Congruence of Perception of Asthma Control Between Parents, Children, and Clinicians

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Honors Research Thesis
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Chapter I: Statement of the Problem

Definition of Terms: *Illness Representation* – An individual's ideas and beliefs about the nature of asthma, cause of the disease, ideas about medication use, treatment expectations, healthcare provider relationship, and emotional aspects of the child surrounding medication use.

Asthma Symptom Perception – The perception of a bodily sensation including the physiological representation of location, intensity, or quality of a sensation.

Spirometry – A pulmonary function test which measures the amount (volume) and/or speed (flow) of air inhaled and exhaled.

Introduction: Childhood asthma is a serious public health issue due to high prevalence and costs. It is currently the most common chronic childhood illness, affecting approximately 7 million children ages 0-17 years. The prevalence in this age group is increasing at a rate of 1.4% per year, and rates are highest in the Northeast and Midwest. (Moorman, J.E., Akinbami, L.J., Bailey, C.M.,et al., 2012) The costs associated with asthma are staggering. It has been estimated that asthma costs the U.S. healthcare system $56 billion annually, inclusive of the direct cost of providing treatment (approximately $1039/child/year) as well as lost productivity costs due to missed school and work and activity limitations. (CDC National Asthma Control Program, 2013)

African American and Puerto Rican children are disproportionately affected compared to White and Mexican children. (CDC National Asthma Control Program, 2013) Latino groups, in particular, seem to struggle the most with symptom perceptual accuracy. (Fritz et al., 2010) Inaccurate perception of symptoms results in an increased likelihood of ED visits, hospitalizations, visits to school clinics, and utilization of primary care providers for asthma exacerbations. (Fritz et al., 2010) Poor perception also leads to poor medication adherence, which further exacerbates asthma symptoms. (Corso, P.,Fertig, A., 2009) Accurate perception of

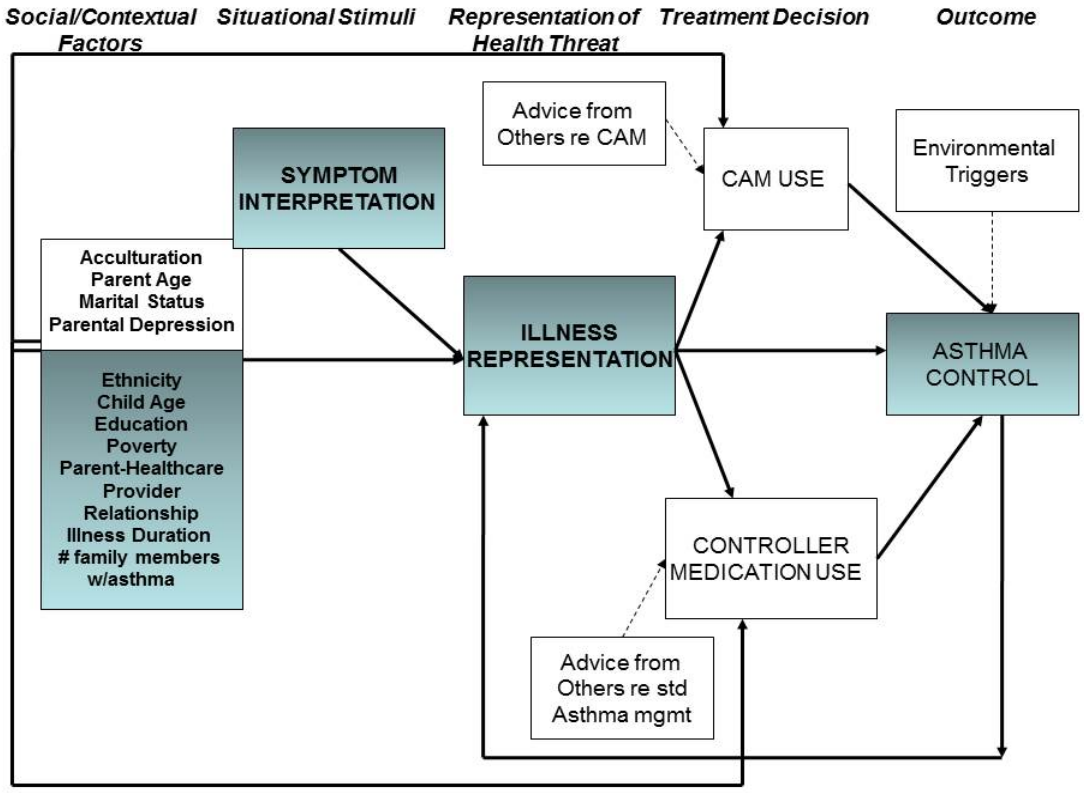
asthma symptoms, level of control and medication adherence are key to improving outcomes and reducing costs incurred.

Purpose of Study: This secondary analysis examines socio-demographic differences in parent and child perceptions of asthma control and compares these subjective perceptions with objective clinician ratings.

Significance of Study: Given the minimal risks and large potential of knowledge to be gained, this study has a high benefit to risk ratio. Understanding parents' and children's perception of asthma control, parental illness representations of asthma, and how these two factors predict clinician ratings of control is critical in identifying potential targets for intervention, which are aimed at improving children's asthma health outcomes. Information from this study will serve to address gaps in our knowledge about Latino parents' beliefs about their child's asthma and its management, which may provide more explanation as to the large health disparities that exist within Latino children's asthma health. The long-term goal is to inform future educational interventions aimed at improving symptom perception and medication adherence and reframing asthma illness representations to align with the professional model of asthma management resulting in decreased number of emergency room visits, hospitalizations, and missed school days.

Theoretical Framework: The Common Sense Model (CSM) of Illness Representations provides the theoretical framework for investigating the specified outcomes through the pathways of symptom perception, illness representations, use of complementary and alternative medicine (CAM), and adherence to controller medications. Situational stimuli (perception of the child's symptoms), objective representation of the health threat (illness representation) with its treatment decisions (controller medication use) and appraisal of the outcomes (asthma control,

pulmonary function, healthcare utilization) are all described in this model and are all shaped by the patient's prior history of asthma control, personality, and social and cultural context. The model contains a feedback loop with illness representations potentially changing over time as the parent gains experience in managing their child's asthma. Illness representations, treatment decisions, and appraisal of outcomes are influenced by the parent's personality, social and cultural environment, and previous experiences managing their child's asthma. *Figure 1* below illustrates the conceptual model for this study:



NOTE: Shaded items are the variables of primary interest.

Research Questions Aim #1: To examine socio-demographic differences in parent and child perceptions of asthma control. RQ #1: Does perceptual accuracy (child and caregiver) differ by age, sex, and ethnicity? **Aim #2: Compare subjective parent and child perceptions of asthma control with objective clinician ratings.** RQ #2: Are parent and child

perceptions of control congruent with clinician ratings? **Aim #3: Explore parents' perception of asthma control, illness representations, and socio-demographic factors on clinician ratings of control.** RQ#3: Does parent perception of asthma control predict clinician rated control? RQ#4: Is the relationship between parent perception of control and clinician rated control mediated by asthma illness representations?

Chapter II: Review of the Literature

Asthma is the most common chronic childhood illness, currently affecting 9.5% of children in the United States. This results in a number of medical expenses, as well as costs incurred for missed school and workdays. Evidence shows that these costs are more strongly associated with children, minorities, and low-income populations. One in five children with asthma went to an emergency department for asthma-related care in 2009 with black and Hispanic children having more ED visits than white children. (CDC National Asthma Control Program, 2013) Accurate perception of asthma symptoms and medication adherence is key to improving outcomes and reducing costs incurred. Inaccurate perception of symptoms results in an increased likelihood to be hospitalized, have ED encounters, visit the school clinics, and utilize primary care providers for asthma exacerbations. In addition, poor perception leads to poor medication adherence, which further exacerbates asthma symptoms. (Corso, P.,Fertig, A., 2009)

Pulmonary function perception is an important aspect in determining how accurate children are at perceiving their illness. A child's ability to accurately predict pulmonary function, results in decreased functional morbidity and fewer hospitalizations, ER episodes, and unscheduled doctor visits. Levels of perceptual accuracy tend to increase as children get older with girls being overall less accurate than boys and also having greater magnification scores

(over-estimation of symptom severity). Poverty is also associated with lower accuracy and higher magnification. (Fritz et al., 2010) In contrast, higher occupational prestige correlated with increased accuracy and decreased symptom magnification. (D. Koinis-Mitchell et al., 2009) One of the most significant discrepancies existed in children from ethnic minority groups. These children tend to have much lower accuracy and much higher symptom magnification than white children. (Kopel et al., 2010) Latino groups in particular seem to struggle the most with accuracy and perception (Fritz et al., 2010).

Discrepancies also exist between parents' and children's individual reports as to how often asthma symptoms are occurring. In a questionnaire of 285 children ages ten to fifteen and their parents, the top three asthma triggers reported by both groups were weather, pollen, and exercise. Despite this agreement regarding triggers, children consistently reported a higher prevalence of asthma symptoms compared with parent reports. Exercise was only reported as a trigger by 35% of parents but by 58% of children. When looking specifically at children's asthma symptoms within the last four weeks, 47% of parents stated that their child never had asthma symptoms triggered by physical activity, while 69% of children said that they did. (Davis, Disantostefano, & Peden, 2011)

Evidence shows that parent's knowledge regarding asthma pathophysiology, pharmacology, and triggers is actually quite accurate. (H. L. Yoos et al., 2007; Sidora-Arcoleo et al., 2010) Discrepancies exist, however, regarding symptom reporting and treatment for their children. The National Asthma Education and Prevention Program (NAEPP) guidelines stress the importance of treating even mild or moderate symptoms if they are persistent (U.S. Department of Health & Human Services: National Asthma Education Program, 2007); however, 39% of parents say they would not report nighttime symptoms that occur more than twice a

month, and 37% would not report the use of rescue medications more than twice a week. (H. L. Yoos et al., 2007) Experts for the National Asthma Control Initiative say both should be reported. (H. L. Yoos et al., 2007) Furthermore, the professional model states that asthma is a chronic illness, yet many parents describe asthma as episodic, acute, and uncontrollable and therefore only focus on treating acute exacerbations and severe symptoms. As a result, 27% of parents believe that medication should be a last resort in treating their child's asthma symptoms with the main concern being potential side effects associated with most anti-inflammatory medications. (H. L. Yoos et al., 2007) Parents and children who have accurate symptom perception and reporting are more likely to have asthma illness representations that are concordant with their health care provider and the professional model of asthma management. As a result, they are more likely to be on an appropriate medication regimen and have better controlled asthma. (H. L. Yoos et al., 2007; Sidora-Arcoleo, Feldman, Serebrisky, & Spray, 2012) Children, however, are reporting a much lower rate of usage for maintenance medication and fast-acting reliever medication than parents. Forty-four percent of parents reported that their child had used their maintenance medication in the last four weeks, while only 35% of children said they had. Furthermore, 90% of parents said that a fast-acting medication had been used, but only 67% of kids said it had. (Davis, Disantostefano, & Peden, 2011)

The link between child perception and family response is important. Evidence suggests that when a child has a tendency to underestimate the severity of their symptoms, the family is more likely to have an inadequate asthma management plan and as a result, there is increased asthma morbidity. (McQuaid et al., 2007) A key aspect of this is the child's ability to accurately predict their peak expiratory flow readings. Modern electronic spirometers give children immediate feedback as to how accurate their estimations are compared to their actual flow score.

Children with this immediate feedback have shown to be better perceivers and are more likely to adhere to their medication regimen. (Paton, 2012; Feldman et al., 2012)

In summary, kids and parents have differing perceptions of their asthma illness. Not only are parents less aware of their child's symptoms, but they are also not reporting symptoms that they should be due to misalignment of illness representations with the professional model. There is a hesitancy to use asthma medications, especially daily anti-inflammatories, because of their associated side effects. The lack of medication adherence causes increased asthma exacerbations, which leads to increased use of resources and increased costs. To improve these outcomes, it is essential to understand parental illness representations of asthma, their beliefs regarding their child's asthma management plan, and why perception tends to be so inaccurate. This will allow the parent, child and healthcare provider to have a better understanding, and they will be able to work together to determine an appropriate plan to improve child and parent symptom perception.

Chapter III: Methodology

Research Design: This is a longitudinal study of parental illness representations and CAM and controller medication use among a diverse sample of 300 Latino families (primarily Mexican and Puerto Rican) of children with asthma ages 5-12 years which is still ongoing. Structured interviews with parents, short interviews with children, objective measures of children's lung function, and children's medical record reviews were conducted at enrollment, and 3, 6, 9, and 12 months post-enrollment. Chi-square, t-tests, and linear regression analyses were conducted. For this thesis, secondary analyses from the baseline data were conducted.

Population and Sample Design: Baseline data were collected from 514 Mexican and Puerto Rican caregivers and children ages 5-12 years with asthma requiring daily controller medications. This age group was selected because children in this range have typically not

assumed daily control for managing their own asthma. Families were recruited from clinics in Phoenix, Arizona and Bronx, New York where there are higher populations of inner-city poor Mexican and Puerto Rican children with asthma. Multiple sites were necessary to obtain a sufficient number of families to conduct the study. A description of each site is presented below: The Neighborhood Action Outreach for Health (NOAH) program, administered by the Scottsdale Healthcare organization, provides primary care services, preventive healthcare, and immunizations for uninsured and under-insured children and families through a mobile unit and two school-based health clinics. In 2007, 3,248 children received urgent primary care services, 647 children received routine, preventive primary care services, and 1,383 dental visits were provided through the NOAH health centers. The NOAH nurse practitioners and medical staff provide much-needed health education to parents through counseling, exhibits, and health screenings for diabetes, asthma, blood pressure, vision, and hearing. Well-child checks and sports physicals are performed at NOAH sites as well. These clinics serve primarily poor Mexican families with no health insurance. Approximately 22% of the children served have a diagnosis of asthma. Dr. Sidora-Arcoleo purchased and installed spirometry equipment in each of the clinics and conducted staff training. These clinics are now incorporating asthma screening procedures per the NAEPP's Expert Panel Report clinical guidelines and it is anticipated that this prevalence rate will increase due to enhanced detection. (U.S. Department of Health & Human Services: National Asthma Education Program, 2007)

The Phoenix Children's Hospital Breathmobile is a self-contained mobile asthma clinic that travels to inner-city schools providing asthma identification, teaching, treatment, and follow-up. Since the inception of the Breathmobile, there has been a greater than 40% reduction in missed school days, a greater than 70% percent reduction in emergency room visits due to

asthma-related problems, and a greater than 73% decrease in asthma-related hospital stays among Breathmobile patients. The Breathmobile visits 19 schools in South Phoenix, where children are more likely to be uninsured. The service requires no referral, and there is no charge for treatment. Once diagnosed, the children receive an asthma action plan that includes education for asthma self-management, follow-up appointments and evaluations, controller medications, and a 24-hour phone number in case questions arise. The Breathmobile staff sees 70 school-aged patients a week and includes a pediatric nurse practitioner, a registered nurse, a respiratory therapist, and an operations coordinator. Seventy-seven percent of the population served is Latino (primarily Mexican), 13% black, and 5% white.

