



Published in final edited form as:

Prog Community Health Partnersh. 2010 ; 4(4): 315–324. doi:10.1353/cpr.2010.0025.

The Development of a Community-Based Family Asthma Management Intervention for Puerto Rican Children¹

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Abstract

Background—Puerto Rican children maintain disproportionately high asthma prevalence rates and effective asthma management interventions are needed.

Objectives—This article describes how community-based participatory research (CBPR) was implemented in the development of a culturally tailored family asthma management intervention for Puerto Rican children: CALMA (a Spanish acronym for Take Control, Empower Yourself, and Achieve Asthma Management).

Method—CALMA was developed according to CBPR principles and contemporary asthma guidelines through the collaboration of diverse members of the local, professional, and medical communities, academia, and local government. All group members contributed unique perspectives, making CALMA's development a collaborative effort.

Lessons Learned—The CALMA community dealt with challenges in both incorporating and managing a diverse group of stakeholders and maintaining equity in decision making power. However, the community maintained strengths, such as incorporating culturally accepted remedies and addressing culturally specific myths in the intervention, as well as having the medical community directly involved in overseeing the accuracy of the intervention.

Conclusion—A CBPR approach enhanced the cultural sensitivity of the intervention as well as its potential for sustainability.

Keywords

Community-based participatory research; process issues; asthma management; asthma intervention; Puerto Rican children

Among minority groups, Puerto Ricans experience disproportionately high asthma prevalence and morbidity. Mainland Puerto Rican children have higher prevalence rates of lifetime asthma than any other ethnic group in the United States,^{1,2} and island Puerto Rican children maintain even higher rates (41.3%) than mainland children (35.3%).³ Moreover, Puerto Rican children experience more asthma attacks^{1,2} and maintain higher rates of asthma-related service utilization than other asthmatic children.^{3,4} Numerous factors may contribute to disparities in asthma care, including genetic and biological factors, exposure to

¹Funding for this project was provided by the National Institutes of Health, grant #P20 MD000537-01, and the National Center for Minority Health and Health Disparities, #1P50 MHO 73469-01, funded by the National Institutes of Health.

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environmental allergens, cultural beliefs about medical management, insurance coverage, stereotyping by providers, and language barriers (see Canino et al.^{5,6} for a review).

Inadequate asthma management has been linked to elevated asthma morbidity, service utilization,^{7,8} and a poor quality of life.⁹ Commonly implemented asthma management strategies promote the four components of asthma care outlined by the National Asthma Education and Prevention Program 2007 Guidelines (NAEPP): (1) regular assessment and observation of asthma severity and control, (2) asthma education provided to the family, (3) control of environmental factors and other medical and psychological conditions that may contribute to or aggravate symptoms, and (4) pharmacologic therapy and education.¹⁰ Asthma management interventions that educate families on how to better control asthma have been shown to be more effective in decreasing asthma morbidity and increasing service utilization than standard treatments.^{11–14} Moreover, culturally tailored asthma management interventions are more effective for minorities than generic interventions applied to minority groups.¹⁵ Because asthma disparities result from a complex set of factors, interventions aimed at reducing asthma disparities must also address these complexities.¹⁶

CBPR is an orientation to research where diverse partners within a community collaborate in an effort to initiate change and improve the community's long-term quality of life.¹⁷ CBPR has proven to be particularly effective in addressing and reducing health disparities in minorities through disease education¹⁸ in a variety of domains, including AIDS,^{19,20} cancer,^{21–23} cardiovascular disease,^{24,25} and pediatric asthma.²⁶ However, a CBPR approach has not been employed in developing asthma management interventions specifically for Puerto Rican children, who disproportionately suffer from this disease. This paper gives a description of the lessons learned regarding a CBPR approach was implemented to develop a culturally tailored asthma management intervention for low-income Puerto Rican families aimed at decreasing childhood asthma morbidity—CALMA.

Methods

Objectives and Results of a Trial of the CALMA Intervention

CALMA was a home-based intervention in which trained counselors delivered eight educational modules about asthma that were culturally tailored for a low-income Puerto Rican population. A randomized, controlled trial was performed to assess the effectiveness of the CALMA intervention in reducing asthma morbidity in poor Puerto Rican children with persistent asthma, and in increasing caregivers' confidence in managing their child's asthma. The randomized, controlled trial was approved by the University of Puerto Rico's Institutional Review Board. As reported,²⁷ children in the CALMA intervention group did better than children in the control group in terms of having 6.5% more symptom-free nights, three times greater control of their asthma, 37% fewer visits to the emergency room, and 68% fewer hospitalizations. Also, caregivers in the intervention group felt more confident in their ability to manage their child's asthma.

