to CHILD'S NAME? ***Show card*** ***Can have more than one answer (up to four)*** Brother or sister ☐ (1) Parent ☐ (2) Grandparent ☐ (3) Auntie or Uncle ☐ (4) Cousin ☐ (5) Other *Specify relationship:* _____ ☐ (6-9)	25b ☐ ☐ ☐ ☐	Question 25b Can have up to FOUR 'types' of relatives with eczema or hayfever No relation = 1 Brother / sister = 2 Parent = 3 Grandparent = 4 Auntie / Uncle = 5 Cousin = 6 Other 7, 8 or 9 – will be specified during coding and included in manual as time goes on	fhecr1 fhecr2 fhecr3 fhecr4	

These questions are about asthma / wheeziness 26 Which of the following are parts of asthma? ***Show card*** Yes (1) No (2) Difficulty breathing ☐ ☐ Wheezing ☐ ☐ Blocked nose ☐ ☐ Cough ☐ ☐ Watery eyes ☐ ☐	☐ 26 ☐ ☐ ☐ ☐	Yes = 1 No = 2 Don't know = 9	akpart1 akpart2 akpart3 akpart4 akpart5	Asthma knowledge – from Rea et al
27 During a severe attack of asthma which of the following things happen ***Show card*** Yes (1) No (2) The muscle around the breathing tube becomes tight ☐ ☐ Swelling of the lining of the breathing tubes ☐ ☐ Excess (too much) mucus production ☐ ☐ Blockage of the nose passages ☐ ☐ The muscles of the chest wall become tired ☐ ☐ Don't know (99) ☐☐	☐ 27 ☐ ☐ ☐ ☐ ☐☐	Yes = 1 No = 2 Don't know = 9	akimpt1 akimpt2 akimpt3 akimpt4 akimpt5	Asthma knowledge – from Rea et al

28 Which of the following are true ***Show card*** (2) Asthma often runs in families ☐ True (1) ☐ False **Asthma is uncommon - it occurs in less than 5 % of people** ☐ ☐ Asthma is associated with having very sensitive breathing tubes ☐ ☐ You can catch asthma from other people ☐ ☐ It is important for people with asthma to avoid tobacco smoke ☐ ☐	☐ 28 ☐ ☐ ☐ ☐	true = 1 false = 2 Don't know = 9	aktf1 aktf2 aktf3 aktf4 aktf5	Asthma knowledge – from Rea et al
29 Which of the following can often result in asthma becoming worse ***Show card*** (2) A hot bath ☐ ☐ Exercise ☐ ☐ Eating food too fast ☐ ☐ Head colds or flu ☐ ☐ Running out of asthma medicines ☐ ☐ Stress, 'nerves' or emotional upsets ☐ ☐ True (1) False	☐ ☐ ☐ ☐ ☐ ☐	true = 1 false = 2 Don't know = 9	akworse1 akworse2 akworse3 akworse4 akworse5 akworse6	Asthma knowledge – from Rea et al

30	**PART A** Your child has been well and attending school. S/he wakes up with a runny nose (thick green discharge) but otherwise seems quite well. What did you do when this happened to your child last? **Scoring:** 1 point: Mentioning a cold or infection 1 point: Mentioning the use of bronchodilator (treater) medicines 1 point: Actively managing the child's condition 1 point: Other management, such as treating the URTI, informing the teacher of the child's illness, sending the child to school despite his/her illness **PART B:** The following day your child seems grumpy and tired, his/her nose is just the same but s/he now has a cough that has woken him/her up once during the night. Has this ever happened to you? (If yes) The last time this happened, what did you do? (If no) If this were to happen, what would you do? **Scoring:** 2 points: Actively monitoring the child's condition and other management such as treating the URTI symptoms, keeping the child home from school etc. 2 points: using the bronchodilator medication (ventolin, respolin etc.) **PART C:** Before going to bed you go into the bedroom to check her/him. S/he seems restless, is breathing fast and has an obvious wheeze. Several times during the night s/he wakes up coughing. Has this ever happened to you? (If yes) Can you remember what you did the last time this happened?	□□ 30	Part A: Maximum score = 4 Part b: Maximum Score = 4 Part C: Maximum score = 7 Maximum total score = 15	scenario	Asthma knowledge – scenarion from Rea et al.

31 Do any people living in the household smoke cigarettes regularly? Yes ☐ (1) No ☐ (2) ***If no smokers go to Question 33***	☐ 31	yes = 1 no = 2	smok	demographics risk factors
32 Is there a smokefree area in the house Yes ☐ (1) No ☐ (2)	☐ 32	yes = 1 no = 2 Don't know = 9	smfree	demographics risk factors
33 Do you have any cats? Yes ☐ (1) No ☐ (2)	☐ 33	yes = 1 no = 2 Don't know = 9	cats	demographics risk factors

These questions are about the types of doctors you use for CHILDS NAME asthma 34 The family doctor (General Practitioner or GP) ***Please look at the card and tell me what sentence about family doctors is best for you and your child.*** I do NOT have a regular family doctor that I go to all the time. I go to whatever doctor I can see when I need to see one. ☐ (1) I have a regular family doctor that I use MOST of the time. I SOMETIMES go to other family doctors. ☐ (2) I have a regular family doctor that I use ALL of the time. I do not go to other family doctors**.** ☐ (3)	☐ 34	Code 1, 2, or 3 I do NOT have a regular family = 1 I have a regular family doctor that I use MOST of = 2 I have a regular family doctor that I use ALL of = 3	gput	health services utilisation

35	After hours doctors and medical clinics (NOT hospital emergency departments and Starship) ***Please look at the card and tell me what sentence about After Hours doctors or medical clinic is best for you and your child.*** I ALWAYS go to an After Hours doctors or medical clinic for CHILDS NAME asthma. I do not use family doctors / GP's. ☐ (1) MOST OF THE TIME I use an After Hours doctors or medical clinic for CHILDS NAME asthma. I OCCASIONALLY use family doctors / GP's. ☐ (2) OCCASIONALLY I use an After Hours doctors or medical clinic for CHILDS NAME asthma. USUALLY I go to the family doctors / GP's. ☐ (3) I have NEVER gone to an After Hours doctors or medical clinic for CHILDS NAME asthma. ☐ (4)	☐ 35	code 1, 2, 3 or 4 I ALWAYS go to an After hours = 1 MOST OF THE TIME I use an After = 2 OCCASIONALLY I use an After = 3 I have NEVER gone to an After hours = 4	ahmc	health services utilisation

36 Hospital emergency departments and Starship Hospital. Have you ever taken CHILD'S NAME to hospital for asthma? No ☐ ***Go to Question 37*** (Code as 4 in box 36a) Yes ☐ ***Go to Question 36 a***		Question 36 If answers NO code as 4 in box 36a	edssa	health services utilisation
36a *Please look at the card and tell me what sentence about Hospital emergency departments and Starship Hospital is best for you and your child.* I ALWAYS go to Hospital emergency departments or Starship Hospital for CHILDS NAME asthma. ☐ (1) MOST OF THE TIME I use the Hospital emergency departments or Starship Hospital for CHILDS NAME asthma. ☐ (2) OCCASIONALLY I use the Hospital emergency departments or Starship Hospital for CHILDS NAME asthma. ☐ (3)	☐ 36a	Otherwise code 1, 2 or3 in Box 36a I ALWAYS go to Hospital = 1 MOST OF THE TIME I use the = 2 OCCASIONALLY I use = 3		
36b ***All caregivers who have taken their children to hospital should be asked this question.*** I only take CHILDS NAME to the hospital emergency department or Starship hospital if my doctor refers us there (gives us a letter and tells me to go to hospital) Yes (1) ☐ No (2) ☐	☐ 36b	Question 36b Code yes = 1 no = 2	ssref	