The pediatric clinic at Jacobi Medical Center (JMC) serves an ethnically diverse group of children who have a broad range of asthma severity. During 2006 at JMC, there were 2,634 visits to the Pediatric Asthma Clinic, 2,507 visits to the Pediatric Allergy Clinic, 40,535 visits to the General Pediatrics Clinic, and 3,182 asthma-related ER visits. The racial/ethnic breakdown of asthma visits at JMC is 51% Latino (of those 48% are Puerto Rican) and 30% Black/African-American.

Data Collection Procedures: To be eligible for the study, children must have met the following criteria: a) The child must be between the ages of 5 and 12, b) had a diagnosis of asthma as obtained from their medical record, c) identified as Latino as described by the child's primary care caregiver, d) had no other significant pulmonary complications or conditions, e) participating parent must have had the majority responsibility for the child's day-to-day asthma management and care, f) no cognitive learning disability that would interfere with the parent or child's ability to participate in the interview process. Computerized data systems within each recruitment site were used to identify patients who fit the specified diagnosis, age, and ethnicity

criteria. Eligible families were recruited through face-to-face invitations during clinic visits, by mailing recruitment letters from the health care provider to potential families, and by making phone calls inviting families to participate. The research nurse/assistant (RNA) at each practice site explained the study and reviewed eligibility criteria with each family before obtaining verbal assent to participate. An appointment was then made for the parent and child to complete the informed consent, child verbal assent, interviews, and spirometry tests. All materials were made available in both English and Spanish.

The RNA conducted a structured interview with the parent that included the Asthma Illness Representation Scale AIRS©, Parent/Health Care Provider Relationship Scale (K. Sidora-Arcoleo, Feldman, Serebrisky, & Spray, 2010; K. J. Sidora-Arcoleo, Feldman, Serebrisky, & Spray, 2010), Parent-Childhood Asthma Symptom Checklist, Asthma Trigger Inventory (Ritz, Steptoe, Bobb, Harris, & Edwards, 2006), and Stephenson Multigroup Acculturation Scale (Stephenson, 2000), as well as information regarding demographics, the child's asthma control, controller medications, and any alternative therapies that are currently being used. Interviewers conducted the interview in either English or Spanish based on parent preference, and each took approximately 60 to 90 minutes. Interviews were completed at enrollment and 3, 6, 9, and 12 months post-enrollment.

Child interviews and spirometry maneuvers were done independently of the parent interviews. Spirometry was done per the guidelines set forth by the American Thoracic Society, and the child should have continued to use his/her prescribed medications prior to any tests. The interview with the child included the Asthma Control Test (Nathan et al., 2004; Liu et al., 2007) to assess the child's reports of symptoms during asthma exacerbations. Interviews were conducted in Spanish or English per child's preference and took approximately 20 to 30 minutes.

The spirometry assessment took place after the interview. These sessions took place at enrollment and 3, 6, 9, and 12 months post-enrollment.

Data Collection Instrument

Ethnicity: Parents were asked to indicate their country of birth. They were also asked to specify which ethnic group they most closely identified with (Mexican, Puerto Rican, Cuban, Dominican, Central American, South American, or other).

Demographic Measures: Perception of poverty is a stronger predictor than actual income of certain psychiatric disorders (Canino et al., 2004) and ataques de nervios (Guarnaccia, Martinez, Ramirez, & Canino, 2005) among Puerto Rican children and has been associated with functional morbidity among African-American and Puerto Rican children, but not Anglo children. (D. Koinis-Mitchell et al., 2006) Using a measure adapted by Gore et al. (Gore, Aseltine, & Colton, 1992), parents were asked "What best describes your family's standard of living?" Response choices ranged from very well off to poor. From the Parent Interview, we obtained the parent's age, educational level, marital status, and employment status. Perception of poverty, educational level, marital status, and employment status are being measured at all follow-up assessments as these variables may change over time. From the child's medical record, we obtained the child's age, gender, date of asthma diagnosis (if known), and type of health insurance.

Asthma Illness Representation: The construct of IR is comprised of the five subscales of the AIRS© and the total score. The five subscales contain items which assess the five components of IR described above under the Theoretical Framework. This instrument is designed to identify barriers and risk factors for under-utilization of controller medications that can be used in research and healthcare settings. The English version of the AIRS© tool was developed and validated among an ethnically diverse sample; primarily white, black, and Puerto Rican. (H. L.

Yoos, Kitzman, & McMullen, 2003; Sidora-Arcoleo et al., 2010) The AIRS© yields five subscales, in addition to an overall score. These subscales are: (1) treatment expectations (8 items, α=.75); (2) attitudes towards medication use (8 items, α=.78); (3) facts regarding asthma (11 items, α=.71); (4) the nature of asthma symptoms (5 items, α=.61); and (5) emotional aspects of medication use (5 items, α=.55). The Cronbach's alpha for the overall scale score was .84. (H. L. Yoos et al., 2007; Sidora-Arcoleo et al., 2010) Each item is scored on a 5-point Likert scale with 1 (strongly agree) to 5 (strongly disagree). When necessary, items within each subscale are reverse scored so that higher values indicate closer alignment with the professional model for asthma management. The subscale and total score are calculated as the mean of the non-missing items. The scale has been translated to Spanish following accepted translation/back-translation methodology and validated among a sample of Mexican and Puerto Rican families by Drs. Sidora-Arcoleo & Feldman. (Sidora-Arcoleo et al, 2010)

Objective Assessment of Asthma Control: Asthma symptom control was assessed through the parent and child interviews and child spirometry assessment per the National Asthma Education and Prevention Program's Expert Panel Reports clinical guidelines. (U.S. Department of Health & Human Services: National Asthma Education Program, 2007) The new clinical guidelines published in 2007 state that an assessment of severity is conducted for children not currently on long term controller medications and that once therapy is initiated, an assessment of control is completed. There are four severity groups (intermittent, mild persistent, moderate persistent, and severe persistent) and three control groups (well-controlled, not well controlled, and very poorly controlled). Dr. Radford (Phoenix) and Dr. Serebrisky (Bronx), both pediatric pulmonologists, assigned the child's severity or control level, as appropriate, based on the parent's and children's responses to structured questions regarding daytime symptoms, nocturnal symptoms, activity

limitations, use of short-acting β2 agonists for the 2-4 week period prior to the interview, and lung function tests conducted during the child's portion of the interview per the 2007 NAEPP Expert Panel Report Guidelines (U.S. Department of Health & Human Services: National Asthma Education Program, 2007).

Subjective Report of Asthma Control: The children completed the Asthma Control Test (ACT) – a short (5-7 items depending on age), validated instrument for assessing asthma control. The original ACT was developed, tested, and validated for use in participants age 12 years and older. (Nathan et al., 2004) This 5-item instrument exhibits good reliability and validity as a short screening tool. The items consist of a subjective assessment of control and frequency estimates of how often asthma keeps the respondent from getting things done, how often the respondent has shortness of breath and nighttime awakenings, and how often the respondent has to use an inhaler or nebulizer. Cronbach's alpha=.84 and the ACT demonstrated a significant correlation with specialists' assessment of control (r=.45, P=.0001). A cut point of 19 showed the highest area under the ROC curve (.73) and overall agreement with the specialists' rating of control was 74.1%. (Nathan et al., 2004) Scores < 19 are indicative of poorly controlled asthma. Recently, a version for children ages 4-11 years (C-ACT) was developed and validated. (Liu et al., 2007) This is a 7-item instrument with 4 items completed by the child (how is your asthma today, do you cough because of asthma, do you wake up at night because of your asthma, and is asthma a problem when you run, exercise, or play sports) and 3 items by the caregiver (frequency in the past 4 weeks of daytime symptoms, wheeze, and nighttime awakenings). Potential scores range from 0-27. Cronbach's alpha=.79 and the C-ACT exhibited moderate to strong correlations with parent and child quality of life measures (r=.47, r=.68, respectively). Cut-point score analyses for the C-ACT yielded similar results to the ACT. A cut point of < 19 indicates poorly controlled

asthma and correctly classifies children 72% of the time. (Lurie, Marsala, Hartley, Bouchon-Meunier, & Dusser, 2007) Because the sample for this study ranged in age from 5-12 years, we administered the age-appropriate version. The ACT has undergone Spanish linguistic translation and validation and has been shown to be a reliable and valid Spanish-language instrument for assessing control. Cronbach's alpha was .84 and the intraclass correlation coefficient was .85. Higher ACT scores were negatively related to exacerbations and positively related to lower symptom intensity and frequency. Sensitivity and specificity were 71.3% and 85.4%, respectively. Consistent with the original version, a score >=19 classifies asthma symptoms as "well-controlled." Scores of 12-18 indicate "not well-controlled" asthma symptoms and scores <12, "very poorly controlled" asthma symptoms. (Vega et al., 2007) A validated Spanish version of the C-ACT is not available. We translated/back-translated this instrument per accepted methodology.

Data Analysis: Eligible participants who declined to participate were compared with those who enrolled on demographic characteristics to check for sample bias. Descriptive statistics were used to identify the distribution of data and total instrument scale scores for each of the study surveys. Means and standard deviations were examined for continuous variables and proportions for categorical variables. Chi-square, t-tests, and linear regression analyses were conducted. *Non-normal Distributions:* Full attention was given to the distributional properties of variables and to regression diagnostics. We make adjustments for outlying data points.

Chapter IV: Research Results

Response Rate of Sample/Population

Enrollment Table (Table 1)

Site	A. Total Enrolled	B. # of Drops	C. Adjusted Total of Enrolled (A-B=C)	D. # of Drops that completed 3+ interviews	E. # of "past due" families that have completed at least 3 interviews
PCH	105	7	98 (148, PCH+SHC)	0	1
SHC	53	3	50	1	2
Jacobi	114	38	76	8	9
Total	*272*	*48*	*224*	*9*	*12*

Site	3-Month	6-Month	9-Month	12-Month (Completed)
PCH	92	86	87	81
SHC	43	37	44	45
Jacobi	57	49	48	49
Total	*192*	*172*	*179*	175

Table 1 presents the enrollment data and follow-up assessments completed as of 3/31/14. Data collection is ongoing and the baseline data were used in this project. The overall attrition rate to date is 17.6%. This is lower than the 20% estimated for the power calculations. When we examined attrition by site, we discovered that the rates were quite low at both Phoenix sites (5.7% at the school-based health clinics and 6.7% at the Breathmobile). The higher than anticipated attrition rate in New York, 33.3% occurred due to four natural disasters which occurred in a 2 year period. There was hurricane Sandy, two blizzards, and a power failure. A number of our families were displaced from their homes when the hurricane hit and ended up moving out of the area.

Representativeness of Sample: The sample recruited from the Bronx was representative of the Bronx population as a whole based on caregiver's age, education level and poverty status. The population in Phoenix, AZ is very diverse socioeconomically and thus, the sample recruited here was not representative of the population regarding education and poverty level. Our families, on average, had lower education levels and more were classified as living in poverty. The average adult age was comparable.

Profile of Sample/Population

Sample Baseline Characteristics Table (Table 2)

Variable	**Mexican (*N*=188)**	**Puerto Rican (*N*=79)**	**Test of Significance**
	N (%)	*N* (%)	*p*-value
Employment Status			
None	114 (60.6)	61 (77.2)	**.01**
Part-time	42 (22.3)	6 (7.6)	
Full-time	32 (17.0)	12 (15.2)	
Married (% Yes)	104 (55.3)	24 (30.4)	**.0002**
Poor (% Yes)	126 (67.0)	25 (31.7)	**<.0001**
High School Graduate (% Yes)	85 (45.5)	48 (60.8)	**.02**
Caregiver Sex (% Female)	180 (95.7)	74 (93.7)	NS
Child Sex (% Female)	62 (33.0)	32 (40.5)	NS
Severity Accuracy-Child			
Under-perception	110 (59.5)	51 (68.0)	NS
Accurate	44 (23.8)	14 (18.7)	
Magnification	31 (16.7)	10 (13.3)	
Severity Accuracy-Parent			
Under-perception	103 (55.4)	46 (61.3)	NS
Accurate	47 (25.3)	15 (20.0)	
Magnification	36 (19.4)	36 (18.7)	
Ever Used CAM (% Yes)	133 (70.7)	65 (82.3)	**.05**
Currently Using CAM (% Yes)	102 (54.3)	56 (70.9)	**.01**
Use OTC Medications for Asthma (% Yes)	59 (31.4)	19 (24.1)	NS
Clinical Depression-Parent (% Yes)	45 (23.9)	34 (43.0)	**.002**
ACT Control-Child (% Inadequate)	82 (43.6)	67 (84.8)	**<.0001**
ACT Control-Parent (% Inadequate)	177 (94.2)	64 (81.0)	**.001**

Clinician Rated Control Well-controlled Not well-controlled Poorly controlled	 102 (57.0) 64 (35.8) 13 (7.3)	 25 (36.2) 35 (50.7) 9 (13.0)	**.01**
Clinician Rated Severity Mild Intermittent Mild Persistent Moderate Persistent Severe Persistent	 32 (7.2) 63 (33.9) 74 (39.8) 17 (9.1)	 11 (14.7) 16 (21.3) 31 (41.3) 17 (22.7)	**.01**
Controller Medication: Past year (% Yes)	140 (74.5)	67 (84.8)	NS
Controller Medication: Past month (% Yes)	130 (69.2)	62 (78.5)	NS
Controller Medication: Past 24 hours (% Yes)	108 (57.5)	50 (63.3)	NS
Any ED Visits: Past Year (% Yes)	58 (30.9)	57 (72.2)	**<.0001**
Any hospitalizations: Past Year (% Yes)	21 (11.2)	20 (25.3)	**.003**
Frequency of missed school None 1-2 times/yr 3-4 times/yr 5-6 times/yr ≥7 times/yr	 61 (32.5) 54 (28.7) 34 (18.1) 11 (5.9) 28 (14.9)	 17 (21.5) 16 (20.3) 15 (19.0) 8 (10.1) 23 (29.1)	**.03**
	Mean (SD)	**Mean (SD)**	**p-value**
# Family Members w/Asthma	1.24 (.73)	0.91 (1.09)	**.02**
Asthma Duration (Months)	67.94 (39.54)	88.46 (31.77)	**<.0001**
Caregiver's Age	35.47 (6.31)	38.42 (10.47)	**.02**
Study Child's Age (Years)	9.67 (2.15)	9.23 (2.23)	NS
# Years Caregiver Lived in US	14.05 (7.75)	33.88 (13.00)	**<.0001**
# Years Study Child Lived in US	8.39 (2.27)	8.23 (2.78)	NS
ACT Score: Parent	28.72 (5.62)	25.38 (6.56)	**<.0001**
ACT Score: Child	19.91 (3.82)	16.46 (3.92)	**<.0001**
Social Network Score	3.19 (.47)	2.95 (.54)	**.0004**
Social Network: Family	3.23 (.54)	2.89 (.70)	**.0001**
Social Network: Friends	3.14 (.55)	3.01 (.61)	NS
AIRS: Nature of Asthma Symptoms	2.74 (.66)	2.72 (.63)	NS
AIRS: Facts About Asthma	3.56 (.41)	3.58 (.34)	NS
AIRS: Attitudes re Medication Use	2.66 (.62)	2.73 (.56)	NS
AIRS: Treatment Expectations	3.07 (.59)	2.75 (.45)	**<.0001**
AIRS: Emotional Aspects re Medication Use	2.98 (.79)	2.86 (.71)	NS
AIRS: Total Score	3.10 (.36)	3.03 (.30)	NS
Parent-Provider Relationship	3.72 (.54)	3.78 (.55)	NS

