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Factors associated with recruitment and retention of diverse children with asthma

Maria Teresa Coutinho,

Bradley/Hasbro Children's Research Center, Warren Alpert Medical School of Brown University, Providence, Rhode Island

Daphne Koinis-Mitchell,

Bradley/Hasbro Children's Research Center, Warren Alpert Medical School of Brown University, Providence, Rhode Island

Sheryl J. Kopel,

Bradley/Hasbro Children's Research Center, Warren Alpert Medical School of Brown University, Providence, Rhode Island

Lilia Romero-Bosch,

Bradley/Hasbro Children's Research Center, Warren Alpert Medical School of Brown University, Providence, Rhode Island

Debra Lobato,

Bradley/Hasbro Children's Research Center, Warren Alpert Medical School of Brown University, Providence, Rhode Island

Elizabeth L. McQuaid,

Bradley/Hasbro Children's Research Center, Warren Alpert Medical School of Brown University, Providence, Rhode Island

Ronald Seifer,

Bradley/Hasbro Children's Research Center, Warren Alpert Medical School of Brown University, Providence, Rhode Island

Gregory K. Fritz, and

Bradley/Hasbro Children's Research Center, Warren Alpert Medical School of Brown University, Providence, Rhode Island

Glorisa Canino

Behavioral Sciences Research Institute, University of Puerto Rico, San Juan, Puerto Rico

Abstract

This study examines factors associated with recruitment and retention of Latino, Dominican (DR) and mainland Puerto Rican (PR), and non-Latino white (NLW) families into a pediatric asthma study. Over eleven hundred (n=1185) families were screened, and 489 (n= 174 NLW, n= 160 DR, n= 155 PR) were enrolled. Rates of recruitment by source of recruitment and rates of retention

differed by ethnic group. Families whose caregiver had never married had lower odds of completing the study. The findings highlight the need for further study to examine the effectiveness of specific recruitment and retention strategies with Latino and non-Latino white families.

Asthma is the most prevalent childhood chronic illness and is associated with considerable morbidity and mortality (Akinbami, Moorman & Liu, 2011). Within the U.S. population, Puerto Rican children experience higher lifetime asthma prevalence rates (16.9%) than any other ethnic group, including Non-Latino Whites (8.2%; Morman, Akinbami, & Bailey, 2012). Given the increased diversity in the American population (Ennis, Rios-Vargas, & Albert, 2011), addressing the participation of ethnic minority populations in clinical research is critical for the development of research with practical, and scientific relevance. This report aims to examine factors associated with the recruitment and retention of a sample of Latino and non-Latino white (NWL) children with asthma in a disparities study.

A number of factors contribute to a history of low ethnic minority participation in clinical research. The abuse of ethnic minority groups during historical events, such as, the Tuskegee syphilis study (Brawley, 1998) have led many to believe that distrust in science and medicine plays a major factor in the limited participation of minorities (Brawley, 1998; Hussain-Gamble, Atkin, & Leese, 2004). Science and medicine's history of paternalism and the tradition of “protecting” vulnerable populations (e.g., the elderly, ethnic minorities and economically disadvantaged populations) may contribute to researchers actively excluding these populations (Hussain-Gamble et al., 2004). Other issues thought to contribute to ethnic minority limited participation in research include: lack of knowledge about the benefits of research (Gul & Ali, 2010; U.S. Department of Health and Human Services, USDHHS, 2002), financial costs associated with study participation, lack of transportation, language requirements for participation (Hussain-Gamble et al., 2004) and subject burden (USDHHS, 2002; Yancey, Ortega, & Kumanyika, 2006). Consequently, there is a need for practices that promote participation and engagement of ethnically diverse groups in research.

Definition of Recruitment and Retention

Recruitment refers to efforts to reach out to, identify and invite eligible participants from the target population to take part in clinical research (Gul & Ali, 2010). Recruitment strategies focus on reaching the greatest number of individuals eligible to participate in a study and providing them with appropriate information to enable them to make an informed decision about whether or not to enroll in a study. A number of recommended strategies for recruitment of minority participants have been identified (Kao et al., 2011; Martinez, McClure, Eddy, Ruth, & Hyers, 2012; Reidy, Orpinas, & Davis, 2011; USDHHS, 2002; Yancey et al., 2006). These address, among other issues, the development of a diverse research team, the involvement of the community of interest, and the development and dissemination of culturally specific study materials. These issues are reflected in the RIPRAC recruitment strategies outlined in table 1.

Retention is conceptualized as a process of providing the conditions necessary such that once enrolled, participants will remain active in the study through its completion (Gul & Ali,

2010). Strategies to promote the retention of participants aim to reduce burdens and barriers to ongoing study participation (Martinez, et al., 2012; Reidy et al., 2011). These strategies include, among others, a research staff that reflects the population targeted, flexible study hours and location, and meaningful incentives. RIPRAC retention strategies, outlined in table 1, reflect these recommendations.