CALMA was developed according to the eight CBPR principles outlined by Israel et al.²⁸ Additionally, the CALMA intervention was designed to educate families on how to manage modifiable individual, family, and environmental factors through behavior modification. The intervention was guided by the 2002 NAEPP's Guidelines for the Diagnosis and Management of Asthma,²⁹ which were the most recent guidelines at the time of CALMA's development. Finally, CALMA was developed in a culturally sensitive manner. Implementation of the eight CBPR principles²⁸ in CALMA's development is described below.

Principle 1: Recognize Community as a Unit of Identity

The CALMA project began in the summer of 2003 when the collaborators formally recognized themselves as an asthma community. The community was broadly defined as diverse members from the local, professional, and medical community, academia, and local government with a vested interest in the health outcomes of Puerto Rican children with asthma. The CALMA intervention was originally conceived by the academic partners, who already maintained collaborative relationships with some pediatric pulmonologists in the community. Early discussions between the academic partners and local medical professionals elucidated the reality that successful implementation of the CALMA intervention for low-income families would not be possible without the collaboration of a diverse group of stakeholders. Together, the academic and medical partners brainstormed which types of organizations and individuals would be beneficial and sought out these potential partners. As new partners committed to the project, they provided additional insight regarding potential collaborators in a cyclical fashion.

Establishing the CALMA community was a long and often arduous process. Commitment to the CALMA project from some collaborators, such as the medical professionals and the Puerto Rico Public Health Department and Health Insurance Administration, was necessary before submitting the grant for the project. Other key partnerships, such as those with caregivers and the Asthma Coalition of Puerto Rico, were sought after grant submission. The formation of the CALMA community was unique in that the researchers were not “outsiders” looking to improve health conditions for a minority group, but were all island Puerto Ricans with preestablished connections to the target community.

The target intervention community was defined as children living in Puerto Rico between the ages of 5 and 12 enrolled in the Puerto Rican government health insurance plan and diagnosed with moderate to severe asthma as defined by the Health Plan Employer Data Information Set and the Puerto Rican Department of Health. In order to qualify for the government health insurance plan at the time of CALMA’s implementation, families must have earned 200% of the federal poverty level or less. Children from low socioeconomic families were targeted for this intervention owing to the link between poverty and asthma prevalence and severity.^{30,31}

Principle 2: Build on Strengths and Resources Within the Community

The CALMA community drew on its personal knowledge and experience to develop a culturally sensitive intervention. Rather than implementing an extant asthma intervention in its entirety, the CALMA community adopted elements of interventions (the A+ Asthma program,³² modified by The Johns Hopkins University’s National Cooperative Inner-City Asthma Study and *Proyecto AIRE*,³³ developed at the University of Puerto Rico), modifying and creating unique components that were culturally tailored for Puerto Rican families. Of the eight educational modules in CALMA (Table 1), four of the modules were created specifically to address the needs of Puerto Rican families (see Principal 4) and the remaining four were modified to include culturally relevant information. For example, in the educational module addressing the causes and symptoms of asthma—What is Asthma?—CALMA partners addressed common myths held by island Puerto Ricans.³⁴ Such myths included beliefs that asthma is caused by an untreated cold or flu, strong positive or negative emotions, and getting wet while sweating (as can occur when children are playing in hot and humid weather and it begins to rain).

In the Asthma Triggers module, CALMA collaborators included climate-specific triggers, such as cockroaches, humidity, and mold, which may not be as prominent in less temperate climates, as well as geographic-specific triggers, such as Sahara dust. The Asthma

Treatment and Asthma Treatment Plan modules were culturally tailored by including only the medications covered by the government health insurance plan. Home remedies believed to be effective asthma treatments for children, such as herbal teas, shark oil, and putting hot water on the chest,³⁴ were also incorporated into the intervention training materials. Asthma counselors emphasized the importance of discussing any use of home remedies with the primary care physician, because some remedies could be dangerous. For example, camphor is frequently used as a cough suppressant or to relieve congestion, but can be toxic to children if applied too liberally or if ingested. Finally, the adopted intervention modules also underwent a rigorous translation and adaptation process to ensure content clarity and cultural sensitivity for Puerto Ricans.³⁵ Culturally congruent pictures of families with similar appearance to the participants were also incorporated into the educational materials.