Parental Depression (CES-D)	10.95 (10.15)	16.03 (12.03)	**.002**
Asthma Symptom Checklist (P-CASCL): General	5.98 (17.30)	58.42 (13.81)	NS
Asthma Symptom Checklist (P-CASCL): Panic-Fear	30.89 (11.88)	30.58 (12.24)	NS
Asthma Symptom Checklist (P-CASCL): Irritability/Hyperventilation	19.92 (8.10)	21.42 (8.00)	NS
# ED Visits: Past Year	0.30 (.65)	0.73 (.86)	**<.0001**
# Hospitalizations: Past Year	0.07 (.25)	0.25 (.54)	**.005**
Acculturation: Ethnic Society Immersion	3.23 (.35)	3.22 (.41)	NS
Acculturation: Dominant Society Immersion	2.98 (.39)	3.40 (.44)	**<.0001**
Asthma Trigger Inventory: Infection	1.82 (.95)	1.75 (1.00)	NS
Asthma Trigger Inventory: Irritants	1.14 (.99)	1.28 (.94)	NS
Asthma Trigger Inventory: Exercise	1.20 (.89)	1.05 (.80)	NS
Asthma Trigger Inventory: Psychological	0.48 (.63)	0.40 (.57)	NS
Asthma Trigger Inventory: Pollen	1.75 (1.22)	1.73 (1.16)	NS
Asthma Trigger Inventory: Animals	0.91 (1.04)	1.30 (1.10)	**.006**
Asthma Trigger Inventory: All Allergens	1.36 (1.01)	1.56 (1.00)	NS

Baseline data were collected from a greater number of Mexicans than Puerto Ricans. Significantly more Puerto Ricans were older, unemployed, had a high school degree, lived in the U.S. longer and demonstrated greater dominant society immersion, had more family members with asthma, reported more animal asthma triggers for their child, and reported higher rates of complementary and alternative medicine use and depression. Puerto Rican children had longer asthma duration, greater rates of ED visits and hospitalizations, missed school days, and poorly controlled asthma as rated by the clinician and children themselves. Significantly more Mexicans were married, poor, had greater social networks, higher ACT scores (indicating better asthma control) for parents and children, and higher scores on the Treatment Expectation subscale of the AIRS.

Reliability of Instrument The AIRS Cronbach's alphas were .55 Nature of Asthma, .64 Facts about Asthma, .73 Attitudes towards Medication Use, .57 Treatment Expectations, .67 Emotional Aspects of Medication Use, and .77 for the total score. The Parent Provider Relationship Cronbach's alpha = .74

Summary of Findings

The chi-square test for Parent Perception of Control by Sex shows no statistically significant differences (Table 3). Although the majority of the participating parents were females, the percentage of parents reporting well-controlled and not well-controlled for both sexes was approximately the same.

Parent Perception of Control By Sex (Table 3)

	Parent Perception of Control			
		Not Well-Controlled	Well-controlled	Total
Caregiver's Sex	Male Row Percent Column Percent	3 23.1% 5.3%	10 76.9% 4.8%	13 100% 4.9%
	Female Row Percent Column Percent	54 21.3% 94.7%	200 78.7% 95.2%	254 100% 95.1%
	Total Row Percent Column Percent	57 21.3% 100%	210 78.7% 100%	267

$X^2 = 0.02$, p = 0.88

There were no statistically significant differences for Parent Perception of Control by Education Level (Table 4). The number of parents with a high school degree versus without a high school degree is equal. Eighty-one percent of the parents without a high school degree rated their child's asthma as well-controlled compared to 76% of the high school graduates.

Parent Perception of Control By Education Level (Table 4)

		Parent Perception of Control		
		Not Well-Controlled	Well-controlled	Total
Parent Education Level	No High School Degree Row Percent Column Percent	25 18.8% 43.9%	108 81.2% 51.7%	133 100% 50%
	High School Degree Row Percent Column Percent	32 24.1% 56.1%	101 75.9% 48.3%	133 100% 50%
	Total Row Percent Column Percent	57 21.4% 100%	209 78.6% 100%	266

$X^2 = 1.09$, $p = 0.3$

Child's Perception of Control By Ethnicity (Table 5)

		Child's Perception of Control		
		Not Well-Controlled	Well-controlled	Total
Child's Ethnicity	Mexican Row Percent Column Percent	166 88.8% 69.5%	21 11.2% 77.8%	187 100% 70.3%
	Puerto Rican Row Percent Column Percent	73 92.4% 30.5%	6 7.6% 22.2%	79 100% 29.7%
	Total Row Percent Column Percent	239 89.8% 100%	27 10.2% 100%	266

$X^2 = 0.8$, $p = 0.37$

The chi-square test for Child's Perception of Control by Ethnicity shows no statistically significant differences (Table 5). The overwhelming majority of the children in both ethnic groups reported that they are not well-controlled.

The t-tests for child and parent perception of control by age (Tables 6 and 7) show statistically significant differences for the children but not for parents. Older children reported their asthma as well-controlled significantly more than younger children. The mean age of parents reporting well-controlled or not well-controlled is about the same.

Child's Perception of Control By Age (Table 6)

	Not Well-Controlled (N = 239)	**Well-Controlled (N = 27)**	**p-Value**	**t-Value**	**DF**
Age of Child	9.2 (2.04)	12.5 (0.42)	$p < .05$	-21.17	194.6

Parent's Perception of Control By Age (Table 7)

	Not Well-Controlled (N = 57)	**Well-Controlled (N = 210)**	**p-Value**	**t-Value**	**DF**
Age of Parent	36.8 (7.4)	36.2 (8.0)	0.63	0.49	94.89

Child's Perception of Control Versus Clinician Control Rating (Table 8)

	Child's Perception of Control			
Clinician Control Rating		Not Well-Controlled	Well-controlled	Total
	Not Well-Controlled Row Percent Column Percent	108 89.3% 48.9%	13 10.7% 50%	121 100% 49%
	Well-Controlled Row Percent Column Percent	113 89.7% 51.1%	13 10.3% 50%	126 100% 51%
	Total Row Percent Column Percent	221 89.5% 100%	26 10.5% 100%	247

$X^2 = 0.012$, $p = 0.91$

The chi-square test for Child's Perception of Control versus Clinician Control Rating (Table 8) revealed no statistically significant differences. Forty-nine percent of the time the child and clinician agreed about the child's level of control. Children tended to over-estimate their lack of control. Forty-six percent viewed themselves as not well-controlled when the clinician rated their asthma as well-controlled. Only 5% of the children reported their asthma as well-controlled when the clinician rate them as not well-controlled.

The chi-square test shows that there is a statistical significance between the perception of control of parents and the clinician control rating (Table 9). Most parents are in agreement with clinicians regarding level of asthma control (63%) but there is also a significant portion of parents that perceive their child as well-controlled when the clinician is saying that they are not well-controlled (32%).

Parent's Perception of Control Versus Clinician Control Rating (Table 9)

	Parent's Perception of Control			
		Not Well-Controlled	Well-controlled	Total
Clinician Control Rating	Not Well-Controlled Row Percent Column Percent	41 33.9% 77.4%	80 66.1% 41%	121 100% 48.8%
	Well-Controlled Row Percent Column Percent	12 9.5% 22.6%	115 90.6% 59%	127 100% 51.2%
	Total Row Percent Column Percent	53 21.4% 100%	195 78.6% 100%	248

$X^2 = 22.02$, $p < .05$

Table 10 illustrates that although not statistically significant, parents and children only agreed 29% of the time about the child's level of control. The large majority of children are reporting that they are not well-controlled while parents are reporting well-controlled asthma (70%).

Parent Perception of Control Versus Child's Perception of Control (Table 10)

	Parent Perception of Control			
		Not Well-Controlled	Well-controlled	Total
Child's Perception of Control	Not Well-controlled Row Percent Column Percent	54 22.6% 94.7%	185 77.4% 88.5%	239 100% 89.8%
	Well-controlled Row Percent Column Percent	3 11.1% 5.3%	24 88.9% 11.5%	27 100% 10.2%
	Total Row Percent Column Percent	57 21.4% 100%	209 78.6% 100%	266

$X^2 = 1.9$, p = 0.17

The regression model accounted for 14.3% of the variance in asthma control (Table 11). Ethnic group ($p < .05$, F = 5.43), parent perception of control ($p < .05$, F = 19.18), and age of the child ($p < .05$, F = 4.81) showed the most statistically significant data. Older children were more likely to report being well-controlled. By clinician rating, 56.5% of Mexicans are under good control, and 38.3% of Puerto Ricans are under good control. In this analysis, asthma illness representations did not mediate the relationship between parental perception of control and clinician-rated control.

Regression Model (Table 11)

Predictors	R-Square	β	F Value	p value
Model Fit	0.14		4.41	<.0001
Ethnic Group		1.21	5.43	0.02
AIRS: Total Score		0.38	1.70	0.19
Parent Perception of Control		4.28	19.18	< .0001
High School Graduate		0.027	0.12	0.73
Parent-Provider Relationship		0.00036	0.00	0.97
Child's Age		1.07	4.81	0.03
# Family Members with Asthma		0.045	0.20	0.65
Asthma Duration (Months)		0.075	0.34	0.56
Poor		0.18	0.82	0.37

Chapter V: Conclusions and Recommendations

Conclusions: Significant discrepancies exist between parent and children's subjective perception of control and clinician's objective assessment. Evidence demonstrates that children, particularly younger children, are poor perceivers of asthma symptoms who frequently over-estimate the severity of their symptoms and under-estimate their level of control when compared with the healthcare provider's objective assessment. Although not the majority, a large

proportion of parents have also shown to be poor perceivers of their child's asthma symptoms; however, they are more likely to under-estimate the severity of their child's asthma symptoms and over-estimate their level of control compared to the healthcare provider's objective assessment. There is a clear disconnect between the child's perception of his or her own symptoms and the parent's perception of his or her child's symptoms. The overwhelming majority of parents and children are incongruent in their perception of asthma symptoms with most children over-perceiving their symptoms and most parents under-perceiving their child's symptoms. The sex, education level, and age of the parents had no effect on their perceptual accuracy. Age and ethnicity of the child, however, played significant roles in their perceptual accuracy with older children being more accurate perceivers and Mexican children being more well-controlled by clinician rating.

Limitations*:* Because this study was a secondary analysis, it was limited to data that had already been previously collected. Additional variables that may have impacted this study but were not measured are objective data for medication adherence collected at baseline, measure of self-efficacy, and measure of barriers to asthma management. Measurement of these variables may have provided more insight as to why we are seeing such discrepancies in perception of symptoms between parents, children, and clinicians, and also why certain socio-demographic qualities make a person more likely to be well-controlled. In addition, measurement of socioeconomic status was based on the parent's subjective rating of living well off, living very comfortable, living reasonably comfortably, just getting along, nearly poor, or poor. To have a more accurate measure of this variable, response options could have listed ranges of annual income and asked the parents to choose which range they fit into.

Implications of Study*:* We have demonstrated that significant discrepancies exist between parent and children's subjective perception of control and clinician's objective assessment. As a result, it is imperative that healthcare providers, parents, and children develop a more unified understanding of asthma illness beliefs and treatment regimens. Healthcare providers, regardless of their practice setting, can best treat children with asthma if they understand what beliefs parents hold about their child's asthma and the factors that influence this. If parents' beliefs are discordant with the healthcare providers' beliefs and are not addressed when devising the management plan, there is increased risk for non-adherence. If parents feel that they are part of the decision-making process regarding treatment of their children's asthma, they may be more likely to adhere to the prescribed medication regimen thereby reducing exacerbations of asthma symptoms, ED visits, hospitalizations, and fatal asthma attacks. Healthcare providers have an opportunity to intervene at the individual level to effect changes aimed at improving adherence to the prescribed treatment regimen through improved communication, education (both parents and themselves), and partnership with the families.

Recommendations Interventions that heighten parents' and children's awareness of asthma symptoms and address cultural beliefs and practices and potential barriers are likely to increase adherence with asthma self-management plans. In addition, interventions that enhance parent-child-provider communication and care coordination will lead to improved self-management. It is important that healthcare providers not only provide information about asthma and self-management strategies but also engage parents and children in discussions about asthma illness beliefs, ethno-cultural practices, and social, cultural, environmental or healthcare system barriers that prevent the child from achieving optimal management. Beliefs, practices, and barriers are frequently overlooked during the asthma visit but are critical factors in children's

medication adherence. (K. Sidora-Arcoleo, 2006; K. Sidora-Arcoleo, Yoos, McMullen, & & Kitzman, 2007; K. Sidora-Arcoleo, Yoos, Kitzman, McMullen, & Anson, 2008; H. L. Yoos, Kitzman, McMullen, Sidora-Arcoleo, & Anson, 2005) Interventions which elicit this information can serve to enlighten the healthcare provider about these factors, lead to a respectful, sensitive discussion and thus, a shared plan for optimal outcomes. When parents and children feel that they are a part of the decision-making process they may be more likely to adhere to the management plan. (D. Drotar & Bonner, 2009; D. Drotar, Crawford, & Bonner, 2010; Fiks, Localio, Alessandrini, Asch, & Guevara, 2010; Lipstein, Brinkman, & Britto, 2012; Wilson et al., 2010) This may lead to short screening questionnaires being used in health care provider offices to give them better insight into their patients. As a result, educational tools and interventions can be tailored to meet the specific needs of the child and the family. Younger children may enjoy the use of a game, while older children may appreciate the use of modern technology in their education. To adequately affect sustained behavior change, however, asthma self-management education must be integrated into and coordinated across all points of care (clinic, hospital, school, pharmacy and home).