Recruitment and retention within the pediatric literature

A few studies have examined the recruitment and retention of Latino participants in pediatric research. The literature identifies face to face contact with the family, establishing personal relationships with community liaisons, participating in cultural and community events geared towards the target population and free childcare services as factors that enhance Latino families' recruitment (Kao et al., 2011; Martinez et al., 2012; Reidy et al., 2011). Ongoing personal contact with research staff, flexible scheduling, availability of free childcare during study sessions and timely and ongoing incentives have been found to encourage retention with Latino populations (Martinez et al., 2012; Reidy et al., 2011). These strategies reflect the ones used in the RIPRAC study retention procedures (see table 1).

Within the pediatric asthma literature caregiver factors have been associated with study retention. Families with younger caregivers (Zebracki et al., 2003), a single parent (Zook et al., 2010) and full time working parents (Lee, Hayes, McQuaid, & Borrelli., 2010) were more likely to drop out prematurely. Additionally, poverty, ethnicity, and access to care have been associated with pediatric asthma healthcare utilization (Canino et al., 2009). While the literature focuses on healthcare utilization, we were interested in the extent to which these factors might be associated with recruitment and retention in clinical research.

Specific to pediatric asthma health disparities, Canino and colleagues (2006) articulated a framework that outlines environmental/contextual (e.g., poverty), health care system (e.g., health insurance policies), process of care, (e.g., access to care) provider (e.g., training) and individual (e.g., ethnicity) characteristics that contribute to disparities in the prevalence, morbidity and severity of asthma. The framework posits that variations in asthma outcomes among Latino children are multi-determined, and are likely the result of an interaction of factors across these levels. For example, poverty may impact families' ability to afford medication co-pays and fill prescriptions with implications for asthma control. Using this framework as a starting point, we sought to examine the impact of characteristics of specific domains outlined in the model, contextual/environmental (e.g., poverty), individual (e.g., child ethnicity, caregiver marital status), process of care (e.g., access to care), and a disparity outcome (e.g., asthma severity) in recruitment and retention in an asthma disparities study.

The Rhode Island- Puerto Rico Asthma Center (RIPRAC) (see Canino et al., 2009 for full study description) recruited children with asthma, from Puerto Rico and Rhode Island, in order to study possible contributors to differences in asthma rates, severity and treatment between Latino and non-Latino children. This report describes recruitment and retention efforts undertaken only in Rhode Island, by the RI RIPRAC investigator team (RI Team). We limit our focus to RI given the efforts to recruit three ethnic groups with an equally

diverse team of staff and researchers. Within RI, the RI Team targeted two Latino subgroups, Puerto Rican (PR) and Dominican (DR) children with asthma and their caregiver, in addition to a non-Latino white (NLW) comparison sample of children and caregivers. The inclusion of an additional Latino subgroup (DR) in the parent study, allowed for a comparison of health disparities factors in two Latino populations which are differentially impacted by asthma, with PR children experiencing higher asthma prevalence rates.

Given the RI team's focus on NLW, PR and DR children with asthma, we were interested in examining whether there were ethnic group differences depending on sources of recruitment (e.g., asthma education program, community providers, Emergency Department). Consistent with previous literature (Kao et al., 2011; Reidy et al., 2011) we expected that Latino families would be more likely to respond to recruitment from venues that allowed for personal contact, such as physician offices, rather than flyers. Additionally, we examined whether factors conceptualized as impacting asthma disparities, including ethnicity, poverty status, asthma severity, access to care indicators, and caregiver marital status (Canino et al., 2006) were associated with study retention. Given findings with Latinos (Reidy et al., 2011), we hypothesized that across ethnic groups, those with higher incomes, who reported greater asthma severity and less access to care, were more likely to complete the study. Families with children with more severe asthma and who perceived less access to care may view study participation as a way to obtain more information and get access to services related to asthma (e.g., pulmonary function testing) and be more motivated to complete the study. Given previous literature (Lee et al., 2010), we hypothesized that single parent families would be more likely to dropout prematurely.

Methods

Latino (Puerto Rican or Dominican) and NLW children (7-15 years old) whose caregivers reported an asthma diagnosis and the caregiver were invited to participate. This study was approved by the IRB at Rhode Island Hospital and University of Puerto Rico. Families were informed about the nature of their participation in the study, and caregivers provided consent, while children provided assent at the initial study session. The study's exclusion criteria included: child with moderate to severe mental retardation, child's inability to complete pulmonary function testing, and other minority status (e.g., Asian). Participants completed 4 sessions over the course of approximately 3 months. In addition to completing study questionnaires, participants completed a clinic visit (session 2), which included pulmonary function and allergy testing, asthma symptom history and a physical exam. Children were trained to use electronic medication monitoring devices and a handheld portable spirometer, which they used daily at home for a month (see Canino et al., 2009; Fritz et al., 2010; McQuaid et al., 2012 for protocol details). Families were given the option to complete the study in English or Spanish as measures were available in both languages.

Variables relevant to the current study

Ethnicity—Child ethnicity was determined by report of the primary caregiver.

Demographic characteristics—A demographics form included questions that assessed caregiver marital status, family annual income, and language preference.

