

# Patient-centered outcomes research to improve asthma outcomes



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**Target Audience:** Physicians and researchers within the field of allergic disease.

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### Activity Objectives:

1. To understand the importance of the guidelines in asthma research.
2. To understand the ongoing studies funded by the Patient-Centered Outcomes Research Institute.

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The Patient-Centered Outcomes Research Institute is funding 8 comparative effectiveness research projects to improve patient-centered outcomes for African American and Hispanic/Latino patients with uncontrolled asthma. These projects aim to compare multilevel interventions with known efficacy at the community, home, and health system levels to enhance patient and clinician uptake of the National Heart, Lung, and Blood Institute's National Asthma Education Prevention Program guidelines and improve outcomes. The National Asthma Education Prevention Program guidelines provide clinicians with a range of acceptable approaches for the diagnosis and management of asthma and define general practices that meet the needs of most patients. Yet disparities in asthma care and outcomes remain pervasive for African Americans and Hispanics/Latinos. The National Heart, Lung, and Blood Institute AsthmaNet consortium has identified several top

research priorities for pediatric and adult populations, including a recommendation to examine tailored approaches based on race/ethnicity. In addition, the guidelines emphasize the need for studies that focus on multicomponent interventions recognizing that single interventions are generally ineffective. This article will describe the Patient-Centered Outcomes Research Institute-funded asthma projects and how they are individually and collectively addressing evidence gaps in asthma care by focusing on multicomponent and tailored approaches for improving outcomes and reducing disparities for African American and Hispanic/Latino patients. (*J Allergy Clin Immunol* 2016;138:1503-10.)

**Key words:** Asthma, Patient-Centered Outcomes Research Institute, comparative effectiveness research, African American, Hispanic/Latino, National Asthma Education and Prevention Program guidelines

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In June 2013, the Patient-Centered Outcomes Research Institute (PCORI) released a funding announcement entitled, "Treatment options for African Americans and Hispanics/Latinos with uncontrolled asthma," with the goal of supporting comparative effectiveness research (CER) to improve patient-centered outcomes among African American and Hispanic/Latino patients with asthma. The funding announcement specifically stated that PCORI was interested in supporting

*Abbreviations used*

CER:	Comparative effectiveness research
CHICAGO:	Coordinated Healthcare Interventions for Childhood Asthma Gaps in Outcomes
CHW:	Community health worker
ED:	Emergency department
EHR:	Electronic health record
GINA:	Global Initiative for Asthma
ICS:	Inhaled corticosteroid
IT:	Information technology
NAEPP:	National Asthma Education Prevention Program
NHLBI:	National Heart, Lung, and Blood Institute
PCORI:	Patient-Centered Outcomes Research Institute

“...studies that focus on reducing adverse outcomes due to poorly controlled asthma in African-American and Hispanic/Latino individuals, populations, and subgroups. More specifically, we seek CER that tests interventions to improve clinician and patient adherence to guidelines produced by the National Asthma Education and Prevention Program (NAEPP) of the National Heart, Lung, and Blood Institute (NHLBI). PCORI’s goal is to fund CER to identify optimal strategies for leveraging the NAEPP evidence-based guidelines to achieve equitable outcomes in asthma care. Studies that assess methods to improve adherence to these evidence-based guidelines coupled with interventions that are tailored to the needs of specific individuals and populations are of particular interest. Recognizing that the guidelines require a multidimensional approach to patient care, we are interested in studies that incorporate interventions at the community, home, and health system levels and that assess combinations of patient-education tools, home-environment interventions, asthma medications, and team-based approaches.”<sup>1</sup>