Appendices:

List of Figures & Tables:

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The Latino Childhood Asthma Project

(05/13/10)

CHILD INTERVIEW

SESSION: *circle one* **Baseline** **3-Month** **6-Month** **9-Month** **12-Month**

STUDY ID#: _____

INTERVIEWER: _____

TODAY'S DATE: MONTH: ☐☐ DAY: ☐☐ YEAR: ☐☐

PARENT/GUARDIAN'S INITIALS: ☐☐

CHILD'S INITIALS: ☐☐

OFFICE USE ONLY:

PI CODED/CHECKED: _____

CODED/CHECKED: _____

RECEIVED: _____

ENTERED: _____

VERIFIED: _____

SECTION I. CHILD SYMPTOM INTERPRETATION

CS1. Thinking about the last 3 months: (Give an anchor - e.g. "since Christmas") please mark an "X" on the line below indicating how severe you think your asthma symptoms are.

No Symptoms — **Very Bad Symptoms**

0 — 100

CS2. Over the past 3 months, if you had to label your asthma, would you call it…

Mild symptoms once in a while..... 1
Mild symptoms frequently..... 2
Moderate asthma..... 3
Severe asthma 4

Children's Asthma Symptom Checklist (C-ASCL)

DIRECTIONS: Rate how often each of the following symptoms occurs during your asthma attacks. There may be other times when you have had each of these symptoms. However, please tell us how often you have each symptom ONLY when you are having your asthma attacks. [HAVE CHILD TURN TO RB2]

		Never	Hardly at all	Some of the time	Most of the time	Always	Refused	Don't Know	N/A
CA1.	Cramps	1	2	3	4	5	97	98	99
CA2.	Panting, Fast Breathing	1	2	3	4	5	97	98	99
CA3.	Numb, No Feeling	1	2	3	4	5	97	98	99
CA4.	Sticky, Mucous in Lungs	1	2	3	4	5	97	98	99
CA5.	Cranky	1	2	3	4	5	97	98	99
CA6.	Get Angry Easily	1	2	3	4	5	97	98	99
CA7.	Hard to Breathe	1	2	3	4	5	97	98	99

		Never	Hardly at all	Some of the time	Most of the time	Always	Refused	Don't Know	N/A
CA8.	Headache	1	2	3	4	5	97	98	99
CA9.	Nervous, Jittery	1	2	3	4	5	97	98	99
CA10.	Frightened	1	2	3	4	5	97	98	99
CA11.	Uncomfortable	1	2	3	4	5	97	98	99
CA12.	Short of Breath	1	2	3	4	5	97	98	99
CA13.	Heavy Feeling in Chest	1	2	3	4	5	97	98	99
CA14.	Afraid of Being Alone	1	2	3	4	5	97	98	99
CA15.	Afraid of Dying	1	2	3	4	5	97	98	99
CA16.	Unhappy with Things	1	2	3	4	5	97	98	99
CA17.	Heart Pounding	1	2	3	4	5	97	98	99
CA18.	Dizzy	1	2	3	4	5	97	98	99
CA19.	Worn Out	1	2	3	4	5	97	98	99
CA20.	Panicky	1	2	3	4	5	97	98	99
CA21.	Weak	1	2	3	4	5	97	98	99
CA22.	Pins and Needles	1	2	3	4	5	97	98	99
CA23.	Hard and Fast Breathing	1	2	3	4	5	97	98	99
CA24.	Don't Care about Things	1	2	3	4	5	97	98	99
CA25.	Feel Like You're Alone	1	2	3	4	5	97	98	99
CA26.	Wheezy	1	2	3	4	5	97	98	99
CA27.	Worried about the Attack	1	2	3	4	5	97	98	99
CA28.	Tingly in Spots	1	2	3	4	5	97	98	99
CA29.	Very Angry, Mad	1	2	3	4	5	97	98	99
CA30.	Chest Tightening	1	2	3	4	5	97	98	99
CA31.	Tired	1	2	3	4	5	97	98	99

		Never	Hardly at all	Some of the time	Most of the time	Always	Refused	Don't Know	N/A
CA32.	Scared	1	2	3	4	5	97	98	99
CA33.	Feel Helpless	1	2	3	4	5	97	98	99
CA34.	Chest filling up	1	2	3	4	5	97	98	99
CA35.	Lonely	1	2	3	4	5	97	98	99
CA36.	Worried	1	2	3	4	5	97	98	99
CA37.	Chest Pain	1	2	3	4	5	97	98	99
CA38.	Rundown, Weak	1	2	3	4	5	97	98	99
CA39.	Mad at the World	1	2	3	4	5	97	98	99
CA40.	Coughing	1	2	3	4	5	97	98	99
CA41.	No Energy	1	2	3	4	5	97	98	99
CA42.	Unhappy	1	2	3	4	5	97	98	99
CA43.	Worried about yourself	1	2	3	4	5	97	98	99
CA44.	Worried about Asthma	1	2	3	4	5	97	98	99
CA45.	Worried in General	1	2	3	4	5	97	98	99
CA46.	Feel Left Out	1	2	3	4	5	97	98	99
CA47.	Breathe Quickly	1	2	3	4	5	97	98	99

CACT 1 – CACT 4 (Use for children 11 or younger)

Childhood Asthma Control Test for children 4 to 11 years.

This test will provide a score that may help the doctor determine if your child's asthma treatment plan is working or if it might be time for a change.

How to take the Childhood Asthma Control Test

Step 1 Let your child respond to **the first four questions (1 to 4)**. If your child needs help reading or understanding the question, you may help, but let your child select the response. Complete the remaining **three questions (5 to 7)** on your own and without letting your child's response influence your answers. There are no right or wrong answers.

Step 2 Write the number of each answer in the score box provided.

Step 3 Add up each score box for the total.

Step 4 Take the test to the doctor to talk about your child's total score.

19 or less If your child's score is 19 or less, it may be a sign that your child's asthma is not controlled as well as it could be. Bring this test to the doctor to talk about the results.

Have your child complete these questions.

[HAVE CHILD TURN TO RB3]

1. How is your asthma today?

0 Very bad	1 Bad	2 Good	3 Very good	SCORE

2. How much of a problem is your asthma when you run, exercise or play sports?

0 It's a big problem, I can't do what I want to do.	1 It's a problem and I don't like it.	2 It's a little problem but it's okay.	3 It's not a problem.	

3. Do you cough because of your asthma?

0 Yes, all of the time.	1 Yes, most of the time.	2 Yes, some of the time.	3 No, none of the time.	

4. Do you wake up during the night because of your asthma?

0 Yes, all of the time.	1 Yes, most of the time.	2 Yes, some of the time.	3 No, none of the time.	

ACT 1 – ACT 5 (Use for children that are 12)

FOR PATIENTS:

Take the Asthma Control Test™ (ACT) for people 12 yrs and older.

Know your score. Share your results with your doctor.

Step 1 Write the number of each answer in the score box provided.

Step 2 Add the score boxes for your total.

Step 3 Take the test to the doctor to talk about your score.

1. In the past **4 weeks**, how much of the time did your **asthma** keep you from getting as much done at work, school or at home?

All of the time	Most of the time	Some of the time		None of the time	SCORE
1	2	3	4	5	

2. During the past **4 weeks**, how often have you had shortness of breath?

More than once a day	Once a day	3 to 6 times a week		Not at all	
1	2	3	4	5	

3. During the past **4 weeks**, how often did your **asthma** symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?

4 or more nights a week	2 or 3 nights a week	Once a week		Not at all	
1	2	3	4	5	

4. During the past **4 weeks**, how often have you used your rescue inhaler or nebulizer medication (such as albuterol)?

3 or more times per day	1 or 2 times per day	2 or 3 times per week		Not at all	
1	2	3	4	5	

5. How would you rate your **asthma** control during the **past 4 weeks**?

Not controlled at all	Poorly controlled	Somewhat controlled		Completely controlled	
1	2	3	4	5	

TOTAL

If your score is 19 or less, your asthma may not be controlled as well as it could be. Talk to your doctor.

FOR PHYSICIANS:

The ACT is:

- A simple, 5-question tool that is self-administered by the patient
- Clinically validated by specialist assessment and spirometry[1]
- Recognized by the National Institutes of Health

Reference: 1. Nathan RA et al. *J Allergy Clin Immunol.* 2004;113:59-65.

SECTION DM. DEMOGRAPHICS

CDM1. Now I would like to ask you about your ethnic background. Which of these groups would you say describes your ethnic background?

Mexican 1
Puerto Rican... 2
Cuban. 3
Dominican..... 4
Hispanic 5
Central American..... 6
South American 7
OTHER (specify)..... 8

CESSAY:
THANK YOU FOR PARTICIPATING IN THIS INTERVIEW!

IS THERE ANYTHING YOU WOULD LIKE TO TELL US ABOUT YOUR EXPERIENCE WITH ASTHMA THAT WE DID NOT COVER IN THIS INTERVIEW?

COMMENTS:

EV: INTERVIEWER EVALUATION

Answer these questions about the child after you complete the questionnaire.

CEV1. During the interview, was the child generally...

Very interested.....1
Somewhat interested.....2
Indifferent.....3
Somewhat bored.....4
Very bored.....5

CEV2. How attentive was child during the interview?

Attentive, involved, responsive.....1
Somewhat inattentive or uninvolved.....2
Easily distracted, needed urging to pay attention.....3

CEV3. In general, how quickly did child respond to questions?

Responded quickly, without hesitation.....1
Deliberated some, but responses were
generally not too slow.....2
Was often slow to respond.....3
Was usually very slow to respond, needed much
urging.....4

CEV4. Which questions, if any, did child have difficulty understanding?

_____

_____

_____

CEV5. How truthful did child seem?

Completely truthful.....1
Mainly truthful.....2
About half and half.....3
Mainly untruthful, evasive.....4

CEV6. At the end of the interview, did child seem to be...

Very tired.....1
Fairly tired.....2
A little tired.....3
Not tired at all.....4

CEV7. At any time during the interview, was there anyone present and able to overhear the interview?

YES.....1
NO.....2

CEV8. What else is there about the interview that will help in interpreting the data?

_____

_____

_____

The Latino Childhood Asthma Project

(01/29/10)

CAREGIVER INTERVIEW

Baseline

STUDY ID#: _____

INTERVIEWER: _____

TODAY'S DATE: MONTH: ☐☐ DAY: ☐☐ YEAR: ☐☐

CAREGIVER'S INITIALS: ☐☐

CHILD'S INITIALS: ☐☐

OFFICE USE ONLY:

PI CODED/CHECKED: _____

CODED/CHECKED: _____

RECEIVED: _____

ENTERED: _____

VERIFIED: _____

Opening comments:

I am going to ask you a number of questions. We ask all of the families the same questions and therefore some might not really apply to your family, but we need to ask them anyway so that all the families get the same interview.

Some of the questions are directly related to (STUDY CHILD) and his or her activity and behaviors as related to his/her asthma. Others help us describe the general household environment.

Remember everything you tell us is held in strict confidence. The only exceptions are behaviors that pose a direct risk to you or (STUDY CHILD'S) safety. Your name is not on any of our data gathering forms. You will be identified by a 4-digit identification number.

Do you have any questions for me?

Let's begin.

SECTION I: PARENTAL ILLNESS REPRESENTATION

Thank you for agreeing to participate in this interview. We are interested in learning about what it's like for parents/caregivers to have a child with asthma and how they feel about asthma treatment. People have different ideas about managing asthma. We are interested in what you think. You will be able to help us most by just answering honestly about your point of view and opinions. We will ask you to give us your opinion about a number of asthma-related statements. The responses go from STRONGLY AGREE to STRONGLY DISAGREE.

[HAND R RESPONSE BOOKLET AND ASK THEM TO TURN TO RB1]
[READ TO R] When I read you a statement, you can just tell me the number of the choice that best gives me your opinion.

Nature of the Disease/Nature of Symptoms

In this section, we would like your perspective on what asthma is like.

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
PI1.1	A child is free of asthma when he/she does not have symptoms	1	2	3	4	5
PI1.2	Asthma symptoms are unpredictable	1	2	3	4	5
PI1.3	Asthma symptoms come on suddenly	1	2	3	4	5
PI1.4	Asthma cannot be controlled	1	2	3	4	5
PI1.5	It's hard to figure out how bad an asthma attack is	1	2	3	4	5
PI1.6	Asthma cannot be cured **(R)**	1	2	3	4	5
PI1.7	It's more important for children with asthma to be medication-free than to be symptom-free	1	2	3	4	5
PI1.8	I have a lot of stressors related to taking care of my child's asthma right now	1	2	3	4	5
PI1.9	There is little I can do to control my child's symptoms	1	2	3	4	5

Now we would like to understand your perspective on what causes or makes asthma worse for children.

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
PI2.1	Airway inflammation causes asthma symptoms **(R)**	1	2	3	4	5
PI2.2	Tobacco smoke can make an asthma episode worse **(R)**	1	2	3	4	5
PI2.3	Exposure to allergens can make an asthma episode worse **(R)**	1	2	3	4	5

PI2.4	Children are more likely to outgrow asthma if they only take medication when they are in real trouble with their asthma.	1	2	3	4	5
PI2.5	Asthma is caused by weak lungs.	1	2	3	4	5
PI2.6	Asthma is caused by exposure to drafts/wind.	1	2	3	4	5
PI2.7	An untreated cold or flu can cause asthma	1	2	3	4	5
PI2.8	Asthma can be inherited **(R)**	1	2	3	4	5
PI2.9	Asthma is an emotional or psychological illness	1	2	3	4	5

In this section of the interview, we would like to get your opinion on asthma medicines and their use. We will be talking about 2 kinds of asthma medications. The first kind are called "quick relief" medicines. They are for use when the child has asthma symptoms to relieve those symptoms. They have names like Proventil, Albuterol or Ventolin. The second kind are those medicines that get persistent asthma under control and keep it under control. They are taken every day whether the child has symptoms or not. Sometimes these medicines are called "maintenance medicines", or "anti-inflammatories", or "inhaled steroids". They have names like Flovent, Aerobid, Vanceril, Pulmicort, and Singulair. We realize that (STUDY CHILD'S) asthma may not be severe enough for him/her to be on these medications. We would nevertheless like your opinion of them.