37	In the last TWELVE months how many times have you seen the doctor because CHILDS NAME was <u>sick</u> with asthma? (Code: Enter number of times, or Don't know = 99) Your regular family doctor ☐☐ Other family doctors ☐☐ After Hours doctors or medical clinics ☐☐ Hospital Emergency Departments ☐☐ Children's asthma Specialist in hospital /private ☐☐	☐☐ 37 ☐☐ ☐☐ ☐☐ ☐☐	Code number of visits to each of the four types of services Number from 0 – 99	s12mgp s12mot s12mam s12med s12spec	health services utilisation
38	In the last THREE months how many times have you seen the doctor because CHILDS NAME was <u>sick</u> with asthma (Code: Enter number of times, or Don't know = 99) Your regular family doctor ☐☐ Other family doctors ☐☐ After hours doctors or medical clinics ☐☐ Hospital Emergency Departments ☐☐ Children's asthma Specialist in hospital /private ☐☐	☐☐ 38 ☐☐ ☐☐ ☐☐ ☐☐	Code number of visits to each of the four types of services Number from 0 – 99	s3mgp s3mot s3mam s3med s3mspec	health services utilisation

39	In the last TWELVE months how many times have you seen the doctor for a <u>regular check up</u> of CHILDS NAME asthma (that is not when s/he is sick with asthma, but for example, needs some more inhalers) (Code: Enter number of times, or Don't know = 99) Your regular family doctor ☐☐ Other family doctors ☐☐ After hours doctors or medical clinics ☐☐ Hospital Emergency Departments ☐☐ Children's asthma Specialist in hospital /private ☐☐	☐☐ 39 ☐☐ ☐☐ ☐☐ ☐☐	Code number of visits to each of the four types of services Number from 0 – 99	r12mgp r12mot r12mam r12med r12spec	health services utilisation
40	In the last THREE months how many times have you seen the doctor for a <u>regular check up</u> of CHILDS NAME asthma (that is not when s/he is sick with asthma, but for example, needs some more inhalers) (Code: Enter number of times, or Don't know = 99) Your regular family doctor ☐☐ Other family doctors ☐☐ After hours doctors or medical clinics ☐☐ Hospital Emergency Departments ☐☐ Children's asthma Specialist in hospital /private ☐☐	☐☐ 40 ☐☐ ☐☐ ☐☐ ☐☐	Code number of visits to each of the four types of services Number from 0 – 99	r3mgp r3mot r3mam r3med r3mspec	health services utilisation

41 This question is about admissions to hospital for asthma ***This does NOT include visits to the Emergency Department where the child was not admitted to a ward.***				health services utilisation
Has your child ever been admitted to hospital for asthma? Yes ☐ (1) No ☐ (2) ***Go to Question 42***	☐	Question 41 Code yes = 1 no =2 Don't know = 9	admever	
Has CHILDS NAME been admitted to hospital for asthma in the past twelve months Yes ☐ (1) No ☐ (2) ***Go to Question 42***	☐	Question 41 Code yes = 1 no =2 Don't know = 9	adyear	
How many times in the last TWELVE months has CHILDS NAME been admitted to hospital for asthma? (Code: Enter number of times, or Don't know = 99) ☐☐	☐☐	Number of admissions in last 12 months: Code number of admissions 1 - 99	ad12m	
How many times in the last THREE months has CHILDS NAME been admitted to hospital for asthma (Code: Enter number of times, or Don't know = 99) ☐☐	☐☐	Number of admissions in last 3 months: Code number of admissions 1 - 99	ad3m	

42 This question is about the use of ambulance services Have you ever had to call an ambulance about CHILDS NAME asthma? Yes ☐ (1) No ☐ (2) ***Go to Question 43***	☐	Ambulance ever Question Code yes = 1 no =2 Don't know = 9	ambever	health services utilisation
Have you called the ambulance about CHILDS NAME asthma in the last twelve months? Yes ☐ (1) No ☐ (2) ***Go to Question 43***	☐	Ambulance in last 12 months Question Code yes = 1 no =2 Don't know = 9	ambyear	
How many times in the last TWELVE months have you called the ambulance about CHILDS NAME asthma? (Code: Enter number of times, or Don't know = 99) ☐☐	☐☐ ☐☐	Code number of times an ambluance has been used 1 - 99	amb12m amb3m	
How many times in the last THREE months have you called the ambulance about CHILDS NAME asthma (Code: Enter number of times, or Don't know = 99) ☐☐				
These questions are about asthma action plans				action plans
43 Have you heard of an action or crisis plan?	☐ 43	yes = 1 no = 2	heardap	

Yes ☐ (1) No ☐ (2)					
44 Have you ever been given an asthma action or asthma crisis plan to help you manage CHILDS NAME asthma? Yes ☐ (1) No ☐ (2) ***Go to Question 55***	☐ 44	yes = 1 no = 2 Don't know = 9	giveap	action plans
45 Who wrote out the plan for you? ***Show card*** GP ☐ (1) Practice nurse ☐ (2) Asthma educator ☐ (3) Hospital doctor ☐ (4) Plunket, District or Public health nurse ☐ (5) Family / whanau ☐ (6) Friend ☐ (7) Other ☐ (8) *Specify:* _____ Don't know ☐ (9)	☐ 45	Code 1 –9 depending on response GP = 1 Practice nurse = 2 asthma educator =3 hospital doctor = 4 Plunket, Districtor Public health nurse = 5 family / whanau = 6 friend = 7 Other = 8 Don't know = 9	whowrote	action plans
46 How long have you had the plan?	☐☐	Convert years and	howlong	action plans

	(Coding convert years and months to months. Code as 1 – 99 months) ☐☐ *(Years)* ☐☐ *(Months)*	46	months to months. Code as 1 – 99 months		
47	Has it been reviewed or updated in the last twelve months? Yes ☐ (1) No ☐ (2)	☐ 47	yes = 1 no = 2 Don't know = 9	review	action plans
48	When it was first given to you, did you use the plan? ***Show card***. All the time ☐ (1) Most of the time ☐ (2) Sometimes ☐ (3) Hardly ever ☐ (4) Not at all ☐ (5) ***Go to Question 55***	☐ 48	Code 1 - 5 all the time = 1 most of the time = 2 sometimes = 3 hardly ever = 4 not at all =5	firstuse	action plans
49	When you were first given the plan, was it useful when you were looking after CHILDS NAME asthma? ***Show card***. Very useful ☐ (1) Useful ☐ (2) A little bit useful ☐ (3) Not useful at all ☐ (4)	☐ 49	Code 1 - 4 very useful = 1 useful = 2 a little bit useful = 3 not useful at all = 4	iniuse	action plans

50 When you were first given the asthma action plan, who explained it to you? ***Show card.*** GP ☐ (1) Practice nurse ☐ (2) Asthma educator ☐ (3) Hospital doctor ☐ (4) Plunket, District or Public health nurse ☐ (5) Family / whanau ☐ (6) Friend ☐ (7) Other ☐ (8) *Specify:* _____ Don't' know ☐ (9)	☐ 50	Code 1 –9 depending on response GP = 1 Practice nurse = 2 asthma educator =3 hospital doctor = 4 Plunket, Districtor Public health nurse = 5 family / whanau = 6 friend = 7 Other = 8 Don't know = 9	iniexp	action plans

51 Thinking about this (the first) explanation, was the explanation: ***Show card*** Clear, easy to understand ☐ (1) I understood most things but there were things I felt unclear or unsure about ☐ (2) I was unclear or unsure about most of the things the person told me ☐ (3)	☐ 51	Code 1, 2 or 3 easy to understand = 1 I understood most things = 2 I was unclear or unsure = 3	plexpl	action plans
52 Thinking about the AMOUNT of information you received when the plan was first explained to you, would you say that the information you were given was ***Show card*** Too much ☐ (1) Enough ☐ (2) Not enough ☐ (3)	☐ 52	Code 1, 2 or 3 too much = 1 enough = 2 not enough = 3	plaminf	action plans
53 Has anyone given you any further information about the action plan? Yes ☐ (1)	☐ 53	yes = 1 no = 2	plmoreinf	action plans

No ☐ (2)					
54 Now, do you use the plan ***Show card.***			Code 1 - 5	curruse	action plans
All of the time ☐ (1) Most of the time ☐ (2) Sometimes ☐ (3) Hardly ever ☐ (4) Never ☐ (5)		☐ 54	all the time = 1 most of the time = 2 sometimes = 3 hardly ever = 4 not at all =5		