Principle 3: Facilitate Collaborative Partnerships in All Phases of the Research

Collaborative partnerships were promoted through the creation of a multidisciplinary panel and focus groups for parents with asthmatic children. The multidisciplinary panel consisted of pediatric pulmonologists, psychologists, nurses, program evaluators, health educators, environmental scientists, academic researchers, and parents of children with asthma. The panel held monthly meetings to develop and discuss each version of the intervention, specifically focusing on its applicability to low-income Puerto Rican families. Specific topics included reviewing the medical content and the environmental triggers for accuracy and relevance to the community, examining the emotional effects and stress experienced by families affected by asthma, standardizing the delivery of the intervention, and developing an intensive asthma counselor certification training program.

Principle 4: Integrate Knowledge and Action for Mutual Benefit of All Partners

CALMA collaborators from local, professional, and medical communities; academia; and government agencies contributed their unique perspectives in the development of the intervention (Table 2). At the local level, focus groups conducted with caregivers of children with asthma resulted in the development of the four educational modules unique to CALMA (Table 1). The module entitled “Asthma and the Family” addressed the caregivers’ concerns regarding asthma’s stressful effects on the family and marital relationships. These stressors included long waits in the emergency room, lost income owing to caring for an asthmatic child who is too ill to go to school, and poor or inadequate care resulting from a lack of financial resources. Because low-income Puerto Rican families may face multiple barriers to receiving high-quality asthma care, methods on how to empower caregivers to overcome barriers were addressed in the “Empowerment: Overcoming Barriers in Asthma Management” module. For example, many caregivers expressed difficulty in asking appropriate questions of their child’s pediatrician regarding asthma management. As a result, suggestions on how to better communicate with health care providers were included. The “Educating your Child and Others about Asthma” module delineated how to educate children, family members, and other caretakers about appropriate asthma management. Because of the prevalence of extended family providing assistance with child care, the module provided details on how to react appropriately to the sudden onset of a child’s asthma symptoms. A final module, summarizing all of the previous modules, called “Final Recommendations,” was suggested by caregivers as a means to facilitate easy understanding of CALMA by families with lower levels of education and literacy. In addition, caregivers stressed the importance of making CALMA interactive, engaging the families during the intervention and assigning homework to maintain focus between sessions.

The professional and medical asthma partners contributed area-specific knowledge to provide a comprehensive understanding of the scientific aspects of asthma. For example, community physicians and a local pharmaceutical company reviewed the intervention’s

medical content for accuracy and descriptions on medication use for effectiveness. In collaboration with caregivers, local physicians developed a table of asthma medications available to low-income families, their benefits, side effects, and whether they should be used as rescue or control medications to simplify the information presented on asthma treatment. Two local private health insurance companies also provided helpful information regarding insurance claims and the specific asthma medications covered by their plans.

Academic partners contributed significantly to the conceptualization, design, and implementation of the study. Researchers relayed previous research findings regarding pediatric asthma,⁷⁻⁹ asthma in Puerto Rico,¹⁻⁴ asthma management interventions,¹¹⁻¹⁴ and the role of CBPR and cultural sensitivity in effective asthma management.^{15,26} This information was used by the CALMA community to make project decisions. Researchers coordinated the caregiver focus groups, the multidisciplinary panel meetings, and training sessions to standardize the asthma counselors in the intervention.

The Puerto Rico Health Department and Health Insurance Administration both provided important data on the targeted community, such as service use rates, and access to the target community. Forming an alliance with the Health Insurance Administration can be beneficial because they can assist with the implementation of effective interventions into the health care system. The Puerto Rico Ombudsman Department provided information on patient's rights as well as common complaints made by asthma patients, such as the cost of medication and pharmacy wait times.³⁶ In addition to the specific group contributions, the CALMA community worked for 3 years to develop the intervention and reviewed 11 drafts for content clarity and comprehension before all partners approved it.