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
PI3.1	Inhaled/oral steroids work by fighting inflammation in the lungs **(R)**	1	2	3	4	5
PI3.2	Inhaled/oral steroids open up airways when they are constricted and tight	1	2	3	4	5
PI3.3	Inhaled/oral steroids work by fighting infection	1	2	3	4	5
PI3.4	Treating a child's asthma with medication now may prevent complications when he/she is older **(R)**	1	2	3	4	5
PI3.5	Using inhaled/oral steroids should be a last resort in treating asthma	1	2	3	4	5
PI3.6	Parents should try to get their children off inhaled/oral steroids as soon as possible	1	2	3	4	5
PI3.7	After a child has taken inhaled/oral steroids for a while, they won't work when they are really needed	1	2	3	4	5
PI3.8	Children with asthma are taking too many inhaled/oral steroids	1	2	3	4	5
PI3.9	Doctors are likely to over-prescribe inhaled/oral steroids.	1	2	3	4	5
PI3.10	Daily inhaled/oral steroids can make children behave differently	1	2	3	4	5
PI3.11	Taking daily medication makes a child feel different from other children	1	2	3	4	5
PI3.12	Albuterol opens airways when they are constricted and tight **(R)**	1	2	3	4	5

PI3.13	If Albuterol controls asthma symptoms then anti-inflammatory medications are not necessary	1	2	3	4	5
PI3.14	I worry about the side effects of inhaled/oral steroids	1	2	3	4	5
PI3.15	I'm worried that my child could become addicted to inhaled/oral steroids.	1	2	3	4	5
PI3.16	My child is reluctant to use an inhaler in front of other children	1	2	3	4	5
PI3.17	Most children with asthma would prefer taking an oral medication to an inhaled medication	1	2	3	4	5
PI3.18	My child thinks that taking daily medicine is a hassle	1	2	3	4	5
PI3.19	My child does not like the taste of inhaled steroids	1	2	3	4	5

These statements reflect what kind of asthma control you believe you can <u>realistically</u> expect for <u>your</u> child with asthma.

		Strongly Agree	**Agree**	**Not Sure**	**Disagree**	**Strongly Disagree**
PI4.1	I believe that my child can be symptom-free most of the time **(R)**	1	2	3	4	5
PI4.2	I expect that asthma will not affect my child's school attendance **(R)**	1	2	3	4	5
PI4.3	I expect that my child <u>will</u> have sleep disruption due to asthma	1	2	3	4	5
PI4.4	I expect that my child can fully participate in gym and normal physical activity **(R)**	1	2	3	4	5
PI4.5	Children with asthma can expect to have symptoms several times a week	1	2	3	4	5
PI4.6	I expect that my child will have no emergency room visits or hospitalizations due to asthma **(R)**	1	2	3	4	5
PI4.7	Asthma makes children more likely to have emotional problems	1	2	3	4	5
PI4.8	I worry that something terrible will happen to my child if I'm not there	1	2	3	4	5

SECTION II: PARENT / HEALTH CARE PROVIDER INTERACTION

We are interested in how you work out the management of your child's asthma with the health care provider. We would like your opinion on what is helpful and not helpful with this interaction. Remember, all information you give us is confidential. [R CAN CONTINUE TO USE RB1]

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
PCP1.1	I am sometimes reluctant to discuss my worries about asthma medicines with my child's health care provider	1	2	3	4	5
PCP1.2	My child's health care provider is clear about what medicines my child needs to control his/her asthma **(R)**	1	2	3	4	5
PCP1.3	My child has a written Action Plan for what asthma medicines to use and when to use them	1	2	3	4	5
PCP1.4	When I call the doctor's office, they understand my concerns **(R)**	1	2	3	4	5
PCP1.5	I worry about "bothering" the doctor when I have questions or worries	1	2	3	4	5
PCP1.6	I see a different health care provider every time I go to the office **(R)**	1	2	3	4	5
PCP1.7	The doctor(s) who treat my child for asthma may understand asthma in general, but they don't understand how asthma affects my child	1	2	3	4	5
PCP1.8	My child's health care provider understands how asthma affects my child's day-to-day life **(R)**	1	2	3	4	5
PCP1.9	My child's health care provider understands how my child's asthma affects our family's day-to-day life **(R)**	1	2	3	4	5
PCP1.10	I'm involved as much as I want to be in making decisions about when to give what medications **(R)**	1	2	3	4	5
PCP1.11	My health care provider's office hours are not convenient for me.	1	2	3	4	5

SECTION III: ASSESSMENT OF ASTHMA SEVERITY

I'd like to ask you some questions about your child's asthma.

AM1. At what age did your child's asthma begin?

☐☐
MONTHS OF AGE

AM2. Please tell me how much you agree with the following statement. My child's asthma is under good control.

Strongly Agree..... 1
Agree.. 2
Not Sure..... 3
Disagree 4
Strongly Disagree 5

AM3. **Thinking about the last 3 months: (Give an anchor - i.e. "since Christmas") please mark an "X" on the line below indicating how severe you think your child's asthma symptoms are.**

No Symptoms **Very Bad Symptoms**
0 100

AM4. Over the past 3 months, if you had to label your child's asthma, would you call it…

Mild symptoms once in a while..... 1
Mild symptoms frequently..... 2
Moderate asthma..... 3
Severe asthma 4

AM5. Thinking about the past three months, is your child's asthma……

Better than usual 1
About the same as usual 2
Worse than usual..... 3

AM6. Has your child had an asthma-related visit with a health care provider in the past year?

YES.... 1
NO..... ....2 **[GO TO AM9]**

AM7. Which health care provider did you take him/her to?	AM8. When was this visit?
a.	|__|__| MON/YR
b.	|__|__| MON/YR
c.	|__|__| MON/YR
d.	|__|__| MON/YR
e.	|__|__| MON/YR
f.	|__|__| MON/YR

AM9. Has your child had an asthma-related visit to an Emergency Department in the past year?

YES.... 1
NO..... ....2 **[GO TO AM12]**

AM10. Which ED did you take him/her to?	AM11. When was this visit?
a.	|__|__| MON/YR
b.	|__|__| MON/YR
c.	|__|__| MON/YR
d.	|__|__| MON/YR
e.	|__|__| MON/YR

AM12. Has your child had an asthma-related hospitalization in the past year?

YES.... 1
NO..... ....2 **[NEXT SECTION]**

AM13. Which hospital was s/he admitted to?	AM14. When was this admission?
a.	|__|__| MON/YR
b.	|__|__| MON/YR
c.	|__|__| MON/YR
d.	|__|__| MON/YR
e.	|__|__| MON/YR

SECTION IV: ASTHMA MEDICATIONS & CONTROL

"Over the Counter"

ME1. Do you give your child over-the-counter cold or allergy medications, (for example, Robitussin, Sudafed, Claritin) to treat his/her asthma symptoms?

YES.... 1
NO..... ....2 **[GO TO ME6]**

ME2. What do you use?	ME3. Do you use (NAME) as the box or label tells you to?	ME4. How do you use (NAME)?	ME5. When (STUDY CHILD) has asthma symptoms do you use (NAME).....
a.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3
b.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3
c.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3
d.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3
e.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3
f.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3

MEDICATION CHECKLIST: Parent Form – NOTE TO INTERVIEWER: RECORD MEDICATION NAME AND STRENGTH (ex. Flovent 110)

NOW I WOULD LIKE TO ASK YOU SOME QUESTIONS REGARDING MEDICATIONS YOU HAVE GIVEN YOUR CHILD IN THE **PAST 12 MONTHS** FOR HIS/HER BREATHING PROBLEMS.

ME6. What is the name of a medication that you have given to your child for asthma in the past 12 months?	ME7. When was the last time your child took their medication? 1= <4 hours 2= 4-8 hours 3= 8-12 hours 4= 12-24 hours 5= > 24 hours 6= 1-2 weeks 7= 2-4 weeks 8= 1 to 6 months 9= > 6 months 97= N/A 98=Refused 99=Don't know	ME8. What form does the medication come in? 1= Inhaler 2= Nebulizer 3= Pill 4= Diskus 5= Liquid 97= N/A 98=Refused 99=Don't know	ME9. How often is the medication supposed to be taken? 1 = As needed, when symptoms act up 2 = Once daily and regardless of symptoms 3 =Twice daily and regardless of symptoms 4= Daily, before taking other asthma medications (e.g., before Flovent) 5 = Before playing sports or going to gym 6 = Before exposure to asthma triggers like animals, smoke or pollen 97= N/A 98=Refused 99=Don't know	ME10. How much medication is given per day? 1= As needed/prn 2= 1 puff/day 3= 2 puffs/day 4= 4 puffs/day 5= 6 puffs/day 6 = 1 pill/day 7= 2 pills/day 97= N/A 98=Refused 99=Don't know	ME11. If before sports or exposure to other triggers, how many times per week? 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = >7 97 = N/A 98=Refused 99=Don't know	ME12. When did the doctor prescribe the medication? 1= < 1 month 2= 1 to 6 months 3= 7 to 12 months 4= > 12 months 97= N/A 98=Refused 99=Don't know
QUICK RELIEF:						
a. Albuterol						
b. Atrovent						
c. Combivent (albuterol/ ipratropium)						
d. Maxair (Pirbuterol) 0.2 mg						
e. Proventil (albuterol)						
f. Ventolin (albuterol)						
g. Xopenex						
ORAL STEROIDS:						
h. Celestone (betamethasone)						
i. Medrol (methyl prednisolone)						
j. Orapred (prednisolone)						
k. Prednisone						
l. Prelone (prednisolone)						
m. Solumedrol (methyl prednisolone)						

NOTE TO INTERVIEWER: RECORD MEDICATION NAME AND STRENGTH (ex. Flovent 110)

ME6. What is the name of a medication that you have given to your child for asthma in the past 12 months?	ME7. When was the last time your child took their medication? 1= <4 hours 2= 4-8 hours 3= 8-12 hours 4= 12-24 hours 5= > 24 hours 6= 1-2 weeks 7= 2-4 weeks 8= 1 to 6 months 9= > 6 months 97= N/A 98=Refused 99=Don't know	ME8. What form does the medication come in? 1= Inhaler 2= Nebulizer 3= Pill 4= Diskus 5= Liquid 97= N/A 98=Refused 99=Don't know	ME9. How often is the medication supposed to be taken? 1 = As needed, when symptoms act up 2 = Once daily and regardless of symptoms 3 =Twice daily and regardless of symptoms 4= Daily, before taking other asthma medications (e.g., before Flovent) 5 = Before playing sports or going to gym 6 = Before exposure to asthma triggers like animals, smoke or pollen 97= N/A 98=Refused 99=Don't know	ME10. How much medication is given per day? 1= As needed/prn 2= 1 puff/day 3= 2 puffs/day 4= 4 puffs/day 5= 6 puffs/day 6 = 1 pill/day 7= 2 pills/day 97= N/A 98=Refused 99=Don't know	ME11. If before sports or exposure to other triggers, how many times per week? 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = >7 97 = N/A 98=Refused 99=Don't know	ME12.When did the doctor prescribe the medication? 1= < 1 month 2= 1 to 6 months 3= 7 to 12 months 4= > 12 months 97= N/A 98=Refused 99=Don't know
QUICK RELIEF (CONT)						
n. OTHER quick-relief: _____						
CONTROLLER						
o. Accolate (zafirlukast) 10 mg tb						
p. Accolate 20 mg tb						
q. Accolate (mg unknown)						
r. Advair 100/50 (fluticasone/salmeterol)						
s. Advair 250/50 (fluticasone/salmeterol)						
t.Advair 500/50 (fluticasone/salmeteol)						
u. Advair (mg unknown)						
v. Aerobid (flunisolide) 250 mcg/inh						

NOTE TO INTERVIEWER: RECORD MEDICATION NAME AND STRENGTH (example: Flovent 110)						
ME6. What is the name of a medication that you have given to your child for asthma in the past 12 months?	ME7. When was the last time your child took their medication? 1= <4 hours 2= 4-8 hours 3= 8-12 hours 4= 12-24 hours 5= > 24 hours 6= 1-2 weeks 7= 2-4 weeks 8= 1 to 6 months 9= > 6 months 97= N/A 98=Refused 99=Don't know	ME8. What form does the medication come in? 1= Inhaler 2= Nebulizer 3= Pill 4= Diskus 5= Liquid 97= N/A 98=Refused 99=Don't know	ME9. How often is the medication supposed to be taken? 1 = As needed, when symptoms act up 2 = Once daily and regardless of symptoms 3 = Twice daily and regardless of symptoms 4= Daily, before taking other asthma medications (e.g., before Flovent) 5 = Before playing sports or going to gym 6 = Before exposure to asthma triggers like animals, smoke or pollen 97= N/A 98=Refused 99=Don't know	ME10. How much medication is given per day? 1= As needed/prn 2= 1 puff/day 3= 2 puffs/day 4= 4 puffs/day 5= 6 puffs/day 6 = 1 pill/day 7= 2 pills/day 97= N/A 98=Refused 99=Don't know	ME11. If before sports or exposure to other triggers, how many times per week? 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = >7 97 = N/A 98=Refused 99=Don't know	ME12.When did the doctor prescribe the medication? 1= < 1 month 2= 1 to 6 months 3= 7 to 12 months 4= > 12 months 97= N/A 98=Refused 99=Don't know
w. Azmacort (Triamcinolone Acetonide) 100 mcg/inh						
x. Flovent 44 mcg/spray (fluticasone)						
y. Flovent 110 mcg/spray						
z. Flovent 220 mcg/spray						
aa. Flovent (mcg unknown)						
bb.Foradil 12 mcg (Formoterol)						
cc. Intal (cromolyn)						
dd. Pulmicort 0.25 (budesonide)						
ee.Pulmicort 0.5 (budesonide)						
ff. Pulmicort 200 (budesonide) Turbuhaler						
gg. Qvar 40 mcg/spray (beclomethasone HFA)						

NOTE TO INTERVIEWER: RECORD MEDICATION NAME AND STRENGTH (example Flovent 110)						
ME6. What is the name of a medication that you have given to your child for asthma in the past 12 months?	ME7. When was the last time your child took their medication? 1= <4 hours 2= 4-8 hours 3= 8-12 hours 4= 12-24 hours 5= > 24 hours 6= 1-2 weeks 7= 2-4 weeks 8= 1 to 6 months 9= > 6 months 97= N/A 98=Refused 99=Don't know	ME8. What form does the medication come in? 1= Inhaler 2= Nebulizer 3= Pill 4= Diskus 5= Liquid 97= N/A 98=Refused 99=Don't know	ME9. How often is the medication supposed to be taken? 1 = As needed, when symptoms act up 2 = Once daily and regardless of symptoms 3 = Twice daily and regardless of symptoms 4= Daily, before taking other asthma medications (e.g., before Flovent) 5 = Before playing sports or going to gym 6 = Before exposure to asthma triggers like animals, smoke or pollen 97= N/A 98=Refused 99=Don't know	ME10. How much medication is given per day? 1= As needed/prn 2= 1 puff/day 3= 2 puffs/day 4= 4 puffs/day 5= 6 puffs/day 6 = 1 pill/day 7= 2 pills/day 97= N/A 98=Refused 99=Don't know	ME11.If before sports or exposure to other triggers, how many times per week? 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = >7 97 = N/A 98=Refused 99=Don't know	ME12. When did the doctor prescribe the medication? 1= < 1 month 2= 1 to 6 months 3= 7 to 12 months 4= > 12 months 97= N/A 98=Refused 99=Don't know
hh. Qvar 80 mcg/spray (beclomethasone HFA)						
ii. Qvar (mcg uk/not given)						
jj. Serevent (salmeterol)						
kk. Singulair 4 mg tablet (montelukast)						
ll. Singulair 5 mg tablet						
mm. Singulair 10 mg tablet						
nn. Singulair (mg unknown)						
oo. Symbicort (80/4.5) (budesonide/formoterol)						
pp. Symbicort (160/4.5) (budesonide/formoterol)						
qq. Theophylline						