Poverty threshold—An income-to-needs ratio was calculated by dividing the family's annual income by the federally established poverty threshold for a family that size for the year of study participation (USDHHS, 2005). Families with a ratio of one or below were considered at or below the poverty line.

Asthma Severity—Asthma severity was classified as “mild intermittent,” “mild persistent,” “moderate persistent” or “severe persistent” as specified by National Institutes of Health (NIH) guidelines that were current at the time of study inception (National Heart, Lung, & Blood Institute, NHLBI, 1997). Study clinicians determined asthma severity using the child's medical history, physical examination and pulmonary function testing completed during the clinic visit (see Esteban et al., 2009).

Access to Care—Access to care was measured using the Health Services Research Questionnaire (Ortega, Belanger, Bracken, & Leaderer, 2001). The measure does not provide a total score and uses discrete variables that assess health care use with yes/no responses (Jandasek et al., 2011). Measure development included focus group testing, and it has been administered in English and Spanish. (Ortega et al., 2001; Ortega, Gergen Paltiel, Bauchner, Belanger, & Leaderer, 2002). For the present study, three items were used to assess continuity of care: use of a consistent healthcare site for regular physicals, use of a consistent asthma care site, and having a consistent asthma provider.

Recruitment sources and procedures—Participants were recruited from 1) hospital and community based primary care clinics and the Emergency Room (ER), 2) primary care physicians collaborating with the study, 3) schools, 4) hospital and community based asthma education program (AEP), 5) general community events, 6) PR and DR cultural festivals, 7) word of mouth and past research, and 8) mailings and advertisements. Flyers were posted at recruitment sources and sent to physicians, schools and other public venues. A detailed description of the recruitment methods used is included on table 1. Consent to Contact (CTC) forms were distributed at all recruitment sources to interested families. Families who returned CTCs indicating interest in study participation received follow up screening calls assessing eligibility and willingness to participate in the study.

Retention—Study retention was defined as completion of all four study sessions. Specific methods used in RIPRAC to enhance retention are detailed in table 1.

Statistical analysis plan

Chi-square analyses were used to examine ethnic group differences in recruitment source and differences in rates of retention as a function of pediatric asthma disparities factors (ethnicity, poverty status, asthma severity, access to care indicators, and caregiver marital status). We used logistical regression to examine the association of study retention rates with pediatric asthma disparities factors and recruitment source. Cramer's Phi (ϕ_c) values

indicated the effect sizes for chi square analyses. The significance of findings was assessed using an alpha of .05.

Results

Screening and enrollment information

A total of 1185 families were screened, 695 were deemed eligible, and 525 agreed to participate in the study. For those who were not eligible ($n=490$), reasons for study ineligibility included reported ethnic identity, child age, and no asthma diagnosis, among others (see figure 1 for details about study eligibility and enrolment). Complete ethnicity data is not available for those eligible who did not enroll in the study ($n=170$). Within those who were eligible to participate, there were no differences in recruitment sources between those who refused and those who opted to participate ($\chi^2=25.70$, $p=.10$). Of the 525 who agreed to participate, further information (e.g., no asthma, evidence of significant cognitive or behavioral issue, presence of other medical condition) provided at the initial session led to the exclusion of 36 participants. In total, 489 children with asthma (7-15 years old) and primary caregivers from NLW ($n=174$), PR ($n=155$) and DR ($n=160$) backgrounds were enrolled.

Recruitment sources—None of the families were recruited from more than one source. Recruitment source was missing for 9% of those who enrolled in the study. There were no significant differences in demographic (e.g., age, gender, ethnicity, caregiver marital status, poverty threshold), access to care and asthma severity, between those with and those without an identified recruitment source. Asthma Education Program (AEP) referrals comprised 28.3 % of all recruitment. The next largest recruitment source (22.7 %) was community based primary care physicians who collaborated with the research program (see table 2).

Demographic information

The mean child age was 10.6 (ages ranged from 7 to 15 years old), and the majority of children were males (55.8%). Latino parents preferred to complete the protocol in Spanish, with all NLW caregivers preferring English (see table 3). Most caregivers reported being currently married (50.1%) or never married (21.1%). There were significant differences in marital status by ethnicity ($\chi^2=63.03$, $p=.000$). Asthma severity was not available for children (18.2%) who did not complete the clinic session. The majority of the children were classified as having moderate persistent (27.2%) and severe persistent (22.1%) asthma. No significant ethnic differences were found in asthma severity ($\chi^2=10.1$, $p=.12$). The majority (56.7%) of the families reported incomes that placed them above the poverty threshold. Ethnic groups differed in the percentage of families living above the poverty threshold ($\chi^2=96.83$, $p=.000$) with 86.2% of NLW, 42.5% of DR and 37.9% of PR families above the poverty line (see table 3).

Ethnic group differences in recruitment sources

We found ethnic group differences in recruitment sources ($\chi^2=128.79$, $p=.000$). Higher percentages of DR families were recruited through community physician research collaborators (47.9%), while NLW families were mostly recruited through AEP (43.3%).

