

# Advancing Health Equity through Better Evidence for Asthma Care: Translating Patient-Centered Outcomes Research Learnings into Equity-Focused Policy Recommendations

## Executive Summary

A central pillar in health system transformation is rewarding and incentivizing high-value, evidence-based care. For transformation efforts to equitably benefit all, decision makers need an evidence base that is representative of diverse communities and transparent about which specific populations it includes. However, our current evidence base is neither.

Historically, clinical and health system research has excluded a number of communities. This exclusion, in turn, has generated an incomplete and sometimes biased evidence base that risks widening racial, ethnic, and other inequities. Ensuring health system transformation efforts are informed by representative and transparent evidence is vital to the elimination of health inequities.

### Patient-Centered Outcomes Research Strengthens the Evidence Base for Equity

Research practices that produce our current evidence base have used mainly young white males as subjects, excluding communities of color, women, the elderly, children, and those with medical complexities.<sup>1,2,3</sup> The health care system has used the results of a homogenous group of subjects, or incomplete evidence, and applied them broadly without consideration of treatment response variation across ethnic and racial groups. This means that, at best, much of the health care we receive is built on

extrapolated assumptions rather than rigorous and inclusionary scientific methods. At worst, it means certain groups may be receiving less effective care that widen, rather than eliminate inequities.

The shortcomings of our evidence base are well recognized and the federal government has enacted legislation to improve research practices to generate representative evidence. The Patient-Centered Outcomes Research Institute (PCORI) was created in 2010 by Congress to fund research that advances the quality and relevance of evidence available to inform health care decision-making centered on patients and subpopulations.<sup>4</sup> Specifically, PCORI funds studies that conduct patient-centered outcomes research (PCOR), an approach that emphasizes the inclusion of diverse populations and the involvement of patients. PCORI-funded research studies prioritize specific populations, including racial and ethnic minorities, low-income communities, women, older adults, those with multiple chronic conditions, and children.<sup>5</sup> As a result, PCOR is a research practice that can advance health equity.

This report synthesizes the available findings from PCORI’s portfolio of asthma research studies and translates them into health equity-focused policy options. Asthma is a serious chronic lung disease and the most common disease among children, but disproportionately affects communities and children of color.<sup>6</sup> The root causes of asthma are unknown and complex, extending beyond individual biology to a variety of psychosocial and environmental factors.<sup>7</sup> A fundamental first step in eliminating asthma inequities is to implement research practices that generate evidence that is representative of the communities that experience these inequities. PCORI’s research studies generate evidence to support the dissemination and implementation of clinical approaches that can improve health equity. However, PCORI’s asthma studies are not without limitations and underscore the importance of explicitly emphasizing equity by making data stratification a central research objective.

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## **Patient-Centered Outcomes Research Studies on Asthma**

This report covers six PCOR studies from PCORI’s asthma portfolio that had publically available findings at the time of writing. The studies measured various interventions’ effects on asthma-related health and quality of life, management and treatment of asthma, and patients’ involvement in their treatment. Data on the effectiveness of some of these interventions is not stratified by race or ethnicity, which limits its applicability to specific ethnic groups.

The first study discussed in this report, “Does a Stress Management Program for Black Parents Increase Asthma Symptom-Free Days for Their Children? — The BEAMS Study,” addresses asthma-related inequities experienced by Black children.<sup>8,9</sup> This study generates evidence that stress management classes for Black parents of children with asthma can reduce their children’s asthma symptoms after 12 months. Stress management classes for parents is effective as a longer-term asthma management intervention and requires sustainable funding. One potential source of funding is Medicaid reimbursement.

The second study discussed in this report, “Comparing Three Ways to Prepare Children and Caregivers to Manage Asthma After an Emergency Room Visit — The Chicago Plan,” addresses asthma-related inequities experienced by Black and Latino children.<sup>10,11,12,13</sup> This study generates evidence that implementing a decision support tool in the emergency room can help Black and Latino children and their caregivers manage asthma symptoms. When combined with home visits from community health workers (CHWs), the decision support tool was especially effective in improving the management of asthma symptoms.

The third study discussed in this report, “Guidelines to Practice (G2P): Reducing Asthma Health Disparities through Guideline Implementation,” addresses inequities in asthma-related quality of life outcomes.<sup>14</sup> This study adds to the mounting evidence that CHWs can improve asthma-related quality of life. This study demonstrates that the integration of CHWs into clinics and provider teams in Washington state as part of a Medicaid Section 1115 waiver has resulted in improved quality of care.<sup>15</sup> Other states can follow a similar path to effectively integrate CHWs into clinics and provider teams.