NOTE TO INTERVIEWER: RECORD MEDICATION NAME AND STRENGTH (example (Flovent 110)						
ME6. What is the name of a medication that you have given to your child for asthma in the past 12 months?	ME7. When was the last time your child took their medication? 1= <4 hours 2= 4-8 hours 3= 8-12 hours 4= 12-24 hours 5= > 24 hours 6= 1-2 weeks 7= 2-4 weeks 8= 1 to 6 months 9= > 6 months 97= N/A 98=Refused 99=Don't know	ME8. What form Does the medication come in? 1= Inhaler 2= Nebulizer 3= Pill 4= Diskus 5= Liquid 97= N/A 98=Refused 99=Don't know	ME9.How often is the medication supposed to be taken? 1 = As needed, when symptoms act up 2 = Once daily and regardless of symptoms 3 = Twice daily and regardless of symptoms 4= Daily, before taking other asthma medications (e.g., before Flovent) 5 = Before playing sports or going to gym 6 = Before exposure to asthma triggers like animals, smoke or pollen 97= N/A 98=Refused 99=Don't know	ME10. How much medication is given per day? 1= As needed/prn 2= 1 puff/day 3= 2 puffs/day 4= 4 puffs/day 5= 6 puffs/day 6 = 1 pill/day 7= 2 pills/day 97= N/A 98=Refused 99=Don't know	ME11. If before sports or exposure to other triggers, how many times per week? 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = >7 97 = N/A 98=Refused 99=Don't know	ME12. When did the doctor prescribe the medication? 1= < 1 month 2= 1 to 6 months 3= 7 to 12 months 4= > 12 months 97= N/A 98=Refused 99=Don't know
rr. Tilade (nedocromil)						
ss. Vanceril 42 mcg/puff (beclomethasone CFC)						
tt. Vanceril 84 mcg/puff (beclomethasone CFC)						
uu. Vanceril (mcg unknown/not given)						
vv. Zyflo (Zileuton) 600mg tab						
ww. OTHER Controller: _____						

P-ACT: *The following questions are about your child's asthma, including symptoms, limitations, medications, asthma attacks and use of healthcare services. There are no right or wrong answers.*

During the last 4 weeks, on average, how many days per month:	**Not at all**	**1-3 days/ mo**	**4-10 days/ mo**	**11-18 days/ mo**	**19-24 days/ mo**	**Everyday**
PACT9. Did your child have any daytime asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT10. Did your child cough during the day because of asthma?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT11. Did your child wheeze during the day because of asthma?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT12. Did you keep your child from running, exercising, or playing sports because of asthma?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT13. Did your child wake up during the night because of asthma?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT14. Did your child have an asthma attack?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT15. Did your child use a rescue or quick-relief medication such as albuterol (Ventolin®, Proventil®), Xopenex® or Maxair™?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

During the last 4 weeks:	**0 times/day**	**1-2 times/day**	**3-4 times/day**	**5-6 times/day**	**≥ 7 times/day**
PACT16. On the worst day, how many times did your child use a rescue or quick-relief medication such as albuterol (Ventolin®, Proventil®), Xopenex® or Maxair™?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

During the last 12 months, how often:	**0 times/yr**	**1-2 times/yr**	**3-4 times/yr**	**5-6 times/yr**	**≥ 7 times/yr**
PACT17. Did your child take oral steroids such as prednisone (Pediapred®, Prelone®, Deltasone®, Orapred®) or Decadron® because of asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PACT18. Did your child miss school or daycare because of asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PACT19. Did your child visit an urgent care facility or a hospital emergency room (without being admitted to the hospital) because of asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PACT20. Did your child have an unscheduled visit to a doctor because of asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PACT21. Did your child stay in the hospital overnight or longer because of asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

SECTION VI: OTHER HELPFUL STRATEGIES FOR MANAGING ASTHMA

We've talked about the medications and treatments your doctor has prescribed. Some parents have told us about other treatments that they have used in managing their child's asthma.

HS1. Have you ever tried medications or treatments other than those prescribed by your doctor to manage your child's asthma?

YES.... 1
NO..... ....2 **[GO TO HS3]**

HS2. What have you tried?

_____

_____

_____

[ASK HS3-7 EVEN IF HS1 IS "NO". NOT ALL PARENTS MAY REALIZE THAT SOME OF THE ITEMS BELOW ARE ALTERNATIVE MEDICINES OR TREATMENTS]

[Now I'm going to ask you about specific treatments that other parents have tried to manage their child's asthma]

	HS3. Have you ever tried….to manage your child's asthma?	**HS4. What did you try/use?**	**HS5. Was it helpful?**	**HS6. Are you still using it?**	**HS7. How often do you use…?**
a. Herbal supplements (St. John's Wort, Ginkgo biloba, ma huang)?	YES…….1 NO……..2 **[GO TO HS3b]**		YES…….1 NO……..2	YES…….1 NO……..2	
b. Herbal teas (chamomile, ginger, wildroot, eucalyptus, etc.)?	YES…….1 NO……..2**[GO TO HS3c]**		YES…….1 NO……..2	YES…….1 NO……..2	
c. Special foods (garlic, onion, watercress, castor oil, cod liver oil, etc.)?	YES…….1 NO……..2**[GO TO HS3d]**		YES…….1 NO……..2	YES…….1 NO……..2	
d. Vitamins (e.g., magnesium, high dose vitamin C)?	YES…….1 NO……..2**[GO TO HS3e]**		YES…….1 NO……..2	YES…….1 NO……..2	
e. Breathing exercises (e.g., Buteyko breathing techniques)?	YES…….1 NO……..2**[GO TO HS3f]**		YES…….1 NO……..2	YES…….1 NO……..2	
f. Relaxation techniques (e.g., yoga, meditation)?	YES…….1 NO……..2**[GO TO HS3g]**		YES…….1 NO……..2	YES…….1 NO……..2	
g. Massage?	YES…….1 NO……..2**[GO TO HS3h]**		YES…….1 NO……..2	YES…….1 NO……..2	
h. Prayer for health purposes?	YES…….1 NO……..2**[GO TO HS3I]**		YES…….1 NO……..2	YES…….1 NO……..2	
i. Spinal manipulation?	YES…….1 NO……..2**[GO TO HS3j]**		YES…….1 NO……..2	YES…….1 NO……..2	
j. Rubs (camphor, Vick's vapor-rub)?	YES…….1 NO……..2**[GO TO HS3k]**		YES…….1 NO……..2	YES…….1 NO……..2	
k. Syrups (Jarabe 7)?	YES…….1 NO……..2**[GO TO HS3l]**		YES…….1 NO……..2	YES…….1 NO……..2	
l. Reflexology?	YES…….1 NO……..2**[GO TO HS3m]**		YES…….1 NO……..2	YES…….1 NO……..2	
m. Acupuncture?	YES…….1 NO……..2**[GO TO HS3n]**		YES…….1 NO……..2	YES…….1 NO……..2	
n. Other (e.g., magnets, bee stings)? (Specify)	YES…….1 NO……..2**[GO TO HS7]**		YES…….1 NO……..2	YES…….1 NO……..2	

[IF HS3 a - n are "NO", go to HS13]

HS8. Do you use the above treatments for asthma instead of prescribed medications?

YES.... 1
NO..... 2

HS9. Do you use the above treatments for asthma along with prescribed medications?

YES.... 1
NO..... 2

HS10. Have you discussed these treatments with your child's doctor?

YES.... 1
NO..... ....2 **[GO TO HS12]**

HS11. What was his/her response?

_____

_____

_____

[GO TO HS13]

HS12. Why didn't you discuss these treatments with him/her?

_____

_____

_____

HS13. Besides your health care provider, are there any other people you turn to for advice on how to manage your child's asthma (i.e., family members, clergy, healers, others with asthma)?

YES.... 1
NO..... ....2 **[NEXT SECTION]**

HS14. Who do you turn to? **[LIST EACH PERSON]**	HS15. What kinds of advice do you get from (PERSON IN HS14)?
a.	
b.	
c.	
d.	

We've talked about medicines or treatments other than those prescribed by your child's doctor that you have used to manage his/her asthma. I'd now like to ask about your use of any medicines or treatments, other than those prescribed by your doctor, to manage any illnesses or conditions you may have had.

HS16. Have you ever used any medicine or treatment other than those prescribed by your doctor or nurse to manage your illness or other health condition?

YES.... 1
NO..... 2

HS17. What did you use?	HS18. What illness or health condition did you use it for?	HS19. How long did you use (NAME OF CAM)?	HS20. Was (NAME OF CAM) helpful?	HS21. Are you still using (NAME OF CAM)?
a.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
b.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
c.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
d.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
e.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
f.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
g.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
h.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2

SECTION VII: DEMOGRAPHICS, CULTURE & ACCULTURATION

Demographics 1

Now I'm going to ask you some questions about you and your family.

DM1. What is your relationship to the child (e.g. mother, grandmother, aunt, etc.)?

_____

DM2. How old are you? |__|__| YEARS

DM3. What was the highest grade or year in school that you completed?
(CIRCLE HIGHEST GRADE COMPLETED. GED = 12)

NO FORMAL SCHOOLING	00
ELEMENTARY SCHOOL	01 02 03 04 05 06
HIGH/VOCATIONAL SCHOOL	07 08 09 10 11 12
COLLEGE OR POST HS VOCAT SCHOOL	13 14 15 16
GRADUATE OR PROFESSIONAL SCHOOL	17 18 19 20+

DM4. What is your marital status?

Married		1
Single but have a partner		2
DM4a.	Male	|__|
	Female	|__|
Widowed		3
Divorced		4
Separated		5
Never married & don't have a partner		6

DM5. Are you currently working?

NO..... 0
YES, PART-TIME 1
YES, FULL-TIME..... 2

DM6. What would you say best describes your family's standard of living? Would you say you are.....

Very well off.. 1
Living very comfortably 2
Living reasonably comfortably..... 3
Just getting along 4
Nearly poor 5
Poor.... 6

DM7. Now I would like to ask you about your ethnic background. Which of these groups would you say describes your ethnic background?

Mexican 1
Puerto Rican... 2
Cuban. 3
Dominican..... 4
Hispanic 5
Central American..... 6
South American 7
OTHER (specify)..... 8

DM8. What country were you born in? _____

DM9. How long have you lived in the United States?

|__|__| MONTHS 1
YEARS 2

DM10. How long has (STUDY CHILD) lived in the United States?

|__|__| MONTHS 1
YEARS 2
SINCE BIRTH 3

Below are a number of statements that evaluate changes that occur when people interact with others of different cultures or ethnic groups. For questions that refer to "COUNTRY OF ORIGIN" or "NATIVE COUNTRY," please refer to the country from which your family originally came. For questions referring to "NATIVE LANGUAGE," please refer to the language spoken where your family originally came. Please tell me the answer that best matches your response to each question. [HAVE R TURN TO RB3]

		False	Partly false	Partly true	True
DM11.	I understand English, but I'm not fluent in English.	1	2	3	4
DM12.	I am informed about current affairs in the United States	1	2	3	4
DM13.	I speak my native language with my friends and acquaintances from my country of origin.	1	2	3	4
DM14.	I have never learned to speak the language of my native country.	1	2	3	4
DM15.	I feel totally comfortable with (Anglo) American people.	1	2	3	4
DM16.	I eat traditional foods from my native culture.	1	2	3	4
DM17.	I have many (Anglo) American acquaintances.	1	2	3	4
DM18.	I feel comfortable speaking my native language.	1	2	3	4
DM19.	I am informed about current affairs in my native country.	1	2	3	4
DM20.	I know how to read and write in my native language.	1	2	3	4
DM21.	I feel at home in the United States.	1	2	3	4
DM22.	I attend social functions with people from my native country.	1	2	3	4
DM23.	I feel accepted by (Anglo) Americans.	1	2	3	4
DM24.	I speak my native language at home.	1	2	3	4

		False	Partly false	Partly true	True
DM25.	I regularly read magazines of my ethnic group.	1	2	3	4
DM26.	I know how to speak my native language.	1	2	3	4
DM27.	I know how to prepare (Anglo) American foods.	1	2	3	4
DM28.	I am familiar with the history of my native country.	1	2	3	4
DM29.	I regularly read an American newspaper.	1	2	3	4
DM30.	I like to listen to music of my ethnic group.	1	2	3	4
DM31.	I like to speak my native language.	1	2	3	4
DM32.	I feel comfortable speaking English.	1	2	3	4
DM33.	I speak English at home.	1	2	3	4
DM34.	I speak my native language with my spouse or partner.	1	2	3	4
DM35.	When I pray, I use my native language.	1	2	3	4
DM36.	I attend social functions with (Anglo) American people.	1	2	3	4
DM37.	I think in my native language.	1	2	3	4
DM38.	I stay in close contact with family members and relatives in my native country.	1	2	3	4
DM39.	I am familiar with important people in American history.	1	2	3	4
DM40.	I think in English.	1	2	3	4
DM41.	I speak English with my spouse or partner.	1	2	3	4
DM42.	I like to eat American foods.	1	2	3	4

Center for Epidemiological Depression Scale (CES-D)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the **past week**: [HAVE R TURN TO RB4]

CESD1. I was bothered by things that don't usually bother me.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD2. I did not feel like eating; my appetite was poor.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD3. I felt that I could not shake off the blues even with the help of my family or friends.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD4. I felt that I was just as good as other people.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD5. I had trouble keeping my mind on what I was doing.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD6. I felt depressed.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD7. I felt everything I did was an effort.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD8. I felt hopeful about the future.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD9. I thought my life had been a failure.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD10. I felt fearful.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD11. My sleep was restless.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD12. I was happy.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD13. I talked less than usual.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD14. I felt lonely.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD15. People were unfriendly.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD16. I enjoyed life.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD17. I had crying spells.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD18. I felt sad.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD19. I felt that people disliked me.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD20. I could not get "going."

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

Demographics 2

I'd like to ask you about the people living in your household.

[ASK DM43 FOR EACH PERSON BEFORE DM44-DM47. DO NOT INCLUDE THE RESPONDENT IN THIS GRID.]