These questions are about asthma education. 55 Where did you learn about asthma? ***Show card.*** ***Tick as many as appropriate*** Self experience ☐ (1) Friends/whanau ☐ (2) Books/pamphlets/videos about asthma ☐ (3) Asthma society ☐ (4) Asthma educator ☐ (5) Family doctor ☐ (6) Practice nurse ☐ (7) Hospital ☐ (8) Plunket nurse, Public Health Nurse, District Nurse or other nurses who visit your home ☐ (9) Other ☐ (10-99) *Specify:* _____ ***If ONLY family or friends are ticked, go to question 66***	55 ☐ ☐ ☐ ☐ ☐ ☐	Code 1 – 99. Add new codes as new 'other' options occur Can have up to six different sources of information self experience = 1 friends/whanau = 2 books/pam = 3 asthma society = 4 asthma educator = 5 family dr. = 6 practice nurse = 7 hospital = 8 Plunket = 9 Other = 10 – 99	whereed1 whereed2 whereed3 whereed4 whereed5 whereed6	asthma education
56 How long ago did you first receive asthma education? (Coding: convert years and months to months and code as number of months 1 – 999) ☐☐ *(years)* ☐☐ *(months)*	☐☐☐ 56	Convert years and months to months. Code as 1 – 999 months	wheninied	asthma education

57 Since then, have you received any more asthma education? Yes ☐ (1) No ☐ (2)	☐ 57	yes = 1 no = 2	moreed	asthma education
58 From whom? ***Show card.*** ***Tick as many as appropriate*** Self experience ☐ (1) Friends/whanau ☐ (2) Books/pamphlets/videos about asthma ☐ (3) Asthma society ☐ (4) Asthma educator ☐ (5) Family doctor ☐ (6) Practice nurse ☐ (7) Hospital ☐ (8) Plunket nurse, Public Health Nurse, District Nurse or other nurses who visit your home ☐ (9) Other ☐ (10-99) *Specify:* _____	☐ 58 ☐ ☐ ☐ ☐ ☐	Code 1 – 99. Add new codes as new 'other' options occur Can have up to SIX different sources of more information self experience = 1 friends/whanau = 2 books/pam = 3 asthma society = 4 asthma educator = 5 family dr. = 6 practice nurse = 7 hospital = 8 Plunket = 9 Other = 10 – 99	whomore1 whomore2 whomore3 whomore4 whomore5 whomore6	asthma education

59 How has information been shared with you? ***Ask about each of the four options presented below***				howed1 howed2 howed3 howed4	asthma education
	Yes (1)	No (2)			
Talking	☐	☐	☐ 59	yes = 1 no = 2	
Written information such as pamphlets	☐	☐	☐		
Video presentation	☐	☐	☐		
Practical demonstration e.g. how to use a spacer or a peak flow meter	☐	☐	☐		
60 What things have you been told about asthma? ***Show card***				Code yes = 1 no = 2 Don't know = 9	whated1 whated2 whated3 whated4 whated5 whated6 whated7	asthma education
	Yes (1)	No (2)			
Medications for asthma / wheeziness and how to use them	☐	☐	☐ 60		
The devices used to give the medicines	☐	☐	☐		
What happens in the lungs to cause asthma	☐	☐	☐		
General information about asthma e.g if asthma runs in families; other health problems that are linked to asthma.	☐	☐	☐		
What things might trigger asthma or wheeziness	☐	☐	☐		
Action or crisis plans	☐	☐	☐		
Peak flow meters	☐	☐			

61 Has the information you have been given about asthma been ***Show card*** Clear, easy to understand ☐ (1) I understood most things but there were things I felt unclear or unsure about ☐ (2) I was unclear or unsure about most of the things the person told me ☐ (3)	☐ 61	Code 1, 2 or 3 easy to understand = 1 I understood most things = 2 I was unclear or unsure = 3	edexpl	asthma education
62 Do you think the amount of information you have been given has been ***Show card*** Too much ☐ (1) Enough ☐ (2) Not enough ☐ (3)	☐ 62	Code 1, 2 or 3 too much = 1 enough = 2 not enough = 3	edinfo	asthma education
63 How useful did you find the information in helping you to understand asthma and how to manage it? ***Show card*** Very useful ☐ (1) Of some use ☐ (2) Not very useful ☐ (3) Of no use ☐ (4)	☐ 63	Code 1 - 4 very useful = 1 useful = 2 a little bit useful = 3 not useful at all = 4	eduse	asthma education

64 Have you ever been referred to an asthma educator? Yes ☐ (1) ***Go to Question 65*** No ☐ (2) ***Go to Question 66***	☐ 64	yes = 1 no = 2	aedref	asthma education
65 What was your experience of the asthma educator? ***Show card*** Excellent ☐ (1) Very good ☐ (2) Good ☐ (3) Not very good ☐ (4) Bad ☐ (5) Did not go to see the educator ☐ (6)	☐ 65	Code 1, 2 ,3 , 4, 5 or 6 Excellent = 1 very good = 2 good = 3 not very good = 4 bad = 5 did not go to see the educator = 6	aedexp	asthma education

FINALLY, we would like to ask you some questions about you and your family. We are nearly finished the questionnaire! 66 Where was your SON / DAUGHTER born? ***Show card*** New Zealand ☐ (1) Samoa ☐ (2) Tonga ☐ (3) Niue ☐ (4) Cook Islands ☐ (5) Australia ☐ (6) United Kingdom ☐ (7) USA ☐ (8) Hong Kong ☐ (9) China ☐ (10) Korea ☐ (11) Vietnam ☐ (12) Other (Please Specify) ☐ (13-98) Don't know ☐ (99)	☐☐ 66	Code 1 – 99. Add new codes as new 'other' options occur New Zealand = 1 Samoa = 2 Tonga = 3 Niue = 4 Cook Islands = 5 Australia = 6 United Kingdom = 7 USA = 8 Hong Kong = 9 China = 10 Korea = 11 Vietnam = 12 Other = 13 – 98 Don't know = 99	childbir	demographics
67 Which country does your child normally live in? *Specify Answer* _____ _____	☐☐ 67	Code 1 – 99. Add new codes as new 'other' options occur	normlive	demographics

	New Zealand = 1 Samoa = 2 Tonga = 3 Niue = 4 Cook Islands = 5 Australia = 6 United Kingdom = 7 USA = 8 Hong Kong = 9 China = 10 Korea = 11 Vietnam = 12 Other = 13 – 98 Don't know = 99		

68 Which ethnic group or groups does your child belong to? ***(Tick all that apply) Show card*** New Zealand Maori ☐ (1) New Zealand European / Pakeha ☐ (2) Samoan ☐ (3) Cook Island Maori ☐ (4) Tongan ☐ (5) Niuean ☐ (6) Tokelauan ☐ (7) Fijian ☐ (8) Other Pacific Groups *Please Specify:*_____ ☐ (9) Other European *Please Specify:*_____ ☐ (10) Southast Asian ☐ (11) Other Asian *Please Specify:*_____ ☐ (12) Chinese ☐ (13) Indian ☐ (14) Other ethnic groups *Please Specify:*_____ ☐ (15) Don't know ☐ (16)	☐☐ 68 ☐☐ ☐☐	Code 1 – 99. Add new codes as new 'other' options occur. Can have up to THREE ethnicities recorded. NZ Maori = 1 New Zealand = 2 Europ / Pakeha = 3 Samoan = 4 Cook Is Maori = 5 Tongan = 6 Niuean = 7 Tokelauan = 8 Fijian = 9 Other Pacific = 10 Other European = 11 Southeast Asian = 12 Other Asian = 13 Chinese = 14 Indian = 15 Other ethnic = 16 – 98 Don't know = 99	ethnic1 ethnic2 ethnic3	demographics

69 ***If you ticked more than one ethnic group*** (a) Is there are group that your child belongs to most? Yes ☐ (1) No ☐ (2) (b) Which ethnic group? ☐☐		69a yes = 1 no = 2 ☐ 69a 69b Code 1 – 99. Add new codes as new 'other' options occur. Single option only. ☐☐ 69b NZ Maori = 1 New Zealand = 2 Europ/Pakeha = 3 Samoan = 4 Cook Is Maori = 5 Tongan = 6 Niuean = 7 Tokelauan = 8 Fijian = 9 Other Pacific = 10 Other European = 11 Southeast Asian = 12 Other Asian = 13 Chinese = 14 Indian = 15	70a prefeth 70b singeth	demographics