Principle 5: Promote a Co-Learning and Empowering Process That Attends to Social Inequalities

Co-learning was a natural and expected result of the collaboration. In addition, the CALMA community recognized its utility and incorporated co-learning into CALMA's implementation. Thus, asthma counselors learned the specific needs and obstacles each family faced, and worked to empower families to modify individual and environmental factors in an effort to decrease asthma morbidity in their children. The CALMA intervention sought to empower low-income families to (1) understand the nature (chronicity) of asthma; (2) identify barriers to care and to appropriate medication usage; (3) better understand the different types of medications and how to use them; (4) appropriately use the health care system and keep follow-up appointments; (5) enhance use of action plans; (6) improve identification of asthma triggers and environmental avoidance techniques; (7) encourage identification of symptom onset and early management; (8) assume an active role in the communication with the provider; and (9) identify asthma-related stressors that may affect the psychological well-being of the parent and identify helpful resources or therapeutic options.

Principle 6: Involve a Cyclical and Iterative Process

Substantive efforts were taken to identify community partners who were committed to decreasing asthma morbidity in Puerto Rican children. Because sustainable interventions are never final, action, reflection, and modification phases should be continuously repeated.³⁷ In terms of CALMA, the action phase included the development and implementation of the intervention in the target community. The reflection phase included the evaluation of the intervention. Study results demonstrated that in comparison to families in a control group, CALMA parents' asthma knowledge and confidence increased while their child's night-time asthma symptoms decreased and service utilization improved (see Canino et al²⁷ for details). However, day-time asthma symptoms did not differ between children receiving the CALMA

intervention or a control treatment. After considering these results, the CALMA community decided that the intervention was successful, but that continued collaboration would be necessary to improve the intervention. Subsequently, CALMA collaborators have begun expanding the intervention to not only address family asthma management, but to improve the quality of care that physicians in government-sponsored health clinics provide their asthma patients. In addition, other organizations have adopted the CALMA intervention (see Principle 8) and must use their own iterative process to continually transform the intervention in a way that sufficiently meets the needs of their specific target communities.

Principle 7: Address Health From Both Positive and Ecological Perspectives

Traditional asthma management interventions tend to focus primarily on biomedical and environmental factors that relate to asthma while ignoring other pertinent factors. However, the CALMA community specifically identified additional factors that impact asthma management in Puerto Rico. CALMA incorporates modules that address the psychological and financial stresses that having a child with asthma places on the family. Examples of these restrictions include absence from social activities and limitations to the types of medications that are provided under government-sponsored health care. Managing asthma using ecological and positive health approaches may address health-related concerns better than examining asthma primarily through a medical lens because it incorporates multiple perspectives and makes the information more accessible for families who experience the consequences of asthma in a variety of domains.

Principle 8: Disseminate Findings and Knowledge Gained to All Partners

Results from the CALMA intervention have been disseminated in both academic and public outlets. Within Puerto Rico, the Department of Education has used the CALMA materials in an island-wide initiative to educate school nurses about asthma and the correct use of asthma medication. A local pharmaceutical company has already sponsored the training of 40 school nurses in the application of CALMA. In addition, a second pharmaceutical company is planning to adopt CALMA for an upcoming asthma education campaign, and the School of Pharmacy at the University of Puerto Rico has implemented CALMA as part of its training. Thus, given continued interest and adaptation of CALMA in a variety of forums, program sustainability seems promising.

Lessons Learned: Challenges and Strengths

Principle 1: Recognize Community as a Unit of Identity

Learning how to create a truly diverse community of stakeholders vested in the success of the CALMA intervention was critical. Some of these partnerships, such as those between the academic collaborators and some of the medical personnel, were already established. Additionally, many caregivers of asthmatic children were eager to participate and share their views. However, the inclusion of insurance companies and government agencies required a substantial investment of time and resources, to capture their attention and demonstrate the eventual benefit to them in joining the CALMA community. The development of the intervention benefitted tremendously from this confluence of stakeholders involved in the treatment of childhood asthma in Puerto Rico.

Principle 2: Build on Strengths and Resources Within the Community

A unique aspect of the CALMA community that strengthened the intervention was the fact that all partners originated from within Puerto Rico. As a result, these collaborators possessed intimate knowledge of the problems, concerns, and beliefs specific to asthma sufferers on the island. The culturally tailored modifications and unique contributions that

were incorporated into CALMA were largely a result of this exclusively Puerto Rican community.

Principle 3: Facilitate Collaborative Partnerships in All Phases of the Research

Differences in asthma-specific knowledge among the partners created a challenging work environment at times. For example, group discussions in the multidisciplinary panel focusing on medication use and other medically specific intervention topics were difficult for nonacademic/medical partners to comprehend. It became clear from early discussions that, for all partners to maintain equitable standing and decision-making power, all partners needed to fully understand the content discussed in the group. Thus, all expert partners were required to provide explanations in a manner appropriate for panelists who were not experts on the topic. Although this was labor intensive, the additional explanations created parity among the partners.