The majority of PR families came from a wider range of sources: outpatient clinics and the ER (20.7%), community physician collaborators (20.7%) and AEP (20%; see table 2).

Rates of retention by ethnic group

From the initially enrolled 489 families, 22 % (n= 106) did not complete the study (see figure 1). Of those initially enrolled, 6% were found ineligible at the initial session, 7% were lost to follow up, and 9% actively withdrew from the protocol for a variety of reasons (e.g., no longer interested, family issues, etc). Seventy-eight percent (n=383) of enrolled families completed the entire protocol. Retention varied by ethnicity ($\chi^2=19.2$, $p=.000$), with NLW families (85%) having greater rates of study completion followed by DR (83%) and PR families (66.5%).

Pediatric asthma disparities factors and their association with study retention

We examined differences between completers and non completers as a function of pediatric asthma disparities factors (poverty status, asthma severity, access to care indicators, and caregiver marital status). We found significant differences in completion rates as a function of poverty threshold ($\chi^2=3.98$, $p=.05$) and marital status ($\chi^2=12.32$, $p=.01$) (see table 4).

Lastly, a logistical regression was completed to examine the extent to which pediatric asthma disparities factors (ethnicity, poverty status, asthma severity, access to care indicators, and caregiver marital status) and recruitment source predicted study retention. We found that families with caregivers who never married were twice as likely to *not* complete the study (see table 5).

Discussion

The goal of the RIPRAC study was the investigation of asthma health disparities in the context of ethnicity and culture, and as such, it focused on three distinct ethnic groups, NLW, DR and PR. Extensive efforts were made within the Rhode Island site to develop and maintain culturally and linguistically appropriate study recruitment and retention methods. Strategies for recruitment and retention used were reflective of NIH guidelines for research with ethnically diverse populations (USDHHS, 2002).

Recruitment source differences by ethnic group

As expected, we found that recruitment rates of specific ethnic groups varied as a function of recruitment source (Kao et al., 2011). A higher percentage of DR families were recruited through a self-identified DR physician. This physician's close connection with the study may have enhanced his commitment to identifying eligible participants within his practice. While we were successful in developing these relationships within the DR community, we were not able to identify physicians within the PR community. This may have contributed to our lower recruitment rates with PR families. Similarly, our greatest source of recruitment, the AEP, has a strong record of serving the communities targeted (e.g., NLW and Latino) and included in its staff members of the RI team. This overlap certainly may have contributed to the high yield of study enrollees from the AEP. For all the targeted groups, we found greater

recruitment success with sources that allowed for more personal contact (e.g., AEP, physicians' offices).

Retention efforts

There were significant differences in rates of study retention, with PR families exhibiting higher rates of study dropout than NLW and DR families. Many of the DR families came from DR community providers, where office staff also volunteered as recruitment staff for the study. Given that research suggests that participants' perceptions of research being connected to their community is more likely to support retention (Yancey et al., 2006), it is possible that this may have carried over to families' decision to remain engaged in the study. Given that this same connection with a community provider was not available in the PR community this may have contributed, in addition to other factors discussed below, to their higher drop out rates. Despite these ethnic group differences our rates of retention are similar to those reported in the pediatric asthma literature with diverse populations (71%-89%) (Lee et al., 2010; Zebracki et al., 2003; Zook et al., 2010).

Factors relevant to pediatric asthma disparities and study retention

We found that families with higher rates of completion tended to be above the poverty line. It is likely that these families may not experience the same stressors as less economically advantaged families and this afforded them the opportunity to remain engaged in the study. PR families who dropped out also reported greater poverty, and it seems feasible that, given economic stressors and competing demands, they were less likely to prioritize study participation. Previous pediatric asthma clinical research, did not find an association between income and study completion (Zebracki et al., 2003). However, this may be due to the fairly homogeneous samples of low income populations in those studies, which may have limited the ability to detect differences in retention by income level (Lee et al., 2010; Zebracki, et al., 2003; Zook et al., 2010).

Similar to other studies we found no association between participant retention and asthma severity (Zebracki et al., 2003). Additionally, access to care variables were not related to study retention. Further research is needed to understand how asthma specific factors may be related to study retention.

As previously found (Zook et al., 2010), married caregivers were more likely to complete the study. Caregivers who share parenting responsibilities with a partner may have the flexibility to engage in research. In our logistical regression procedures never married caregivers were two times more likely to drop out of the study when compared with caregivers endorsing any other marital status. This finding highlights the need for retention procedures to address the specific needs of single parent families involved in clinical research. While we attempted to address difficulties related to scheduling, childcare and transportation, it may be possible that the added responsibility to participate in the study in and of itself may have contributed to these caregivers choosing to opt out.