			Other ethnic = 16 – 98 Don't know = 99		
70 Who is / are the main caregiver(s) for the child? Mother ☐ (1) Father ☐ (2) Grandparent ☐ (3) Auntie or Uncle ☐ (4) Friend ☐ (5) Other *Please specify:*_____ ☐ (6 - 9)		☐ 70 ☐	Code 1, 2, 3, 4, 5, 6, 7, 8, or 9. Add new codes as new 'other' options occur. Mother = 1 Father = 2 Grandparent = 3 Auntie or Uncle = 4 Friend = 5 Other = 6 - 9	maincare1 maincare2	demographics

71 Where was the main caregiver(s) born? ***Show card*** New Zealand ☐ (1) Samoa ☐ (2) Tonga ☐ (3) Niue ☐ (4) Cook Islands ☐ (5) Australia ☐ (6) United Kingdom ☐ (7) USA ☐ (8) Hong Kong ☐ (9) China ☐ (10) Korea ☐ (11) Vietnam ☐ (12) Other (*Please Specify*) ☐ (13 - 98) Don't know ☐ (99)	☐☐ 71 ☐☐	Code 1 – 99. Add new codes as new 'other' options occur New Zealand = 1 Samoa = 2 Tonga = 3 Niue = 4 Cook Islands = 5 Australia = 6 United Kingdom = 7 USA = 8 Hong Kong = 9 China = 10 Korea = 11 Vietnam = 12 Other = 13 – 98 Don't know = 99	mcborn1 mcborn2	demographics
72 How long has the main caregiver been in New Zealand? (Coding: Convert years and months to months and code as number of months 1 – 999) ☐☐ ☐☐ *year* *months*	☐☐☐ 72 ☐☐☐	Convert years and months to months. Code as 1 – 999 months	mc1nz mc2nz	demographics

73 Where was the child's father (not the main caregiver) born? ***Show card*** New Zealand ☐ (1) Samoa ☐ (2) Tonga ☐ (3) Niue ☐ (4) Cook Islands ☐ (5) Australia ☐ (6) United Kingdom ☐ (7) USA ☐ (8) Hong Kong ☐ (9) China ☐ (10) Korea ☐ (11) Vietnam ☐ (12) Other (*Please Specify*) ☐ (13) Don't know ☐ (99)	☐☐ 73	Code 1 – 99. Add new codes as new 'other' options occur New Zealand = 1 Samoa = 2 Tonga = 3 Niue = 4 Cook Islands = 5 Australia = 6 United Kingdom = 7 USA = 8 Hong Kong = 9 China = 10 Korea = 11 Vietnam = 12 Other = 13 – 98 Don't know = 99	otcg	demographics
74 How long has the father (not the main caregiver) been in New Zealand? (Coding: Convert years and months to months and code as number of months 1 – 999) ☐☐ ☐☐ *year* *months*	☐☐☐ 74	Convert years and months to months. Code as 1 – 999 months	otcgnz	demographics

75 What language is usually spoken at home? ***Show card*** English ☐ (1) Maori ☐ (2) Samoan ☐ (3) Tongan ☐ (4) Niuean ☐ (5) Cook Island Maori ☐ (6) Other Pacific *Please specify:*_____ ☐ (7) Cantonese ☐ (8) Mandarin ☐ (9) Other Asian *Please specify:*_____ ☐ (10) Other language *Please specify:*_____ ☐ (11) Don't know ☐ (99)	☐☐ 75	Code 1 – 99. Add new codes as new 'other' options occur English = 1 Maori = 2 Samoan = 3 Tongan = 4 Niuean = 5 Cook Is Maori = 6 Other Pacific = 7 Cantonese = 8 Mandarin = 9 Other Asian= 10 Other language = 11-99	lang	demographics
76 Did you (the main caregiver) finish Primary School ☐ (1) Intermediate School ☐ (2) Secondary School ☐ (3)	☐ 76	Code 1, 2 or 3 Primary = 1 Intermediate = 2 Secondary = 3	mcsch	demographics

77	Did you finish a course at University ☐ (1) Polytechnic / apprenticeships / hospital trained nurses ☐ (2) Training College ☐ (3) None of the above ☐ (4)	☐ 77	Code 1, 2, 3 or 4 University = 1 Polytech = 2 Training Coll. = 3 None = 4	mctert	demographics
78	What best describes your (the main caregiver) current position? ***Show card*** Full time employment ☐ (1) Part time employment ☐ (2) Part time employment and benefit ☐ (3) On a benefit ☐ (4) Full time home maker ☐ (5) A student ☐ (6) Other *Please specify:*_____ ☐ (7)	☐ 78	Code 1 – 9. Add new codes as new 'other' options occur FT employ = 1 PT employ = 2 PT empl + bene = 3 Benefit = 4 FT home = 5 Student = 6 Other = 7	mcposn	demographics

79 Please describe <u>in full</u> the job of the main income earner in your household? _____ _	☐☐ 79	Code as per the Alley – Irving scale guide	minjob	demographics
80 What is the total income for your household from all sources (wages and benefits), before tax or anything was taken out of it, in the last twelve months? ***Show card*** Code 0 -10 ☐☐ If you do not know this amount please tell us what the NET (after tax is taken out) WEEKLY income is in your house. $_____	☐ 80	code 0 – 10	totinc	demographics
Questions 81 – 83 Please answer the following questions ONLY IF the father or male partner is currently part of the household i.e. living at home 81 Did the father or male partner (not the main caregiver) finish Primary School ☐ (1) Intermediate School ☐ (2) Secondary School ☐ (3)	☐ 81	code 1, 2 or 3 Primary = 1 Intermediate = 2 Secondary = 3	otcgsch	demographics

82	Did the father or male partner finish a course at University ☐ (1) Polytechnic / apprenticeship / hosptial trained nurse ☐ (2) Training College ☐ (3) None of the other ☐ (4)		☐ 82	Code 1, 2, 3 or 4 University = 1 Polytech = 2 Training Coll. = 3 None = 4	otcgtert	demographics
83	What best describes the father or male partner's current position? ***Show card*** Full time employment ☐ (1) Part time employment ☐ (2) Part time employment and benefit ☐ (3) On a benefit ☐ (4) Full time home maker ☐ (5) A student ☐ (6) Other *Please specify:*_____ ☐ (7)		☐☐ 83	Code 1 – 9. Add new codes as new 'other' options occur FT employ = 1 PT employ = 2 PT empl + bene = 3 Benefit = 4 FT home = 5 Student = 6 Other = 7	otcgpos	demographics

Appendix 10 Questionnaire

The Primary Care Management of Childhood Asthma.

A University of Auckland Research Project

ID Number:_____

The aim of this questionnaire is to collect information about how asthma in children is treated.

All the information you give is strictly confidential.
No one other than the researchers will have access to this information.

Thank you for participating in this study. We appreciate the time you are giving.

Office Use Only

1. The child who is participating in the study is a
   (Tick the appropriate box)

   Boy ☐ (1)
   Girl ☐ (2)

   ☐ 1

2 S/he was born on

   ☐☐ ☐☐ ☐☐ (dd/mm/yy) ☐☐☐☐☐☐2

   These questions are about CHILD'S NAME asthma and whether there is asthma and similar problems in your family.

3 S/he has had asthma or wheeziness for
   (Coding: convert years and months to months and code as number of months 1 – 999)

   Parents opinion ☐☐ *(years)* ☐☐ *(months)* ☐☐☐ 3

   GP / Doctor diagnosis ☐☐ *(years)* ☐☐ *(months)* ☐☐☐

4 What symptoms of asthma does your child get?
   Ask parent to volunteer symptoms first. Then specifically ask about any symptoms not mentioned by the caregiver.