Deciding how to manage conflicts was another challenge. Although quite time consuming, the partners agreed that conflicts should be resolved through group discussion and consensus. For example, a main source of discord between the partners involved the number of home visits a family should receive. Caregivers advocated for at least three home visits, whereas the health insurance companies favored a single home visit. In the end, the groups compromised with two home visits.

Principle 4: Integrate Knowledge and Action for Mutual Benefit of All Partners

A significant strength of CALMA's developmental process was the unique contribution of each individual partner (Table 2). The level of knowledge and input required to create CALMA was beyond the means of any one partner. The intervention benefitted greatly from the expertise of the medical collaborators in overseeing the accuracy of the medical-related content, the varied experiences and opinions of the caregivers in creating four educational modules, the resources and guidance provided by the government agencies and professional partners, and the organizational commitment of the academic research team.

Principle 5: Promote a Co-Learning and Empowering Process That Attends to Social Inequalities

In the development of CALMA, time was a major hindrance to the caregivers' active participation. Professional partners could schedule CALMA activities into their work schedules, whereas caregivers had less flexibility due to financial and other constraints. Because the project was time limited, the CALMA community decided to conduct focus groups with caregivers throughout the development of CALMA to secure their input without overburdening them. However, a small group of caregivers were able to make monthly commitments and were involved in the decision-making process on a more consistent basis.

Principle 6: Involve a Cyclical and Iterative Process

For the CALMA intervention to be cyclical and iterative, and ultimately sustainable within the target community, the academic partners must cede control of the intervention to nonacademic partners and outside organizations. Because the academic partners invested substantial resources and time in developing the intervention to meet the rigorous standards of the scientific community, relinquishing control of the intervention represented a substantial challenge. For example, a portion of school nurses in Puerto Rico have been trained, evaluated, and certified to implement CALMA in the schools. The academic partners, who previously supervised the implementation process, were no longer in a position to specify the way in which CALMA is implemented within the schools; further,

the continuation of CALMA in the schools solely depends on the Department of Education's continued interest in the program.

Principle 7: Address Health From Both Positive and Ecological Perspectives

Although the NAEPP guidelines¹⁰ were used as the foundation in CALMA's development, incorporating an ecological perspective allowed for a more culturally sensitive intervention. For example, although the NAEPP guidelines delineate effective asthma medications, low-income Puerto Rican children receiving state-sponsored insurance coverage are less likely than children insured by the private sector to receive long-term controller medications recommended for persistent asthma.³⁸ Thus, families were also educated about the benefits of controller medications and how to effectively discuss them with their child's physician. In addition, because many caregivers fear that the daily use of preventative asthma medication may be harmful to their children,³⁹ families were educated about the effectiveness and negative consequences associated with both prescription medications and home remedies.

Principle 8: Disseminate Findings and Knowledge Gained to All Partners

A multipronged approach to dissemination was used to share results regarding CALMA's efficacy to all the partners as well as other interested communities. Results were disseminated within both academic and local, public realms. If dissemination efforts were focused solely on the academic realm, many local organizations and agencies, such as the Puerto Rico Department of Education, would not have been aware of the intervention and may not have adopted it for their school-wide initiative to decrease asthma morbidity. Likewise, without publishing the results from the randomized, controlled clinical trial,²⁷ or the process of implementing a CBPR approach in the design of an effective asthma management intervention for low-income Puerto Ricans (the current paper), researchers interested in using a CBPR approach would not have had access to the intervention or the method in which it was developed.

Conclusion

Through CBPR's collaborative approach, CALMA, a family asthma management intervention, was developed and culturally tailored for low-income Puerto Rican children with asthma. The eight principles of CBPR²⁸ were implemented, and CALMA was created to educate families how to modify their behaviors, on an individual and familial level and in relation to the environment to decrease asthma morbidity. CALMA has been shown to be effective in a low-income Puerto Rican community²⁷ and shows potential for sustainability in Puerto Rico and adaptability in other marginalized communities.