Limitations

While we examined factors associated with recruitment and retention, given the secondary data analysis in this report, we cannot distinguish which recruitment and retention methods were effective. For example, complete information is not available for those who did not enroll in the study, and we are not able to accurately calculate ethnic group enrollment rates. Additional specific information about varied efforts to recruit and retain participants (e.g., number of phone calls to schedule sessions, other contacts and amount of contact time per family) that may provide a more adequate understanding of recruitment and retention success are not fully documented. Future research should fully document those efforts. Missing data regarding recruitment source is an additional limitation. Given the study's focus, the findings may not be applicable to other Latino groups (e.g., Mexicans) or to populations with other chronic illnesses. Despite our efforts there were ethnic group differences in level of poverty, which may be a confound for recruitment and retention rates. Additionally, we did not examine factors related to caregiver acculturation and length of residence in the U.S. and their potential association with recruitment and retention.

Implications for Practice

The findings support the utility of a pediatric asthma disparities framework (Canino et al., 2006) in understanding ethnically diverse families' participation in clinical research. It is important that investigators working with ethnically diverse and low income populations become more systematic in documenting, monitoring, and disseminating their efforts to recruit and retain participants. Systematic documentation and dissemination of effective research recruitment and retention would contribute to enhancing the participation of diverse populations in clinical research. Given the greater diversity in family composition around the world, it becomes imperative to further understand how caregivers negotiate and make decisions about enrollment and sustained participation in clinical research, and specific individual and research related factors that may impact those decisions. Including these considerations in study design is important for investigators to develop strategies to support the representation of diverse populations and families in clinical research endeavors.

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References

- Akinbami, L.J.; Moorman, J.E.; Liu, X. National Health Statistics Report. Vol. no 32. Hyattsville, MD: National Center for Health Statistics; 2011. Asthma prevalence, health care use, and mortality: United States, 2005-2009.
- Brawley OW. The study of untreated syphilis in the Negro male. *International Journal of Radiation Oncology, Biology, Physics*. 1998; 40(1):5–8.10.1016/S0360-3016(97)00835-3
- Canino G, Koinis-Mitchell D, Ortega AN, McQuaid EL, Fritz GK, Alegria M. Asthma disparities in the prevalence, morbidity, and treatment of Latino children. *Social Science & Medicine*. 2006; 63(11):2926–37.10.1016/j.socscimed.2006.07.017 [PubMed: 16956704]

- Canino G, McQuaid EL, Alvarez M, Colon A, Esteban C, Febo V, Fritz G, et al. Issues and methods in disparities research: the Rhode Island-Puerto Rico asthma center. *Pediatric Pulmonology*. 2009; 44:899–908.10.1002/ppul.21075 [PubMed: 19658111]
- Ennis, S.; Rios-Vargas, M.; Albert, N. Washington, DC: US Census Bureau; 2011. The Hispanic population: 2010. NoC2010BR-04<http://www.census.gov>
- Esteban C, Klein RB, McQuaid EL, Fritz GK, Seifer R, Kopel S, Canino G, et al. Conundrums in childhood asthma severity, control, and health care use: PR vs. RI. *Journal of Allergy and Clinical Immunology*. 2009; 124:238–44.10.1016/j.jaci.2009.05.014 [PubMed: 19615729]
- Fritz GK, McQuaid EL, Kopel SJ, Seifer R, Klein RB, Koinis Mitchell D, Canino G. Ethnic differences in perception of lung function: A factor in pediatric asthma disparities? *American Journal of Respiratory & Critical Care Medicine*. 2010; 182:12–18.10.1164/rccm.200906-0836OC [PubMed: 20299534]
- Gul R, Ali P. Clinical trials: the challenge of recruitment and retention of participants. *Journal of Clinical Nursing*. 2010; 19:222–233.10.1111/j.1365-2702.2009.03041.x
- Hussain-Gamble M, Atkin K, Leese B. Why ethnic minority groups are under-represented in clinical trials: a review of the literature. *Health and Social Care in the Community*. 2004; 12(5):382–388.10.1111/j.1365-2524.2004.00507.x [PubMed: 15373816]
- Jandasek B, Ortega AN, McQuaid EL, Canino G, Koinis-Mitchell D, Colon A, Fritz GK, et al. Health care access and use of health services for Latino children with asthma. *Medical Care Research and Review*. 2011; 68:683–698.10.1177/1077558711404434 [PubMed: 21536604]
- Kao B, Lobato D, Grullon E, Cheas L, Plante W, Seifer R, Canino G. Recruiting Latino and Non-Latino families in pediatric research: Considerations from a study on childhood disability. *Journal of Pediatric Psychology*. 2011; 36(10):1093–1101.10.1093/jpepsy/jsr030 [PubMed: 21685459]
- Lara M, Akinbami L, Flores G, Morgenstern H. Heterogeneity of childhood asthma among Hispanic children: Puerto Rican children bear a disproportionate burden. *Pediatrics*. 2006; 117:43–53.10.1542/peds.2004-1714 [PubMed: 16396859]
- Lee CS, Hayes RB, McQuaid EL, Borrelli B. Predictors of retention in smoking cessation treatment among Latino smokers in the Northeast United States. *Health Education Research*. 2010; 25(4): 687–697.10.1093/her/cyq010 [PubMed: 20237106]
- Martinez CR, McClure HH, Eddy JM, Ruth B, Hyers MJ. Recruitment and retention of Latino immigrant families in prevention research. *Prevention Science*. 2012; 13:25–26.10.1007/s11121-011-0239-0
- McQuaid EL, Everhart RS, Seifer R, Kopel SJ, Koinis-Mitchell D, Klein RB, Canino G, et al. Medication adherence among Latino and Non-Latino White children with asthma. *Pediatrics*. 2012; 129(6):e1404–10.10.1542/peds.2011-1391 [PubMed: 22566417]
- Moorman, JE.; Akinbami, LJ.; Bailey, CM. Vital Health Stat. Vol. 3. National Center for Health Statistics; 2012. National Surveillance of Asthma: United States 2001-2010.
- National Heart, Lung, and Blood Institute. Guidelines for the diagnosis and management of asthma. 2005. Retrieved from <http://www.nhlbi.nih.gov/guidelines/asthma/asthsumm.pdf>
- Ortega A, Belanger K, Paltiel A, Horwitz SM, Bracken MB, Leaderer BP. Use of health services by insurance status among children with asthma. *Medical Care*. 2001; 39:1065–1074.10.1097/00005650-200110000-00004 [PubMed: 11567169]
- Ortega AN, Gergen PJ, Paltiel AD, Bauchner H, Belanger KD, Leaderer BP. Impact of site of care, race, and Hispanic ethnicity on medication use for childhood asthma. *Pediatrics*. 2002; 109:E1.10.1542/peds.109.1.e1 [PubMed: 11773569]
- Reidy M, Orpinas P, Davis M. Successful recruitment and retention of Latino study participants. *Health Promotion Practice*. 2011; 13(6):779–787.10.1177/1524839911405842 [PubMed: 21540195]
- U.S. Department of Health and Human Services, Public Health Service. National Institutes of Health: Outreach notebook for the NIH guidelines on inclusion of women and minorities as subjects in clinical research. Bethesda, MD: National Institute of Health; 2002. (NIH Pub No. 03-7036). <http://orwh.od.nih.gov>
- U.S. Department of Health and Human Services. The 2005 HHS Poverty Guidelines. Washington, DC: U.S. Department of Health and Human Services; 2005. <http://aspe.hhs.gov>