	Yes (1)	No (2)	
4.1. Wheeziness or tight chest during the day	☐	☐	☐
4.2. Wheeziness or tight chest at night	☐	☐	☐
4.3. Wheeziness or tight chest during exercise	☐	☐	☐
4.4. Asthma type cough during the day	☐	☐	☐
4.5. Asthma type cough during the night	☐	☐	☐
4.6. Asthma type cough during exercise	☐	☐	☐

4.7. Shortness of breath	☐	☐	☐

5 What things bring CHILDS NAME asthma on or make it worse?
Ask parent to volunteer symptoms first. Then specifically ask about any symptoms not mentioned by the caregiver.

	Yes (1)	No (2)	
Colds and flu's	☐	☐	☐
Emotions	☐	☐	☐
Changes in the weather	☐	☐	☐
Dusty places	☐	☐	☐
Exercise	☐	☐	☐
Closed in spaces	☐	☐	☐
Eating some sorts of food	☐	☐	☐
Being close to pets	☐	☐	☐
Wearing damp clothes	☐	☐	☐
Being around smokers	☐	☐	☐
Asthma / wheeziness just comes by itself	☐	☐	☐
Other *(Specify)*_____	☐	☐	

6 Have you ever changed CHILD'S NAME diet because you thought some foods seemed to make asthma worse?

☐ 6

Yes	☐	(1)
No	☐	(2)

7 (a) Is your house carpeted?

☐

Yes	☐	(1)	7a
No	☐	(2)	

(b) Is CHILD'S NAME bedroom carpeted?

☐

Yes	☐	(1)	7b
No	☐	(2)	

8 Have you put a special asthma mattress cover on CHILD'S NAME mattress?

Yes	☐	(1)	☐
No	☐	(2)	8

9 Has your child used any of the following medicines (regularly or occasionally) for asthma or wheeziness. *Show Card*

	Currently		Last 3 months		Last 12 months		
	Yes (1)	No (2)	Yes (1)	No (2)	Yes (1)	No (2)	9
Ventolin / Aeromir	☐	☐	☐	☐	☐	☐	☐☐☐
Bricanyl	☐	☐	☐	☐	☐	☐	☐☐☐
Atrovent	☐	☐	☐	☐	☐	☐	☐☐☐
Respolin	☐	☐	☐	☐	☐	☐	☐☐☐
Intal / Vicrom	☐	☐	☐	☐	☐	☐	☐☐☐
Becotide	☐	☐	☐	☐	☐	☐	☐☐☐
Pulmicort	☐	☐	☐	☐	☐	☐	☐☐☐
Respocort	☐	☐	☐	☐	☐	☐	☐☐☐
Flixotide	☐	☐	☐	☐	☐	☐	☐☐☐
Oral Steroids (Betnesol or Prednisone)	☐	☐	☐	☐	☐	☐	☐☐☐
Becloforte	☐	☐	☐	☐	☐	☐	☐☐☐
Zasten (Ketotifen)	☐	☐	☐	☐	☐	☐	☐☐☐
Serovent	☐	☐	☐	☐	☐	☐	☐☐☐
Combivent	☐	☐	☐	☐	☐	☐	☐☐☐
Tilade	☐	☐	☐	☐	☐	☐	☐☐☐
Floridil	☐	☐	☐	☐	☐	☐	☐☐☐

10 Which of your child's current medicines will relieve wheezing straight away? *Record the names of ALL the medicines the caregiver states are relievers.*

Drugs _____
_____
_____

☐ 10

11 How does CHILDS NAME take their medicines at the moment? *(Can have up to 3 responses) Show card.*

Uses a nebuliser all the time	☐ (1)
Uses a nebuliser sometimes	☐ (2)
Uses an inhaler	☐ (3)
Uses an inhaler with a spacer	☐ (4)
Uses an inhaler with a spacer and mask	☐ (5)
Has syrup medicines	☐ (6)

Specify which medicines are given in syrup form:

_____
_____
_____

☐ 11

12 *Ask this question if the child is NOT using a nebuliser currently (all the time or sometimes). Otherwise go to question 13.*

In the past TWELVE months has CHILD'S NAME ever needed a nebuliser?

Yes ☐ (1)
No ☐ (2)

☐ 12

13 *Ask this question if the child is NOT using a spacer +/- mask currently. Otherwise go to question 14.*

In the Past TWELVE months has CHILDS NAME ever used a spacer +/- mask to take their medicine?

Yes ☐ (1) *Go to Question 14*
No ☐ (2) *Go to Question 15*

☐ 13

14 *Answer this question if the child has used a spacer in the last twelve months*

Which of the following comments about spacers are TRUE and which are FALSE?

You should only put one puff of inhaler into the spacer at the same time: *True (1)* *False (2)*

☐ ☐ ☐ 14

You should wash the spacer with warm water and detergent and dry it in the air: True (1) ☐ False (2) ☐ ☐

You should never rinse out your mouth after using the spacer: True (1) ☐ False (2) ☐ ☐

You should hold the spacer over the mouth until the child has taken FIVE breaths: True (1) ☐ False (2) ☐

15 In general over the last TWELVE MONTHS, would you say that CHILDS NAME asthma has been ☐ 15

Show card

Very mild ☐ (1)
Mild ☐ (2)
Moderate ☐ (3)
Severe ☐ (4)
Very severe ☐ (5)

16 How often has CHILDS NAME asthma prevented him/her from participating in activities ☐ 16

Show card

Never ☐ (1)
Very occasionally ☐ (2)
Sometimes ☐ (3)
Often ☐ (4)
Very often ☐ (5)

17 How often has CHILDS NAME asthma stopped family activities ☐ 17

Show card

Never	☐ (1)
Very occasionally	☐ (2)
Sometimes	☐ (3)
Often	☐ (4)
Very often	☐ (5)

18 How often do you feel frightened because of CHILDS NAME asthma? ☐ 18

Show card

Never	☐ (1)
Sometimes	☐ (2)
Often	☐ (3)

Questions 19 - 21 have a 5 point visual analogue scale which is shown to parent/caregiver and their response is scored

19 How certain are you that you can recognise the signs of an asthma attack? ☐ **19** ☐

20 How certain are you that you can prevent your child from having an asthma attack? ☐ **20** ☐

21 How certain are you that you can manage (or control) your child's asthma? ☐ **21** ☐

22 Does anyone in your family have asthma, get wheezy or use asthma type medicines? ☐ 22

Yes	☐	(1)
No	☐	(2) *Go to Question 24*

23 What is this person's relationship to the child? *Show card*
Can have more than one answer (up to four)

☐ 23

Brother or sister	☐ (1)	☐
Parent	☐ (2)	
Grandparent	☐ (3)	☐
Auntie or Uncle	☐ (4)	
Cousin	☐ (5)	☐
Other		
Specify relationship: _____	☐ (6-9)	

24 Did CHILD'S NAME mother or father have asthma, wheeziness or need asthma type medicines when they were a child?

☐ 24

Yes ☐ (1)
No ☐ (2)

25 Does anyone in your family have eczema or hayfever?

(a) Yes ☐ (1) ☐
No ☐ (2) *Go to Question 26* 25a

(b) What is this persons relationship to CHILD'S NAME? *Show card*
Can have more than one answer (up to four)

Brother or sister	☐ (1)	
Parent	☐ (2)	25b ☐
Grandparent	☐ (3)	
Auntie or Uncle	☐ (4)	☐
Cousin	☐ (5)	
Other		☐
Specify relationship: _____	☐ (6-9)	
		☐

These questions are about asthma / wheeziness

26 Which of the following are parts of asthma? *Show card*

	Yes (1)	No (2)	
Difficulty breathing	☐	☐	☐ 26
Wheezing	☐	☐	☐
Blocked nose	☐	☐	☐
Cough	☐	☐	☐
Watery eyes	☐	☐	☐

27 During a severe attack of asthma which of the following may be important *Show card*

	Yes (1)	No (2)	
The muscle around the breathing tube becomes tight	☐	☐	☐ 27
Swelling of the lining of the breathing tubes	☐	☐	☐
Excess (too much) mucus production	☐	☐	☐
Blockage of the nose passages	☐	☐	☐
The muscles of the chest wall become tired	☐	☐	☐

28 Which of the following are true *Show card*

	True (1)	False (2)	
Asthma often runs in families	☐	☐	☐ 28
Asthma is uncommon - it occurs in less than 5 % of people	☐	☐	☐
Asthma is associated with having very sensitive breathing tubes	☐	☐	☐
You can catch asthma from other people	☐	☐	☐
It is important for people with asthma to avoid tobacco smoke	☐	☐	☐

29 Which of the following can often result in asthma becoming worse *Show card*

	True (1)	False (2)	
A hot bath	☐	☐	☐
Exercise	☐	☐	☐
Eating food too fast	☐	☐	☐
Head colds or flu	☐	☐	☐
Running out of asthma medicines	☐	☐	☐
Stress, ‘nerves’ or emotional upsets	☐	☐	☐

30 (a) Your child has been well and attending school. S/he wakes up with a runny nose (thick green discharge) but otherwise seems quite well.