Acknowledgments

The authors thankfully acknowledge all of the CALMA collaborators: all the caregivers of children with asthma who participated, the physicians and professional partners, the Asthma Coalition of Puerto Rico, the Puerto Rico Health Department, the Puerto Rico Health Insurance Administration, the Puerto Rico Patients' Ombudsman Department, the University of Puerto Rico, Medical Sciences Campus, the University of Turabo, and Glaxo Corporation, which provided some of the funding for the development of the intervention

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Table 1**Asthma Modules Included in CALMA**

Module	Description	Primary Contributors
1. Asthma and the Family*	Identifies how asthma impacts families, ways to reduce stress, and community resources.	Caregivers, Psychologists
2. What is Asthma?	Defines asthma and describes its symptoms. Commonly held myths about what causes asthma are discussed.	Academics, Caregivers, Medical Professionals
3. Asthma Triggers	Identifies allergens and environmental and physical irritants that may trigger asthma, especially those common in PR.	Academics, Environmental Scientists
4. Asthma Treatment	Describes various types of asthma medications and when and how to use them properly. The module focuses on medications covered by the government-sponsored health insurance plan	Academics, Caregivers, Government, Medical Professionals, Pharmaceutical Companies
5. The Asthma Treatment Plan	Describes how to monitor asthma and identify controlled asthma. Provides a plan to track progress and achieve controlled asthma.	Academics, Caregivers, Medical Professionals
6. Empowerment: Overcoming Barriers in Asthma Management*	Identifies ways that parents can overcome health care barriers and improve communication with their child's pediatrician and other health care providers.	Caregivers, Government
7. Educating your Child and Others about Asthma*	Discusses the importance of, and how to educate a child and other caretakers about asthma.	Caregivers, Medical Professionals
8. Final Recommendations*	Summarizes key points in the CALMA manual. Designed for those with lower levels of education and literacy.	Academics, Caregivers

Note: CALMA is the Spanish acronym for Take Control, Empower Yourself, and Achieve Asthma Management. Modules with asterisks represented those created specifically for the CALMA intervention.

Table 2**Contributions Made and Benefits Received by CALMA Partners**

CALMA Partners	Contributions	Benefits
Community		
Asthma Coalition of PR	Provided outreach platform to educate patients at health fairs	Dissemination of CALMA to the public
Caregivers	Shared common beliefs about asthma causes and effective treatments	Education modules were tailored to address beliefs held by Puerto Rican families
	Expressed concerns about psychological stress, barriers to treatment, and need to educate other caregivers about asthma treatment	Caregiver concerns were addressed through the inclusion of 4 unique CALMA modules
	Helped evaluate CALMA asthma counselors	Influenced how CALMA was implemented
	Taught other CALMA partners about asthma from the caregiver's perspective	Actively contributed to the development of an intervention aimed at improving their child's quality of life
Medical and Professional		
Environmental scientists	Identified environmental triggers in PR	Educational modules were tailored for island Puerto Ricans
Health educators	Trained and evaluated CALMA asthma counselors	Can disseminate CALMA's educational modules to the public
Nurses	Provided up-to-date treatment guidelines and knowledge on appropriate treatment use	Contributed to an intervention that may decrease asthma morbidity
Pediatric pulmonologists		
Pharmaceutical companies	Provided financial resources for CALMA's final product	Established platform to advertise asthma medications
Private health insurance companies	Provided helpful information regarding insurance claims and medications covered	Learned about potential intervention to cover under disease management
Program evaluators	Assisted in planning study methodology and in evaluating intervention efficacy	Determined efficacy of CALMA in low-income Puerto Rican children
Academic		
University of PR	Conducted literature reviews on CBPR, pediatric asthma and asthma management interventions	Aided in the development of an evidence-based asthma intervention
University of Turabo		
Asthma researchers outside PR	Collaborated with physicians to ensure CALMA was in line with most recent NAEPP guidelines	Could scientifically test efficacy of intervention and contribute to the relevant literature
	Assisted in training CALMA asthma counselors	
	Coordinated caregiver focus groups, multi-disciplinary panel meetings, asthma counselor training	Created community partnerships that can be used in future endeavors
	Disseminated results through academic and community mediums	
Government		
PR Health Dept.	Authorized a release of information for this population	CALMA included the types of medications covered by state-sponsored insurance
PR Health Insurance Administration	Provided asthma-related data on target population	
	Limited treatment modules to covered medications	
PR Patients' Ombudsman Dept.	Provided information on patients' rights and common complaints made	Asthma patients will learn about their rights and how to overcome barriers to treatment

Note. CALMA is the Spanish acronym for Take Control, Empower Yourself, and Achieve Asthma Management; Dept. is Department; NAEPP is National Asthma Education and Prevention Program; PR is Puerto Rico