- Yancey A, Ortega A, Kumanyika S. Effective recruitment and retention of minority research participants. *Annual Review of Public Health*. 2006; 27:1–28.10.1146/annurev.publhealth.27.021405.102113
- Zebracki K, Drotar D, Kirchner L, Schluchter M, Redline S, Kercsmar C, Walders N. Predicting attrition in a pediatric asthma intervention study. *Journal of Pediatric Psychology*. 2003; 28(8): 519–528.10.1093/jpepsy/jsg042 [PubMed: 14602842]
- Zook PM, Jordan C, Adams B, Visness CM, Walter M, Pollenz K. Retention strategies and predictors of attrition in an urban pediatric asthma study. *Clinical Trials*. 2010; 7:400–410.10.1177/17407745103737 [PubMed: 20571137]

Figure 1. Screening, eligibility and enrollment of participants

Note. Ethnicity data is incomplete for participants who did not enroll in the study

Table 1
Recruitment & retention strategies implemented by the RI RIPRAC Study

Recruitment Strategies	Description of Methods
1) Research team reflective of target population	<ul style="list-style-type: none"> Human resources postings noting our preference for bilingual and bicultural staff Collaborators within the targeted communities were informed of the research staff positions and asked to inform qualified individuals in their communities 41% of the research team self-identified as Latino RI Team was comprised of 11 bicultural and bilingual research assistants, 18% of the staff identified as Dominican or Puerto Rican The recruitment specialist self-identified as Dominican
2) Relationships with hospital and community clinic providers (CCP)	<ul style="list-style-type: none"> Investigators in the team were staff members at the local children's hospital, with ongoing relationships with the hospital and targeted communities CCP identified through practices in the area and relationships from the investigators' previous clinical and research efforts. Relationship development involved a full description of the project by the recruitment specialist and investigators, regular visits and presentations at staff meetings. During these presentations lunch and/or snacks were provided to the office staff.
3) Recruitment monitoring strategies.	<ul style="list-style-type: none"> Recruitment sites were visited weekly to collect consent to contact (CTC) forms. Recruitment sources with low CTCs were visited more often and recruitment procedures were revised to decrease clinic burden and address barriers. For example, at one medical office, bilingual staff members were trained to be volunteer research staff and assist with recruitment in that capacity. Office staff was provided with thank you letters and gift baskets (e.g., fruit, cookies) as ongoing gratitude for their recruitment assistance.
4) Culturally appropriate promotional materials	<ul style="list-style-type: none"> Posters, information boxes and other materials were developed by the research staff and a local artist in English and translated into Spanish. English and Spanish materials were displayed in medical offices, schools and other community settings. Spanish language materials were distributed in community venues (e.g., hair salons, bodegas). Advertisements were placed in local radio, cable network TV, newspapers, and community newsletters targeting the populations of interest.
5) Community benefits of research.	<ul style="list-style-type: none"> The investigators and staff through word of mouth, personal contacts and participation in community events, consistently provided the message of the importance of learning about pediatric asthma disparities from the Latino community itself. For example, presentations were made by Latino providers from the Community Asthma Program at a Hispanic Support group.
6) Population-specific dissemination strategies.	<ul style="list-style-type: none"> "Word of mouth" strategies were used to disseminate information about the study and benefits of participation. Research staff used informal and formal opportunities to raise awareness about the study and identify potential participants with community contacts, local media, and contact with the wider medical community.
Retention Strategies	Description of methods
1) Development of ongoing relationships.	<ul style="list-style-type: none"> The bilingual research team allowed for families' preferences to guide the protocol language. Research assistants were assigned to specific families through study completion, developing consistent relationships.
2) Logistical support for participants.	<ul style="list-style-type: none"> Taxi vouchers were provided if participants required transportation to and from clinic visits. Meals were provided during clinic sessions.