What did you do when this happened to your child last? ☐ 30a

_____

_____

_____

(b) The following day your child seems grumpy and tired, his/her nose is just the same but s/he now has a cough that has woken him/her up once during the night. ☐ 30b

Has this ever happened to you?

(If yes) The last time this happened, what did you do?
(If no) If this were to happen, what would you do?

_____

_____

_____

(c) Before going to bed you go into the bedroom to check her/him. S/he seems restless, is breathing fast and has an obvious wheeze. Several times during the night s/he wakes up coughing. ☐ 30c

Has this ever happened to you?

(If yes) Can you remember what you did the last time this happened? Can you remember what you did the following morning?

(If no) What would you do during the night?
What would you do in the morning?

_____

_____

_____

(d) (All participants) Do you think that this represents asthma? Yes / No ☐ 30d

31 Do any people living in the household smoke cigarettes regularly? ☐ 31

Yes ☐ (1)
No ☐ (2)

If no smokers go to Question 33

32 Is there a smokefree area in the house

Yes ☐ (1)
No ☐ (2) ☐ 32

33 Do you have any cats?

Yes ☐ (1)
No ☐ (2) ☐ 33

These questions are about the types of doctors you use for CHILDS NAME asthma

34 The family doctor (General Practitioner or GP) ☐ 34
Please look at the card and tell me what sentence about family doctors is best for you and your child.

I do NOT have a regular family doctor that I go to all the time. I go to whatever family doctor I can see when I need to see one. ☐ (1)

I have a regular family doctor that I use MOST of the time. I SOMETIMES go to other family doctors. ☐ (2)

I have a regular family doctor that I use ALL of the time. I do not go to other family doctors**.** ☐ (3)

35 After hours doctors and medical clinics (NOT hospital emergency departments and Starship) ☐ 35

Please look at the card and tell me what sentence about After Hours doctors or medical clinic is best for you and your child.

I ALWAYS go to an After Hours doctors or medical clinic for CHILDS NAME asthma. I do not use family doctors / GP's. ☐ *(1)*

MOST OF THE TIME I use an After Hours doctors or medical clinic for CHILDS NAME asthma. I OCCASIONALLY use family doctors / GP's. ☐ (2)

OCCASIONALLY I use an After Hours doctors or medical clinic for CHILDS NAME asthma. USUALLY I go to the family doctors / GP's. ☐ (3)

I have NEVER gone to an After Hours doctors or medical clinic for CHILDS NAME asthma. ☐ (4)

36 Hospital emergency departments and Starship Hospital.

36a *Please look at the card and tell me what sentence about Hospital emergency departments and Starship Hospital is best for you and your child.*

I ALWAYS go to Hospital emergency departments or Starship Hospital for CHILDS NAME asthma. ☐ *(1)* ☐ 36a

MOST OF THE TIME I use the Hospital emergency departments or Starship Hospital for CHILDS NAME asthma. ☐ (2)

OCCASIONALLY I use the Hospital emergency departments or Starship Hospital for CHILDS NAME asthma. ☐ (3)

I have NEVER gone to the Hospital emergency departments or Starship Hospital for CHILDS NAME asthma. ☐ (4)

36b *All caregivers who have taken their children to hospital should be asked this question.*

I only take CHILDS NAME to the hospital emergency department or Starship hospital if my doctor refers us there (gives us a letter and tells me to go to hospital) ☐ 36b

Yes (1) ☐ No (2) ☐

37 In the last THREE months how many times have you seen the doctor because CHILDS NAME was <u>sick</u> with asthma?

(Code: Enter number of times, or Don't know = 99)

Your regular family doctor	☐☐	☐☐ 37
Other family doctors	☐☐	☐☐
After Hours doctors or medical clinics	☐☐	☐☐
Hospital Emergency Departments	☐☐	☐☐

38 In the last TWELVE months how many times have you seen the doctor because CHILDS NAME was <u>sick</u> with asthma

(Code: Enter number of times, or Don't know = 99)

Your regular family doctor	☐☐	☐☐ 38
Other family doctors	☐☐	☐☐
After hours doctors or medical clinics	☐☐	☐☐
Hospital Emergency Departments	☐☐	☐☐

39 In the last THREE months how many times have you seen the doctor for a regular check up of CHILDS NAME asthma (that is not when s/he is sick with asthma, but for example, needs some more inhalers)

(Code: Enter number of times, or Don't know = 99)

Your regular family doctor	☐☐	☐☐ 39
Other family doctors	☐☐	☐☐
After hours doctors or medical clinics	☐☐	☐☐
Hospital Emergency Departments	☐☐	☐☐

40 In the last TWELVE months how many times have you seen the doctor for a regular check up of CHILDS NAME asthma (that is not when s/he is sick with asthma, but for example, needs some more inhalers)

(Code: Enter number of times, or Don't know = 99)

Your regular family doctor	☐☐	☐☐ 40
Other family doctors	☐☐	☐☐
After hours doctors or medical clinics	☐☐	☐☐
Hospital Emergency Departments	☐☐	☐☐

41 This question is about admissions to hospital for asthma
This does NOT include visits to the Emergency Department where the child was not admitted to a ward.

Has your child ever been admitted to hospital for asthma? ☐

Yes ☐ (1)
No ☐ (2) *Go to Question 42*

Has CHILDS NAME been admitted to hospital for asthma in the past twelve months ☐

Yes ☐ (1)
No ☐ (2) *Go to Question 42*

How many times in the last THREE months has CHILDS NAME been admitted to hospital for asthma? ☐☐

(Code: Enter number of times, or Don't know = 99) ☐☐ ☐☐

How many times in the last TWELVE months has CHILDS NAME been admitted to hospital for asthma

(Code: Enter number of times, or Don't know = 99) ☐☐

42 This question is about the use of ambulance services

Have you ever had to call an ambulance about CHILDS NAME asthma? ☐

Yes ☐ (1)
No ☐ (2) *Go to Question 43*

Have you called the ambulance about CHILDS NAME asthma in the last twelve months? ☐

Yes ☐ (1)
No ☐ (2) *Go to Question 43*

How many times in the last THREE months have you called the ambulance about CHILDS NAME asthma? ☐☐

(Code: Enter number of times, or Don't know = 99) ☐☐

How many times in the last TWELVE months have you called the ambulance about CHILDS NAME asthma ☐☐

(Code: Enter number of times, or Don't know = 99) ☐☐

These questions are about asthma action plans

43 Have you heard of an action or crisis plan? ☐ 43

Yes ☐ (1)
No ☐ (2)

44 Have you ever been given an asthma action or asthma crisis plan to help you manage CHILDS NAME asthma? ☐ 44

Yes ☐ (1)
No ☐ (2) *Go to Question 55*

45 Who wrote out the plan for you? *Show card* ☐ 45

GP ☐ (1)
Practice nurse ☐ (2)
Asthma educator ☐ (3)
Hospital doctor ☐ (4)
Plunket, District or Public health nurse ☐ (5)
Family / whanau ☐ (6)
Friend ☐ (7)
Other ☐ (8)
Don't know ☐ (9)
Specify: _____

46 How long have you had the plan? ☐☐

(Coding convert years and months to months. Code as 1 – 99 months) 46

☐☐ *(Years)* ☐☐ *(Months)*

47 Has it been reviewed or updated in the last twelve months? ☐ 47

Yes ☐ (1)
No ☐ (2)

48 When it was first given to you, did you use the plan? *Show card.* ☐ 48

All the time ☐ (1)
Most of the time ☐ (2)
Sometimes ☐ (3)
Hardly ever ☐ (4)
Not at all ☐ (5) *Go to Question 55*