In 2014, asthma affected nearly 24 million Americans and disproportionately affected racial and ethnic minorities.<sup>2</sup> Asthma is more prevalent and severe among African Americans and Hispanics/Latinos, particularly Puerto Ricans, compared with their white counterparts. The burden of asthma in African Americans and Hispanics/Latinos is accompanied by poor health outcomes and quality of life and high rates of emergency department (ED) visits and hospitalizations. Almost 4 million African Americans (approximately 10%) have asthma.<sup>2</sup> Hispanic/Latino populations are also disproportionately affected; 3.65 million US Hispanics/Latinos (approximately 7%) have asthma.<sup>2</sup> African Americans and Hispanic/Latino children have a greater chance of dying from asthma compared with non-Hispanic/Latino whites. In 2014, the asthma-related death rate for African Americans was almost 3 times that of whites.<sup>2</sup> From 2012-2014, for Hispanic/Latino children, the asthma-related death rate was 2 times that of whites.<sup>3</sup> Finally, African American and Hispanic/Latino patients are less likely than their white counterparts to receive guideline-based treatment in accordance with the NAEPP guidelines, which have been available for over 20 years.<sup>4</sup> These guidelines provide clinicians with a range of acceptable evidence-based approaches for the diagnosis and management of asthma and define general practices that meet the needs of most patients.<sup>5</sup> However, disparities in asthma care and outcomes remain pervasive.<sup>6</sup>

To address evidence gaps, PCORI is supporting 8 projects that test multicomponent interventions at the community, home, and health system levels to facilitate patient and clinician uptake of the NAEPP guidelines. We describe the projects and how they are addressing evidence gaps in asthma care for African Americans and Hispanics/Latinos.

## EVIDENCE GAPS IN ADHERENCE TO THE NAEPP GUIDELINES

Although research shows that adherence to guideline-based care can improve asthma symptoms and outcomes, its use is lacking. Guideline-based care can facilitate improvements in processes and outcomes, but if not tailored to the needs of patients, it is often ineffective. Generally, it tends toward efforts to promote consistency and standardization of clinical decisions based on scientific evidence to improve the quality of care patients receive. However, a single standard of care will likely not work universally for all groups. On the other hand, patient-centered care promotes a level of individualized care that one could argue might lead to greater variability.<sup>7</sup> Striving for balance of both elements is important.

To this end, the PCORI-funded studies have designed tailored interventions that are geared to enhance guideline-based care. Some of the core questions that these studies seek to address focus on how interventions can be tailored and adapted to foster patient and clinician uptake of guideline-based care and facilitate patient participation in making health care decisions.<sup>8</sup> These elements align with PCORI’s mission to understand what works best, for whom, and under what circumstances; to address important evidence gaps to inform practice; and to ensure engagement of patients, caregivers, and other stakeholders (eg, clinicians, payers, and health systems) in all the studies it funds.

Adherence to guideline-based care is challenging for multiple reasons.<sup>9-13</sup> Clinicians are often not aware of the guidelines, and when they are, many express doubt about their effectiveness. Clinicians have also expressed lack of confidence in the ability of patients to implement their recommendations. These factors, coupled with clinical inertia, general practice barriers, and time constraints, make adherence to guidelines challenging.<sup>14,15</sup>

Patient factors also influence adherence, particularly for populations at risk for experiencing disparities in care. Both community and individual dynamics, such as poverty, environmental stressors, language barriers, health literacy and numeracy, and other socioeconomic circumstances, play a role.<sup>16</sup> Patient preferences, lack of access to appropriate care, and poor adherence to asthma medications and preventive treatments contribute to increased asthma symptoms and exacerbations, leading to poor outcomes.<sup>17-19</sup>

The NAEPP guidelines emphasize multilevel, multicomponent interventions for improving asthma outcomes. These approaches include patient and clinician education, systems-based tactics, such as use of electronic health records (EHRs), and community- and home-based interventions to address potential environmental triggers. For example, the guidelines specifically indicate that patient education should occur in a range of settings, such as clinics, EDs, hospitals, schools, and homes. However, only 60% of patients with asthma receive education on how to recognize symptoms, and less than 35% of patients report having an Asthma Action Plan.<sup>20</sup> Additionally, the guidelines stress controlling environmental factors that can cause asthma exacerbations (eg, mold, house dust mite, cockroach, animal dander, or secretory

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