Recruitment Strategies	Description of Methods
	<ul style="list-style-type: none"> Childcare was available for research sessions, when needed.
3) Population specific study materials.	<ul style="list-style-type: none"> Measures were translated by the investigators in Puerto Rico and adapted using procedures that focused on establishing cross-cultural semantic, content, and technical domain equivalence (Canino et al., 2009). The RI translation committee included native Spanish speakers who assessed the translations provided by the Puerto Rico team.
4) Flexible study participation.	<ul style="list-style-type: none"> Data collection strategies were tailored to the families' needs, accommodating families' work schedules, school and other responsibilities. Most sessions took place in the afternoon, evenings and during the weekend.
5) Alternate contact information.	<ul style="list-style-type: none"> Families provided alternate contact information at the beginning of the study. If families did not have phones, additional home visits were conducted and reminder letters were sent.
6) Providing tangible benefits.	<ul style="list-style-type: none"> At the final session, the participants were given a summary of the all relevant clinical findings, including allergy and lung function testing. With the families' consent, primary care physicians were contacted at study completion and provided with information regarding clinical assessments completed as part of the study. In the course of study participation, if needs related to asthma or other concerns arose, the team worked together to identify and provide appropriate resources as needed.
7) Appropriate and timely incentives	<ul style="list-style-type: none"> Families received \$25 for sessions 1, 3, and 4. For the clinical session (session 2), families received \$75. Families were compensated \$50 for returning each of the two devices at the end of monitoring. Those who completed all sessions received a total of \$250.

Table 2
Recruitment Sources – N (%)

Recruitment Source	Overall (% within rec. sources)	NLW (% within NLW)	PR (% within PR)	DR (% within DR)
Asthma Education Program	125 (28.3%)	68 (43.3%)	28 (20%)	29 (20.1%)
Community physicians	100 (22.7%)	2 (1.3%)	29 (20.7%)	69 (47.9%)
Community events	67 (15.2%)	28 (17.8%)	23 (16.4%)	16 (11.1%)
Outpatient clinics & ER	60 (13.6%)	19 (12.1%)	29 (20.7%)	12 (8.3%)
Schools	37 (8.4%)	24 (15.3%)	6 (4.3%)	7 (4.9%)
Mailings/Advertisements	23 (5.2%)	11 (7%)	9 (6.4%)	3 (2.1%)
Word of Mouth	15 (3.4%)	2 (1.3%)	9 (6.4%)	4 (2.8%)
Cultural Events	14 (3.2%)	3 (1.9%)	7 (5%)	4 (2.8%)

Notes. Recruitment sources not available for those who did not enroll in the study

Missing recruitment source for 48 participants.

Table 3

Participant characteristics (percentages) and differences by ethnic group

	All (N= 489)	NLW (n=174)	PR (n=155)	DR (n= 160)	Differences [§]	Effect Size ^{§§}
Age in Years- M (SD)	10.6 (2.5)	10.6 (2.6)	10.7 (2.4)	10.5 (2.4)	F(2,486)= .198	$\omega^2_p = -.003$
Sex (% male)	273 (55.8)	111 (63.8)	79 (51)	83 (51.9)	$\chi^2=6.95^*$	$\phi_c = .12$
Spanish as Caregiver Language (%)	177 (44.3)	0 (0)	61 (54.5)	116 (84.7)	$\chi^2=215.32^{***}$	$\phi_c = .73$
Marital Status (%)	245 (50.4)	121 (69.5)	52 (33.8)	71 (45.6)	$\chi^2=58.72^{**}$	$\phi_c = .24$
Separated	53 (10.9)	4 (2.3)	23 (14.9)	26 (16.5)		
Divorced	77 (15.8)	25 (14.4)	25 (16.2)	27 (17.1)		
Widowed	8 (1.6)	2 (1.1)	5 (3.2)	1 (.6)		
Never Married	103 (21.2)	22 (12.6)	49 (31.8)	32 (20.3)	$\chi^2=96.84^{**}$	$\phi_c = .44$
Poverty Threshold (%)	276 (56.4)	150 (86.2)	58 (37.9)	68 (42.5)		
Above	211 (43.1)	24 (13.8)	95 (62.1)	92 (57.5)		
Below	65 (13.3)	29 (19.2)	14 (12.5)	22 (16.1)	$\chi^2=10.1$	
Mild Intermittent	94 (19.2)	39 (25.8)	30 (26.8)	25 (18.2)		
Mild Persistent	153 (27.2)	51 (33.8)	40 (35.7)	42 (30.7)		
Moderate Persistent	108 (22.1)	32 (21.2)	28 (25)	48 (35)		$\phi_c = .11$
Severe Persistent						

Notes.