49 When you were first given the plan, was it useful when you were looking after CHILDS NAME asthma? *Show card.* ☐ 49

Very useful ☐ (1)
Useful ☐ (2)
A little bit useful ☐ (3)
Not useful at all ☐ (4)

50 When you were first given the asthma action plan, who explained it to you? *Show card.* ☐ 50

GP ☐ (1)
Practice nurse ☐ (2)
Asthma educator ☐ (3)
Hospital doctor ☐ (4)
Plunket, District or Public health nurse ☐ (5)
Family / whanau ☐ (6)
Friend ☐ (7)
Other ☐ (8)
Specify: _____
Don't' know ☐ (9)

51 Thinking about this (the first) explanation, was the explanation: ☐ 51

Show card

Clear, easy to understand ☐ (1)

I understood most things but there were things I felt unclear or unsure about ☐ (2)

I was unclear or unsure about most of the things the person told me ☐ (3)

52 Thinking about the AMOUNT of information you received when the plan was first explained to you, would you say that the information you were given was ☐ 52

Show card

Too much ☐ (1)
Enough ☐ (2)
Not enough ☐ (3)

53 Has anyone given you any further information about the action plan? ☐ 53

Yes ☐ (1)
No ☐ (2)

54 Now, do you use the plan *Show card.* ☐ 54

All of the time ☐ (1)
Most of the time ☐ (2)
Sometimes ☐ (3)
Hardly ever ☐ (4)
Never ☐ (5)

These questions are about asthma education.

55 Where did you learn about asthma? *Show card.*
Tick as many as appropriate

55 ☐

Self experience	☐	(1)
Friends/whanau	☐	(2)
Books/pamphlets/videos about asthma	☐	(3)
Asthma society	☐	(4)
Asthma educator	☐	(5)
Family doctor	☐	(6)
Practice nurse	☐	(7)
Hospital	☐	(8)
Plunket nurse, Public Health Nurse, District Nurse or other nurses who visit your home	☐	(9)
Other	☐	(10-99)

Specify: _____

56 Has anyone ever talked to you in depth about asthma (asthma education)?

☐ 56

Yes ☐ (1) *Go to Question 57*
No ☐ (2) *Go to Question 67*

57 How long ago did you first receive asthma education?

☐☐☐ 57

(Coding: convert years and months to months and code as number of months 1 – 999)

☐☐ *(years)* ☐☐ *(months)*

58 Since then, have you received any more asthma education?

☐ 58

Yes ☐ (1)
No ☐ (2)

59 From whom? *Show card.* ☐ 59
Tick as many as appropriate

☐

Self experience	☐ (1)	
Friends/whanau	☐ (2)	☐
Books/pamphlets/videos about asthma	☐ (3)	
Asthma society	☐ (4)	☐
Asthma educator	☐ (5)	
Family doctor	☐ (6)	☐
Practice nurse	☐ (7)	
Hospital	☐ (8)	☐
Plunket nurse, Public Health Nurse, District Nurse or other nurses who visit your home	☐ (9)	
Other	☐ (10-99)	

Specify: _____

60 How has information been shared with you? *Ask about each of the four options presented below*

	Yes (1)	No (2)	
			☐
Talking	☐	☐	☐
Written information such as pamphlets	☐	☐	☐
Video presentation	☐	☐	☐
Practical demonstration e.g. how to use a spacer or a peak flow meter	☐	☐	☐

61 What things have you been told about asthma?

	Yes (1)	No (2)	
Medications for asthma / wheeziness and how to use them	☐	☐	☐ 61
The devices used to give the medicines	☐	☐	☐
What happens in the lungs to cause asthma	☐	☐	☐
General information about asthma e.g if asthma runs in families; other health problems that are linked to asthma.	☐	☐	☐
What things might trigger asthma or wheeziness	☐	☐	☐
Action or crisis plans	☐	☐	☐
Peak flow meters	☐	☐	☐

62 Has the information you have been given about asthma been *Show card*

☐

Clear, easy to understand	☐ (1)	62
I understood most things but there were things I felt unclear or unsure about	☐ (2)	
I was unclear or unsure about most of the things the person told me	☐ (3)	

63 Do you think the amount of information you have been given has been *Show card* ☐ 63

Too much	☐ (1)
Enough	☐ (2)
Not enough	☐ (3)

64 How useful did you find the information in helping you to understand asthma and how to manage it? *Show card* ☐ 64

Very useful	☐ (1)
Of some use	☐ (2)
Not very useful	☐ (3)
Of no use	☐ (4)

65 Have you ever been referred to an asthma educator? ☐ 65

Yes	☐	(1) *Go to Question 66*
No	☐	(2) *Go to Question 67*

66 What was your experience of the asthma educator? *Show card* ☐ 66

Excellent	☐ (1)
Very good	☐ (2)
Good	☐ (3)
Not very good	☐ (4)
Bad	☐ (5)
Did not go to see the educator	☐ (6)

FINALLY, we would like to ask you some questions about you and your family. We are nearly finished the questionnaire!

67 Where was your SON / DAUGHTER born? *Show card* ☐☐ 67

New Zealand	☐ (1)
Samoa	☐ (2)
Tonga	☐ (3)
Niue	☐ (4)
Cook Islands	☐ (5)
Australia	☐ (6)
United Kingdom	☐ (7)
USA	☐ (8)
Hong Kong	☐ (9)
China	☐ (10)
Korea	☐ (11)
Vietnam	☐ (12)
Other (Please Specify)	☐ (13-98)
Don't know	☐ (99)

68 Which country do you normally live in? *Specify Answer* ☐☐

_____ 68

_____

69 Which ethnic group or groups does your child belong to? ☐☐ 69
(Tick all that apply) Show card

New Zealand Maori	☐ (1)
New Zealand European / Pakeha	☐ (2)
Samoan	☐ (3)
Cook Island Maori	☐ (4)
Tongan	☐ (5)
Niuean	☐ (6)
Tokelauan	☐ (7)
Fijian	☐ (8)
Other Pacific Groups	
*Please Specify:*_____	☐ (9)
Other European	
*Please Specify:*_____	☐ (10)
Southast Asian	☐ (11)
Other Asian	
*Please Specify:*_____	☐ (12)
Chinese	☐ (13)
Indian	☐ (14)
Other ethnic groups	
*Please Specify:*_____	☐ (15)
Don't know	☐ (16)

70 *If you ticked more than one ethnic group*

(a) Is there are group that your child belongs to most? ☐ 70a

Yes ☐ (1)
No ☐ (2) ☐ 70b

(b) Which ethnic group? ☐☐

71 Who is the main caregiver for the child?

Mother	☐ (1)
Father	☐ (2)
Grandparent	☐ (3)
Auntie or Uncle	☐ (4)
Friend	☐ (5)
Other	☐ (6)
*Please specify:*_____	☐ (7)

☐ 71

72 Where was the main caregiver born? ☐☐ 72

Show card

New Zealand	☐ (1)
Samoa	☐ (2)
Tonga	☐ (3)
Niue	☐ (4)
Cook Islands	☐ (5)
Australia	☐ (6)
United Kingdom	☐ (7)
USA	☐ (8)
Hong Kong	☐ (9)
China	☐ (10)
Korea	☐ (11)
Vietnam	☐ (12)
Other (*Please Specify*)	☐ (13)

73 How long has the main caregiver been in New Zealand? ☐☐☐ 73

(Coding: Convert years and months to months and code as number of months 1 – 999)

☐☐ ☐☐
year *months*

74 Where was the child's father (not the main caregiver) born? ☐☐ 74

Show card

New Zealand	☐ (1)
Samoa	☐ (2)
Tonga	☐ (3)
Niue	☐ (4)
Cook Islands	☐ (5)
Australia	☐ (6)
United Kingdom	☐ (7)
USA	☐ (8)
Hong Kong	☐ (9)
China	☐ (10)
Korea	☐ (11)
Vietnam	☐ (12)
Other (*Please Specify*)	☐ (13)
Don't know	☐ (99)

75 How long has the father (not the main caregiver) been in New Zealand? ☐☐☐ 75

(Coding: Convert years and months to months and code as number of months 1 – 999)