DM43. Please give me the first name of all people living in your household. **[DO NOT INCLUDE R.]**	DM44. **[ASK OR CONFIRM:]** Is (PERSON) male or female?	DM45. How old was (PERSON) on (his/her) last birthday?	DM46. What is (PERSON'S) relationship to you?	DM47. Does (PERSON) have asthma?
a.	MALE.....1 FEMALE.....2	|__|__| MONTHS.....1 YEARS.....2		NO.....0 YES.....1
b.	MALE.....1 FEMALE.....2	|__|__| MONTHS.....1 YEARS.....2		NO.....0 YES.....1
c.	MALE.....1 FEMALE.....2	|__|__| MONTHS.....1 YEARS.....2		NO.....0 YES.....1
d.	MALE.....1 FEMALE.....2	|__|__| MONTHS.....1 YEARS.....2		NO.....0 YES.....1
e.	MALE.....1 FEMALE.....2	|__|__| MONTHS.....1 YEARS.....2		NO.....0 YES.....1
f.	MALE.....1 FEMALE.....2	|__|__| MONTHS.....1 YEARS.....2		NO.....0 YES.....1
g.	MALE.....1 FEMALE.....2	|__|__| MONTHS.....1 YEARS.....2		NO.....0 YES.....1
h.	MALE.....1 FEMALE.....2	|__|__| MONTHS.....1 YEARS.....2		NO.....0 YES.....1
i.	MALE.....1 FEMALE.....2	|__|__| MONTHS.....1 YEARS.....2		NO.....0 YES.....1
j.	MALE.....1 FEMALE.....2	|__|__| MONTHS.....1 YEARS.....2		NO.....0 YES.....1

SECTION SN. SOCIAL NETWORKS

The next few questions are about your social life, **not including** your husband, wife, or partner.

SN1. How often do you talk on the phone or get together with family or relatives who do not live with you? Would you say…

MOST EVERY DAY	1
A FEW TIMES A WEEK	2
A FEW TIMES A MONTH	3
ONCE A MONTH	4
LESS THAN ONCE A MONTH	5

SN2. **Not including your husband, wife, or partner,** how much can you rely on relatives who do not live with you for help if you have a serious problem?

A LOT	1
SOME	2
A LITTLE	3
NOT AT ALL	4

SN3. **Not including your husband, wife, or partner,** how much can you open up to relatives who do not live with you if you need to talk about your worries?

A LOT	1
SOME	2
A LITTLE	3
NOT AT ALL	4

SN4. **Not including your husband, wife or partner,** how often do your relatives or children make too many demands on you?

OFTEN	1
SOMETIMES	2
RARELY	3
NEVER	4

SN5. **Not including your husband, wife or partner,** how often do your family or relatives argue with you?

OFTEN	1
SOMETIMES	2
RARELY	3
NEVER	4

SN6. How often do you talk on the phone or get together with friends?

MOST EVERY DAY	1
A FEW TIMES A WEEK	2
A FEW TIMES A MONTH	3
ONCE A MONTH	4
LESS THAN ONCE A MONTH	5

SN7. How much can you rely on your friends for help if you have a serious problem?

A LOT	1
SOME	2
A LITTLE	3
NOT AT ALL	4

SN8. How much can you open up to your friends if you need to talk about your worries?

A LOT	1
SOME	2
A LITTLE	3
NOT AT ALL	4

SN9. How often do your friends make too many demands on you?

OFTEN	1
SOMETIMES	2
RARELY	3
NEVER	4

SN10. How often do your friends argue with you?

OFTEN	1
SOMETIMES	2
RARELY	3
NEVER	4

SN11. When you have a problem or worry, how often do you let your husband/wife/partner know about it?
[NOTE TO INTERVIEWER: CODE N/A IF NO HUSBAND, WIFE, OR PARTNER]

ALWAYS	1
MOST OF THE TIME	2
SOMETIMES	3
RARELY	4
NEVER	5
N/A	97

SN12. When you have a problem or worry, how often do you let someone (else) know about it?

ALWAYS	1
MOST OF THE TIME	2
SOMETIMES	3
RARELY	4
NEVER	5

SECTION VIII: PARENT-CHILD ASTHMA SYMPTOM CHECKLIST (P-CASCL)

DIRECTIONS: Rate how often each of the following symptoms occurs during your child's asthma attacks. There may be other times when he/she has had each of these symptoms. However, please tell us how often he/she has had each symptom ONLY when he/she is having his/her asthma attacks. [HAVE R TURN TO RB5]

		Never	Hardly at all	Some of the time	Most of the time	Always	Refused	Don't Know	N/A
PCA1.	Cramps	1	2	3	4	5	97	98	99
PCA2.	Panting, Fast Breathing	1	2	3	4	5	97	98	99
PCA3.	Numb, No Feeling	1	2	3	4	5	97	98	99
PCA4.	Sticky, Mucous in Lungs	1	2	3	4	5	97	98	99
PCA5.	Cranky	1	2	3	4	5	97	98	99
PCA6.	Get Angry Easily	1	2	3	4	5	97	98	99
PCA7.	Hard to Breathe	1	2	3	4	5	97	98	99
PCA8.	Headache	1	2	3	4	5	97	98	99
PCA9.	Nervous, Jittery	1	2	3	4	5	97	98	99
PCA10.	Frightened	1	2	3	4	5	97	98	99
PCA11.	Uncomfortable	1	2	3	4	5	97	98	99
PCA12.	Short of Breath	1	2	3	4	5	97	98	99
PCA13.	Heavy Feeling in Chest	1	2	3	4	5	97	98	99
PCA14.	Afraid of Being Alone	1	2	3	4	5	97	98	99
PCA15.	Afraid of Dying	1	2	3	4	5	97	98	99
PCA16.	Unhappy with Things	1	2	3	4	5	97	98	99
PCA17.	Heart Pounding	1	2	3	4	5	97	98	99
PCA18.	Dizzy	1	2	3	4	5	97	98	99
PCA19.	Worn Out	1	2	3	4	5	97	98	99
PCA20.	Panicky	1	2	3	4	5	97	98	99
PCA21.	Weak	1	2	3	4	5	97	98	99

PCA22.	Pins and Needles	1	2	3	4	5	97	98	99
PCA23.	Hard and Fast Breathing	1	2	3	4	5	97	98	99
PCA24.	Doesn't Care about Things	1	2	3	4	5	97	98	99
PCA25.	Feels Like he/she is alone	1	2	3	4	5	97	98	99
PCA26.	Wheezy	1	2	3	4	5	97	98	99
PCA27.	Worried about the Attack	1	2	3	4	5	97	98	99
PCA28.	Tingly in Spots	1	2	3	4	5	97	98	99
PCA29.	Very Angry, Mad	1	2	3	4	5	97	98	99
PCA30.	Chest Tightening	1	2	3	4	5	97	98	99
PCA31.	Tired	1	2	3	4	5	97	98	99
PCA32.	Scared	1	2	3	4	5	97	98	99
PCA33.	Feel Helpless	1	2	3	4	5	97	98	99
PCA34.	Chest Filling UP	1	2	3	4	5	97	98	99
PCA35.	Lonely	1	2	3	4	5	97	98	99
PCA36.	Worried	1	2	3	4	5	97	98	99
PCA37.	Chest Pain	1	2	3	4	5	97	98	99
PCA38.	Rundown, Weak	1	2	3	4	5	97	98	99
PCA39.	Mad at the World	1	2	3	4	5	97	98	99
PCA40.	Coughing	1	2	3	4	5	97	98	99
PCA41.	No Energy	1	2	3	4	5	97	98	99
PCA42.	Unhappy	1	2	3	4	5	97	98	99
PCA43.	Worried about him/herself	1	2	3	4	5	97	98	99
PCA44.	Worried about Asthma	1	2	3	4	5	97	98	99
PCA45.	Worried in General	1	2	3	4	5	97	98	99
PCA46.	Feel Left Out	1	2	3	4	5	97	98	99
PCA47.	Breathes Quickly	1	2	3	4	5	97	98	99

SECTION IX. ASTHMA TRIGGER INVENTORY

There are many different causes for asthmatic symptoms. Situations causing symptoms can vary considerably from one person to the other. Please indicate for each of the listed causes below how often they are involved when your child experiences symptoms of asthma. Please base your answers on your *own child's experience, not* on what you think should lead to asthma for the typical patient.

The following things can trigger my child's asthma alone or in part. [HAVE R TURN TO RB6]

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS
1. Having a cold	0	1	2	3	4
2. Cigarette smoke	0	1	2	3	4
3. Running	0	1	2	3	4
4. Being angry	0	1	2	3	4
5. Pollen from trees	0	1	2	3	4
6. Feeling alone	0	1	2	3	4
7. Exhaust fumes	0	1	2	3	4
8. Bicycle riding	0	1	2	3	4
9. Stress at home	0	1	2	3	4
10. Certain intensive odors	0	1	2	3	4
11. Pollen from grass	0	1	2	3	4
12. Feeling tense	0	1	2	3	4
13. Climbing flights of stairs	0	1	2	3	4
14. Depressed mood	0	1	2	3	4
15. Smell of paint	0	1	2	3	4
16. Sport activities	0	1	2	3	4
17. Perfumes	0	1	2	3	4
18. Arguments with people	0	1	2	3	4
19. Flu	0	1	2	3	4
20. Sinus problems	0	1	2	3	4
21. Being excited	0	1	2	3	4
22. Intense worries	0	1	2	3	4
23. Feeling unhappy	0	1	2	3	4
24. Animal hair	0	1	2	3	4
25. Overexertion	0	1	2	3	4
26. Viruses	0	1	2	3	4
27. Feeling weak	0	1	2	3	4
28. Pollen from weeds	0	1	2	3	4
29. Feathers from birds	0	1	2	3	4
30. Sprays	0	1	2	3	4
31. Cats	0	1	2	3	4
32. House dust	0	1	2	3	4

PESSAY:
THANK YOU FOR PARTICIPATING IN THIS INTERVIEW!

IS THERE ANYTHING YOU WOULD LIKE TO TELL US ABOUT YOUR EXPERIENCE WITH ASTHMA THAT WE DID NOT COVER IN THIS INTERVIEW?

COMMENTS:

EV: INTERVIEWER EVALUATION

Answer these questions about the mother after you complete the questionnaire.

EV1. During the interview, was the mother generally...

Very interested.....1
Somewhat interested.....2
Indifferent.....3
Somewhat bored.....4
Very bored.....5

EV2. How attentive was the mother during the interview?

Attentive, involved, responsive.....1
Somewhat inattentive or uninvolved.....2
Easily distracted, needed urging to pay attention.....3

EV3. In general, how quickly did the mother respond to questions?

Responded quickly, without hesitation.....1
Deliberated some, but responses were generally not too slow.....2
Was often slow to respond.....3
Was usually very slow to respond, needed much urging.....4

EV4. Which questions, if any, did the mother have difficulty understanding?

_____

_____

_____

EV5. How truthful did the mother seem?

Completely truthful.....1
Mainly truthful.....2
About half and half.....3
Mainly untruthful, evasive.....4

EV6. At the end of the interview, did the mother seem to be...

Very tired.....1
Fairly tired.....2
A little tired.....3
Not tired at all.....4

EV7. At any time during the interview, was there anyone present and able to overhear the interview?

YES.....1
NO.....2

EV8. What else is there about the interview that will help in interpreting the data?

_____

_____

_____

*Types of instruments

BATCH # _____

PARENT INTERVIEW – PART II
The Latino Childhood Asthma Project
(11/03/09)

STUDY ID#: _____

INTERVIEWER: _____

TODAY'S DATE: MONTH: ☐☐ DAY: ☐☐ YEAR: ☐☐

PARENT/GUARDIAN'S INITIALS: ☐☐

OFFICE USE ONLY:

PI CODED/CHECKED: _____

CODED/CHECKED: _____

RECEIVED: _____

ENTERED: _____

VERIFIED: _____

SECTION I: DEMOGRAPHICS

I have a few more questions about your child and then some general questions about you.

DM1. Tell me how much you agree with the following statement: My child's asthma is under good control.

STRONGLY AGREE 1
AGREE 2
UNSURE 3
DISAGREE.... 4
STRONGLY DISAGREE 5

DM2. How old is your son/daughter?

[ ][ ]
YEARS

DM3. How old are you?

[ ][ ]
YEARS

DM4. What was the highest grade or year in school that you completed?
(CIRCLE HIGHEST GRADE COMPLETED. GED = 12)

NO FORMAL SCHOOLING	00
ELEMENTARY SCHOOL	01 02 03 04 05 06
HIGH/VOCATIONAL SCHOOL	07 08 09 10 11 12
COLLEGE OR POST HS VOCAT SCHOOL	13 14 15 16
GRADUATE OR PROFESSIONAL SCHOOL	17 18 19 20+

DM4. What is your marital status?

a. Married [ ]
b. Single but have a partner [ ]
c. Widowed [ ]
d. Divorced [ ]
e. Separated [ ]
f. Never married & don't have a partner [ ]

DM5. What would you say best describes your family's standard of living? Would you say you are.....

Very well off.. 1
Living very comfortably 2
Living reasonably comfortably..... 3
Just getting along 4
Nearly poor 5
Poor.... 6

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week.

	<1 day	1-2 days	3-4 days	5-7 days
DM6. I was bothered by things that usually don't bother me.	0	1	2	3
DM7. I had trouble keeping my mind on what I was doing.	0	1	2	3
DM8. I felt depressed.	0	1	2	3
DM9. I felt that everything I did was an effort.	0	1	2	3
DM10. I felt hopeful about the future (R)	0	1	2	3
DM11. I felt fearful.	0	1	2	3
DM12. My sleep was restless.	0	1	2	3
DM13. I was happy. (R)	0	1	2	3
DM14. I felt lonely.	0	1	2	3
DM15. I could not "get going."	0	1	2	3

We are interested in how you work out the management of your child's asthma with the health care provider. We would like your opinion on what is helpful and not helpful with this interaction. Remember, all information you give us is confidential.

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
PCP1.1	I am sometimes reluctant to discuss my worries about asthma medicines with my child's health care provider	1	2	3	4	5
PCP1.2	My child's health care provider is clear about what medicines my child needs to control his/her asthma **(R)**	1	2	3	4	5
PCP1.3	My child has a written Action Plan for what asthma medicines to use and when to use them	1	2	3	4	5
PCP1.4	When I call the doctor's office, they understand my concerns **(R)**	1	2	3	4	5
PCP1.5	I worry about "bothering" the doctor when I have questions or worries	1	2	3	4	5
PCP1.6	I see a different health care provider every time I go to the office **(R)**	1	2	3	4	5

PCP1.7	The doctor(s) who treat my child for asthma may understand asthma in general, but they don't understand how asthma affects my child	1	2	3	4	5
PCP1.8	My child's health care provider understands how asthma affects my child's day-to-day life **(R)**	1	2	3	4	5
PCP1.9	My child's health care provider understands how my child's asthma affects our family's day-to-day life **(R)**	1	2	3	4	5
PCP1.10	I'm involved as much as I want to be in making decisions about when to give what medications **(R)**	1	2	3	4	5
PCP1.11	My health care provider's office hours are not convenient for me.	1	2	3	4	5

I'd like to thank you for taking the time to talk with me today. Is there anything else that we haven't talked about that you'd like to share?