* p < .05;

** p < .01

Spanish as caregiver language reflects preferred language.

§ Some degrees of freedom vary due to missing data on specific variables

§§ Partial omega squared (ω^2_p) is interpreted as small (.01), medium (.06) or large (.14). Cramer's Phi (ϕ_c) is used to denote chi square effect size; its interpretation is similar to a point-biserial correlation

Table 4
Chi-squares (effect size) between those who completed and those who did not complete all 4 sessions

	Completed all 4 sessions					Did not complete 4 sessions				
Ethnic groups	$\chi^2=19.15^{**} (\phi_c = .14)$									
N (%)	All 383 (78.3)	NLW 148 (85.1)	PR 103(66.5)	DR 132 (82.5)	All 106(21.7)	NLW 26(14.9)	PR 52 (33.5)	DR 28 (17.5)		
Poverty Threshold	$\chi^2=71.7^{**}(\phi_c = .43)$					$\chi^2=23.03^{**} (\phi_c = .47)$				
Above Thresh.	226 (46.4)	127 (73)	42 (22.5)	57(35.6)	50(10.3)	23 (13.2)	16(10.5)	11(6.9)		
Below Thresh.	157(32.2)	21(12.1)	61(39.9)	75(46.9)	54 (11.1)	3(1.7)	34(22.2)	17(10.6)		
Asthma severity	$\chi^2=9.37 (\phi_c = .11)$					$\chi^2=3.12 (\phi_c = .30)$				
Mild Intermittent	65 (16.3)	29 (19.2)	14(12.5)	22 (16.1)	0(0)	0 (0)	0(0)	0 (0)		
Mild Persistent	91(22.8)	38 (25.2)	29 (25.9)	24 (17.5)	3(8)	1 (7)	1 (.9)	1 (7)		
Mod. Persistent	123(30.8)	50(33.1)	33(29.5)	40(29.2)	10(2.5)	1(7)	7 (6.3)	2(1.5)		
Severe Persistent	104(26)	3120.5)	27 (24.1)	46(33.6)	4(1)	1(7)	1(9)	2 (1.5)		
Marital Status	$\chi^2=58.23^{**} (\phi_c =.27)$					$\chi^2=21.15^* (\phi_c = .32)$				
Married	204 (42)	108(62.1)	35 (22.7)	61(38.6)	41(8.4)	13 (7.5)	17(11)	11(7)		
Separated	37 (7.6)	1 (6)	17 (11)	19 (12)	16 (3.3)	3(1.7)	6(3.9)	7(4.4)		
Divorced	64 (13.2)	20 (11.5)	20 (13)	24 (15.2)	13 (2.7)	5(2.9)	5 (3.2)	3(1.9)		
Widowed	6(1.2)	0(0)	5 (3.2)	1(6)	2 (.4)	2(1.1)	0 (0)	0 (0)		
Never Married	71(14.4)	19 (10.9)	26(16.9)	26(16.5)	32(6.6)	3(1.7)	23(14.9)	6(3.8)		

Notes. Cells include sample size followed by (%) within overall sample or ethnic group).

* $p < .05$;

** $p < .01$

Table 5
Bivariate logistical regression for study completion

Variable		OR	95% CI
Ethnicity	(NLW reference)	---	
	Puerto Rican	.367	.078-1.73
	Dominican	.605	.107-3.41
Marital Status	(Married reference)	---	
	Separated	.606	.077-4.79
	Divorced	.599	.086-4.16
	Widowed	.552	.000-.000
	Never Married	.150**	.035-.654
Poverty Threshold (%)	Above	---	
	Below	.566	.157-2.03
Recruitment Source	(Outpatient clinics & ER reference)	---	
	Mailings/Advertisements	2.15	.18-25.90
	Community physicians	2.39	.412-13.91
	Asthma Education Program	1.23	.286-5.36
	Community events	1.40	.209-9.36
	Cultural Events	.122	.000-.000
	Schools	.459	.000-.000
	Word of Mouth	.784	.088-6.95
Asthma severity	(Mild Intermittent reference)	---	
	Mild Persistent	.000	---
	Moderate Persistent	.000	---
	Severe Persistent	.000	---
Access to care:	Consistent site for physical care	.000	---
(no as reference)	Consistent site for asthma care	.000	---
	Consistent provider for asthma	.278	.051-1.52

Notes.

* p <.05;

** p<.01.

N= 395, missing data for 94 participants. OR = Odds Ratio; 95% CI= 95% Confidence Interval