☐☐ ☐☐
year *months*

76 What language is usually spoken at home? ☐☐ 76

Show card

English	☐ (1)
Maori	☐ (2)
Samoan	☐ (3)
Tongan	☐ (4)
Niuean	☐ (5)
Cook Island Maori	☐ (6)
Other Pacific	
*Please specify:*_____	☐ (7)
Cantonese	☐ (8)
Mandarin	☐ (9)
Other Asian	
*Please specify:*_____	☐ (10)
Other language	
*Please specify:*_____	☐ (11)
Don't know	☐ (99)

77 Did you (the main caregiver) complete ☐ 77

Primary School	☐ (1)
Intermediate School	☐ (2)
Secondary School	☐ (3)

78 Did you go to ☐ 78

University	☐ (1)
Polytechnic	☐ (2)
Training College	☐ (3)
None of the above	☐ (4)

79 What best describes your (the main caregiver) current position? ☐ 79

Show card

Full time employment	☐ (1)
Part time employment	☐ (2)
Part time employment and benefit	☐ (3)
On a benefit	☐ (4)
Full time home maker	☐ (5)
A student	☐ (6)
Other	
*Please specify:*_____	☐ (7)

80 Who is the main income earner in your household? ☐☐ 80

_____

81 What is the total income for your household from all sources (wages and benefits), before tax or anything was taken out of it, in the last twelve months? ☐ 81

Show card

Code 0 -9 ☐

Questions 82 – 84 Please answer the following questions ONLY IF the father or male partner is currently part of the household i.e. living at home

82 Did the father or male partner (not the main caregiver) go to ☐ 82

Primary School	☐ (1)
Intermediate School	☐ (2)
Secondary School	☐ (3)

83 Did the father or male partner go to ☐ 83

University	☐ (1)
Polytechnic	☐ (2)
Training College	☐ (3)
None of the other	☐ (4)

84 What best describes the father or male partner's current position? ☐☐
84

Show card

Full time employment	☐ (1)
Part time employment	☐ (2)
Part time employment and benefit	☐ (3)
On a benefit	☐ (4)
Full time home maker	☐ (5)
A student	☐ (6)
Other *Please specify:*_____	☐ (7)

Congratulations and many thanks, we have finished!!!

Appendix 11 Response cards

Question 11

Uses a nebuliser all the time

1. Uses a nebuliser sometimes
2. Uses an inhaler
3. Uses an inhaler with a spacer
4. Uses an inhaler with a spacer and mask
5. Has syrup medicines

Question 15

1. very mild
2. mild
3. moderate
4. severe
5. very severe

Questions 16 and 17

1: Never

2: Very occasionally

3: Sometimes

4: Often

5: Very often

Question 18

1: Never

2: Sometimes

3: Often

Questions 19 – 21

very uncertain ----------very certain

1 2 3 4 5

Question 23 and 25

1: Brother or sister

2: Parent

3: Grandparent

4: Auntie or Uncle

5: Cousin

6: Other

Question 26

1: difficulty breathing

2: wheezing

3: blocked nose

4: cough

5: watery eyes

Question 27

1: the muscle around the breathing tube becomes tight

2: swelling of the lining of the breathing tubes

3: excess (too much) mucus production

4: blockage of the nose passages

5: the muscles of the chest wall become tired

Question 28

1: asthma often runs in families

2: asthma is uncommon - it occurs in less than 5 % of people

3: asthma is associated with having very sensitive breathing tubes

4: you can catch asthma from other people

5: it is important for people with asthma to avoid tobacco smoke

Question 29

1: a hot bath

2: exercise

3: eating food too fast

4: head colds or flu

5: running out of asthma medicines

6: stress, ‘nerves’ or emotional upsets

Question 34

1: I do NOT have a regular family doctor that I go to all the time. I go to whatever family doctor I can see when I need to see one.

2: I have a regular family doctor that I use MOST of the time. I SOMETIMES go to other family doctors.

3: I have a regular family doctor that I use ALL of the time. I do not go to other family doctors.

Question 35

1: I ALWAYS go to an After hours doctors or medical clinic for CHILDS NAME asthma. I do not use family doctors / GP's.

2: MOST OF THE TIME I use an After hours doctors or medical clinic for CHILDS NAME asthma. I OCCASIONALLY use family doctors / GP's.

3: OCCASIONALLY I use an After hours doctors or medical clinic for CHILDS NAME asthma. USUALLY I go to the family doctors / GP's.

4: I have NEVER gone to an After hours doctors or medical clinic for CHILDS NAME asthma.

Question 36

1: I ALWAYS go to Hospital emergency departments and Starship Hospital for CHILDS NAME asthma.

2: MOST OF THE TIME I use the Hospital emergency departments and Starship Hospital for CHILDS NAME asthma.

3: OCCASIONALLY I use the Hospital emergency departments and Starship Hospital for CHILDS NAME asthma.

4: I have NEVER gone to the Hospital emergency departments and Starship Hospital for CHILDS NAME asthma.

Question 45

1: GP

2: Practice nurse

3: Asthma educator

4: Hospital doctor

5: Plunket, District or Public health nurse

6: Family / whanau

7: Friend

8: Other

9: Don’t know

Question 48

1: All of the time

2: Most of the time

3: Sometimes

4: Hardly ever

5: Not at all

Question 49

1: Very useful

2: Useful

3: A little bit useful

4: Not useful at all

Question 50

1: GP

2: Practice nurse

3: Asthma educator

4: Hospital doctor

5: Plunket, District or Public health nurse

6: Family / whanau

7: Friend

8: Other

9: Don’t know

Question 51

1: clear, easy to understand

2: I understood most things but there were things I felt unclear or unsure about

3: I was unclear or unsure about most of the things the person told me

Question 52

1: too much

2: enough

3: not enough

Question 54

1: All of the time

2: Most of the time

3: Sometimes

4: Hardly ever

5: Not at all

Question 55 and 59

1: Self experience

2: Friends/whanau

3: Books/pamphlets/videos about asthma

4: Asthma society

5: Asthma educator

6: Family doctor

7: Practice nurse

8: Hospital

9: Plunket nurse, Public Health Nurse, District Nurse or other nurses who visit your home

10: Other

Question 61

1: Medications for asthma / wheeziness and how to use them

2: The devices used to give asthma medicines

3: What happens in the lungs to cause asthma

4: general information about asthma e.g. other health problems that may be linked with asthma etc.

5: What things might trigger asthma or wheeziness

6: Action or crisis plans

7: Peak flow meters

Question 62

1: clear, easy to understand

2: I understood most things but there were things I felt unclear or unsure about

3: I was unclear or unsure about most of the things the person told me

Question 63

1: too much

2: enough

3: not enough

Question 64

1: Very useful

2: Useful

3: A little bit useful

4: Not useful at all

Question 66

1: Excellent

2: Very good

3: Good

4: Not very good

5: Bad

6: Did not go to see the educator

Questions 67, 72 and 74

1: New Zealand
2: Samoa
3: Tonga
4: Niue
5: Cook Islands
6: Australia
7: United Kingdom
8: USA
9: Hong Kong
10: China
11: Korea
12: Vietnam
13: Other
14: Don’t know

Question 69

1: New Zealand Maori

2: New Zealand European / Pakeha
3: Samoan
4: Cook Island Maori
5: Tongan
6: Niuean
7: Tokelauan
8: Fijian
9: Other Pacific Groups
10: Other European
11: Southast Asian
12: Other Asian
13: Chinese
14: Indian
15: Other ethnic groups
16: Don’t know

Question 76

1: English
2: Maori
3: Samoan
4: Tongan
5: Niuean
6: Cook Island Maori
7: Other Pacific
8: Cantonese
9: Mandarin
10: Other Asian
11: Other language
12: Don’t know

Question 79 and 84

1: Full time employment
2: Part time employment
3: Part time employment and benefit
4: On a benefit
5: Full time homemaker
6: A student
7: Other

Question 81

1: Loss / zero

2: $1 - $15000

3: $15001 - $30000

4: $30001 - $40000

5: $40001 - $70000

6: $70000 or more

7: Don’t know

8: Prefer not to answer the question