Arcoleo, Kimberly

From: Allen, Beth <Beth.Allen@nationwidechildrens.org>
Sent: Saturday, February 25, 2012 7:38 AM
To: Arcoleo, Kimberly
Subject: RE: Asthma Education Tool
Attachments: APPES Results for Pulm AAP team.pptx

Potential questions:

- What worries you the most regarding your child's asthma?
- What has been the most difficult aspect of taking care of your child's asthma?
- Short of curing your child's asthma (which can't be done - yet), what do you hope asthma treatment will accomplish?
- Do you feel like you understand what your child's medications do, and when you should use them?
- What has been most helpful for you regarding treating your child's asthma?
- Do you feel like you are completely able to manage your child's asthma if they start having symptoms? If not, why not? (what is missing?)
- What do your health care providers not understand about your child's asthma? (or What do you wish your child's healthcare providers would know about your struggle with asthma?)
- If your child takes daily medications for asthma, what has been the hardest part about giving them? What tricks have you learned that help you make sure they are given as recommended?
- Do your think other family members, friends, your child's school, understand what you are dealing with when it comes to your child's asthma?

Also - have attached a powerpoint synopsis of a study one of our medical students is submitted for presentation at the American Thoracic Society. He's working on a manuscript as well. I think it represents a different way of looking at what families understand about asthma - in a very practical way - that correlates with how their asthma is "doing." I'd love to hear what you think.

Beth

From: Arcoleo, Kimberly [karcoleo@con.ohio-state.edu]
Sent: Friday, February 24, 2012 11:43 AM
To: Gleeson, Sean; Stukus, David; Ayres, Gloria; O Connor, Christine; Bowman, Emily; Allen, Beth; Jonathan Feldman; Juliana Rodriguez (julianarguez21@gmail.com); Harris, Judith A.; Sauerhoefer, Tanya; April Hawthorne (april.hawthorne@asu.edu); Rachelle Begay (Rachelle.Begay@asu.edu); Luis E Zayas (lezayas@asu.edu); Mcgwire, Gerd
Subject: Asthma Education Tool

Hi everyone,
I thought I'd share the Asthma Education Tool we developed as well as the paper we published on the results as part of the larger AIRS study we did in Rochester. It may help guide your questions for the focus groups. I apologize for not remembering that we had done this sooner! If I could have your list by March 9th that would be great!
Warm regards,
Kim

Kimberly J. Arcoleo, PhD, MPH
Associate Professor
Director, Center for Promoting Health in
Infants, Children, Adolescents & Women

The FREQ Procedure

Table of CHCONTB by PARCONTB

CHCONTB(CHILD'S PERCEPTION OF CONTROL (ACT5):BASELINE)
PARCONTB(WELL-CONTROLLED ASTHMA:PARENT REPORT (AM2)-BASELINE)

Frequency ~~Percent~~ Row Pct Col Pct	0	1	Total
0	54 ~~20.30~~ 22.59 94.74	185 ~~69.55~~ 77.41 88.52	239 89.85
1	3 ~~1.13~~ 11.11 5.26	24 ~~9.02~~ 88.89 11.48	27 10.15
Total	57 21.43	209 78.57	266 100.00

Frequency Missing = 1

The FREQ Procedure

Statistics for Table of CHCONTB by PARCONTB

Statistic	DF	Value	Prob
Chi-Square	1	1.8999	0.1681
Likelihood Ratio Chi-Square	1	2.1719	0.1406
Continuity Adj. Chi-Square	1	1.2791	0.2581
Mantel-Haenszel Chi-Square	1	1.8928	0.1689
Phi Coefficient		0.0845	
Contingency Coefficient		0.0842	
Cramer's V		0.0845	

Fisher's Exact Test

Cell (1,1) Frequency (F)	54
Left-sided Pr <= F	0.9570
Right-sided Pr >= F	0.1260
Table Probability (P)	0.0830
Two-sided Pr <= P	0.2192

Effective Sample Size = 266
Frequency Missing = 1

The FREQ Procedure

Table of clincon by CHCONTB

clincon

CHCONTB(CHILD'S PERCEPTION OF CONTROL (ACT5):BASELINE)

Frequency ~~Percent~~ Row Pct Col Pct	0	1	Total
0	108 ~~43.72~~ 89.26 48.87	13 ~~5.26~~ 10.74 50.00	121 ~~48.99~~
1	113 ~~45.75~~ 89.68 51.13	13 ~~5.26~~ 10.32 50.00	126 ~~51.01~~
Total	221 89.47	26 10.53	247 100.00

Frequency Missing = 20

The FREQ Procedure

Statistics for Table of clincon by CHCONTB

Statistic	DF	Value	Prob
Chi-Square	1	0.0119	0.9131
Likelihood Ratio Chi-Square	1	0.0119	0.9131
Continuity Adj. Chi-Square	1	0.0000	1.0000
Mantel-Haenszel Chi-Square	1	0.0119	0.9133
Phi Coefficient		-0.0069	
Contingency Coefficient		0.0069	
Cramer's V		-0.0069	

Fisher's Exact Test

Cell (1,1) Frequency (F)	108
Left-sided Pr <= F	0.5386
Right-sided Pr >= F	0.6243
Table Probability (P)	0.1629
Two-sided Pr <= P	1.0000

Effective Sample Size = 247
Frequency Missing = 20

The FREQ Procedure

Table of CGSEX by PARCONTB

CGSEX(CAREGIVER'S SEX: 0=MALE 1=FEMALE)
PARCONTB(WELL-CONTROLLED ASTHMA:PARENT REPORT (AM2)-BASELINE)

Frequency ~~Percent~~ Row Pct Col Pct	0	1	Total
0	3 1.12 23.08 5.26	10 3.75 76.92 4.76	13 4.87
1	54 20.22 21.26 94.74	200 74.91 78.74 95.24	254 95.13
Total	57 21.35	210 78.65	267 100.00

The FREQ Procedure

Statistics for Table of CGSEX by PARCONTB

Statistic	DF	Value	Prob
Chi-Square	1	0.0243	0.8761
Likelihood Ratio Chi-Square	1	0.0239	0.8772
Continuity Adj. Chi-Square	1	0.0000	1.0000
Mantel-Haenszel Chi-Square	1	0.0242	0.8763
Phi Coefficient		0.0095	
Contingency Coefficient		0.0095	
Cramer's V		0.0095	

WARNING: 25% of the cells have expected counts less than 5. Chi-Square may not be a valid test.

Fisher's Exact Test

Cell (1,1) Frequency (F)	3
Left-sided Pr <= F	0.7077
Right-sided Pr >= F	0.5509
Table Probability (P)	0.2587
Two-sided Pr <= P	1.0000

Sample Size = 267

The TTEST Procedure

Variable: CGAGE_B (CAREGIVER'S AGE:BASELINE)

PARCONTB	N	Mean	Std Dev	Std Err	Minimum	Maximum
0	57	36.7719	7.3825	0.9778	26.0000	57.0000
1	210	36.2238	8.0079	0.5526	19.0000	74.0000
Diff (1-2)		0.5481	7.8799	1.1769		

PARCONTB	Method	Mean	95% CL Mean		Std Dev
0		36.7719	34.8131	38.7308	7.3825
1		36.2238	35.1344	37.3132	8.0079
Diff (1-2)	Pooled	0.5481	-1.7691	2.8653	7.8799
Diff (1-2)	Satterthwaite	0.5481	-1.6817	2.7779	

PARCONTB	Method	95% CL Std Dev	
0		6.2327	9.0564
1		7.3083	8.8568
Diff (1-2)	Pooled	7.2623	8.6131
Diff (1-2)	Satterthwaite		

Method	Variances	DF	t Value	Pr > |t|
Pooled	Equal	265	0.47	0.6418
Satterthwaite	Unequal	94.888	0.49	0.6267

Equality of Variances

Method	Num DF	Den DF	F Value	Pr > F
Folded F	209	56	1.18	0.4780

The TTEST Procedure

Variable: CAGEY_B (CHILD'S AGE IN YEARS:BASELINE)

CHCONTB	N	Mean	Std Dev	Std Err	Minimum	Maximum
0	239	9.2021	2.0379	0.1318	5.0568	13.0787
1	27	12.4825	0.4234	0.0815	11.0144	13.2485
Diff (1-2)		-3.2804	1.9395	0.3938		

CHCONTB	Method	Mean	95% CL Mean		Std Dev
0		9.2021	8.9424	9.4618	2.0379
1		12.4825	12.3150	12.6500	0.4234
Diff (1-2)	Pooled	-3.2804	-4.0557	-2.5050	1.9395
Diff (1-2)	Satterthwaite	-3.2804	-3.5860	-2.9747	

CHCONTB	Method	95% CL Std Dev	
0		1.8701	2.2390
1		0.3335	0.5803
Diff (1-2)	Pooled	1.7872	2.1203
Diff (1-2)	Satterthwaite		

Method	Variances	DF	t Value	Pr > |t|
Pooled	Equal	264	-8.33	<.0001
Satterthwaite	Unequal	194.56	-21.17	<.0001

Equality of Variances

Method	Num DF	Den DF	F Value	Pr > F
Folded F	238	26	23.16	<.0001

The FREQ Procedure

Table of ETHGRP by CHCONTB

ETHGRP(ETHNIC GROUP 1=MEXICAN 2=PUERTO RICAN)
CHCONTB(CHILD'S PERCEPTION OF CONTROL (ACT5):BASELINE)

Frequency Percent Row Pct Col Pct	0	1	Total
MEXICAN	166 62.41 88.77 69.46	21 7.89 11.23 77.78	187 70.30
PUERTO RICAN	73 27.44 92.41 30.54	6 2.26 7.59 22.22	79 29.70
Total	239 89.85	27 10.15	266 100.00

Frequency Missing = 1

The FREQ Procedure

Statistics for Table of ETHGRP by CHCONTB

Statistic	DF	Value	Prob
Chi-Square	1	0.8046	0.3697
Likelihood Ratio Chi-Square	1	0.8460	0.3577
Continuity Adj. Chi-Square	1	0.4554	0.4998
Mantel-Haenszel Chi-Square	1	0.8016	0.3706
Phi Coefficient		-0.0550	
Contingency Coefficient		0.0549	
Cramer's V		-0.0550	

Fisher's Exact Test

Cell (1,1) Frequency (F)	166
Left-sided Pr <= F	0.2546
Right-sided Pr >= F	0.8701
Table Probability (P)	0.1247
Two-sided Pr <= P	0.5057

Effective Sample Size = 266
Frequency Missing = 1

The FREQ Procedure

Table of CONTCLB by PARCONTB

CONTCLB(CLINICIAN-RATED CONTROL:BASELINE)
PARCONTB(WELL-CONTROLLED ASTHMA:PARENT
REPORT (AM2)-BASELINE)

Frequency Percent Row Pct Col Pct	0	1	Total
1	12 4.84 9.45 22.64	115 46.37 90.55 58.97	127 51.21
2	31 12.50 31.31 58.49	68 27.42 68.69 34.87	99 39.92
3	10 4.03 45.45 18.87	12 4.84 54.55 6.15	22 8.87
Total	53 21.37	195 78.63	248 100.00

Frequency Missing = 19

Statistics for Table of CONTCLB by PARCONTB

Statistic	DF	Value	Prob
Chi-Square	2	24.1599	<.0001
Likelihood Ratio Chi-Square	2	24.4986	<.0001
Mantel-Haenszel Chi-Square	1	23.6853	<.0001
Phi Coefficient		0.3121	
Contingency Coefficient		0.2979	
Cramer's V		0.3121	

Effective Sample Size = 248
Frequency Missing = 19

The GLM Procedure

Class Level Information

Class	Levels	Values
ETHGRP	2	MEXICAN PUERTO RICAN

Number of Observations Read	267
Number of Observations Used	247

The GLM Procedure

Dependent Variable: clinconB

Source	DF	Sum of Squares	Mean Square	F Value
Model	9	8.85033689	0.98337077	4.41
Error	237	52.85006797	0.22299607	
Corrected Total	246	61.70040486		

Source	Pr > F
Model	<.0001
Error	
Corrected Total	

strength

R-Square	Coeff Var	Root MSE	clinconB Mean
0.143440	91.84211	0.472225	0.514170

Source	DF	Type I SS	Mean Square	F Value
ETHGRP	1	2.20781408	2.20781408	9.90
AIRSTOT	1	0.92136797	0.92136797	4.13
PARCONTB	1	4.32700255	4.32700255	19.40
HIGHGRAD_B	1	0.04394333	0.04394333	0.20
HCPRELAT	1	0.00034096	0.00034096	0.00
CAGEY_B	1	1.04259725	1.04259725	4.68
NFAMASTH	1	0.03255675	0.03255675	0.15
ASTHDUR	1	0.09253236	0.09253236	0.41
POOR_B	1	0.18218164	0.18218164	0.82

Source	Pr > F
ETHGRP	0.0019
AIRSTOT	0.0432
PARCONTB	<.0001
HIGHGRAD_B	0.6575
HCPRELAT	0.9688
CAGEY_B	0.0316
NFAMASTH	0.7027
ASTHDUR	0.5201
POOR_B	0.3670

The GLM Procedure

Dependent Variable: clinconB

table reading
F

Source	DF	Type III SS	Mean Square	F Value
ETHGRP	1	1.20979414	1.20979414	5.43
AIRSTOT	1	0.37814655	0.37814655	1.70
PARCONTB	1	4.27721068	4.27721068	19.18
HIGHGRAD_B	1	0.02657947	0.02657947	0.12
HCPRELAT	1	0.00036279	0.00036279	0.00
CAGEY_B	1	1.07308902	1.07308902	4.81
NFAMASTH	1	0.04503193	0.04503193	0.20
ASTHDUR	1	0.07500504	0.07500504	0.34
POOR_B	1	0.18218164	0.18218164	0.82

Source	Pr > F
ETHGRP	0.0207
AIRSTOT	0.1941
PARCONTB	<.0001
HIGHGRAD_B	0.7302
HCPRELAT	0.9679
CAGEY_B	0.0292
NFAMASTH	0.6536
ASTHDUR	0.5625 ns
POOR_B	0.3670

The GLM Procedure
Least Squares Means

ETHGRP	clinconB LSMEAN	H0:LSMean1= LSMean2 Pr > |t|
MEXICAN	0.56504039	0.0207
PUERTO RICAN	0.38293927	