The fourth study discussed in this report, “Using a Home- or Clinic-Based Program to Help Older Adults Manage Their Asthma — The SAMBA Study,” addresses asthma-related inequities experienced by Black and Latino older adults.<sup>16</sup> This study generates evidence that the SAMBA asthma self-management program can improve quality of life and asthma management for Black and Latino adults over the age of 60. Decision makers should increase resources for CHWs and Asthma Care Coaches (ACCs) like those used in the SAMBA program. Because the SAMBA program was effective in both home- and clinic-based settings, decision makers have flexibility in determining where to implement this intervention and can allow patients to elect the setting in which they would prefer to receive this treatment intervention.

The fifth study discussed in this report, “Improving Youth Question-Asking and Provider Education During Pediatric Asthma Visits,” addresses inequities in patient engagement in doctors’ offices. This study generates evidence that completing a question prompt list and watching an educational video prior to receiving

treatment can make patients more likely to ask questions and get educated by their providers. Because this study did not stratify data by race or ethnicity, we cannot know whether the intervention was less successful for patients from specific communities.

The sixth study discussed in this report, “Training Staff at Doctors’ Offices to Use Shared Decision-Making with Patients Choosing Asthma Treatments — The SDM Study,” also addresses inequities related to patient engagement in doctors’ offices. This study generates evidence that a customized 12-week, facilitator-led training in doctors’ offices is an effective strategy for implementing asthma interventions in primary care practices. However, the SDM intervention in this study did not result in improved asthma-related health outcomes.

## Key Recommendations

After analyzing and synthesizing these studies’ findings, we developed three key equity-focused policy recommendations:

1. Researchers should be required to stratify study results by race, ethnicity, and gender.
2. Community Health Worker interventions continue to show success in addressing inequities and improving outcomes and should be funded as valuable interventions, particularly in Medicaid, which covers a large proportion of children and adults of color.<sup>17</sup>
3. Research on children of color needs to include qualitative data from parents.

## Advancing Health Equity through Better Evidence for Asthma Care

The central objective of health care system transformation is to improve health outcomes and reduce health care costs by designing and implementing evidence-based alternative delivery and payment models. To ensure these transformation efforts equitably benefit all, decision makers require an evidence base that is both representative of the communities it serves and transparent about the specific populations included in its generation. Our current evidence base is neither. It is incomplete (and consequently often biased), raising questions about its applicability and effectiveness for diverse patients and risking widening racial, ethnic, and other health inequities. As health system transformation increasingly rewards and incentivizes evidence-based care, diversifying the evidence base so it is representative and ensuring that the limitations and applicability of findings are transparently reported are vital to eliminating health inequities.

A review of recent research on asthma funded by the Patient Centered Outcomes Research Institute (PCORI) shows the potential of patient-centered comparative effectiveness research (CER) strategies focused on care delivery and non-traditional provider interventions to identify and promote clinical and policy approaches that can improve health equity. But the limitations of these studies also demonstrate the need for an explicit focus on equity that includes stratified outcomes data as a central research objective. An important aspect of these studies is that they track with established research priorities for addressing health equity in children, as well as adults, and show some promising outcomes as well as some important limitations. Health equity research priorities include using community health workers (CHWs), improving child health by employing multi-generational interventions that support parents directly and improve their well-being, changing pediatric practice through training, and improving implementation of clinical practice guidelines.

### Patient-Centered Outcomes Research Strengthens the Evidence Base for Equity

Historically, clinical and health system research has produced incomplete and frequently biased evidence. Research practices that generate our current evidence base have relied primarily on a homogenous group of subjects — young white males — and tended to exclude communities of color, women, the elderly, children, and people with medical complexities.<sup>18, 19, 20</sup> Yet the health care system has long generalized these incomplete results to apply to all, without testing how they actually work for diverse populations. At best, this means that much of the health care we provide is built on extrapolated assumptions instead of science; at worst, some groups may be receiving less effective — and even risky — treatments that widen health inequities. For example, albuterol is the standard treatment for asthma attacks. However, research has shown that this

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medication is significantly less effective for Black and Puerto Ricans, populations that already experience disproportionately high rates of the disease,<sup>21</sup> as well as higher rates of asthma-related hospitalizations and fatalities.<sup>22,23</sup> Greater transparency about differences in response rates to treatment and better representation in research could generate more effective treatments and prevent these inequitable outcomes.

Many factors contribute to the underrepresentation of people of color, children, women, and other groups in medical research. These include lack of trust based on historical and ongoing mistreatment by the health care system, underrepresentation of people of color among the researchers themselves, lack of incentives and resources to recruit and retain people of color despite the often significant transportation and time constraints many people of color face, and implicit bias.<sup>24</sup> To a great extent, some of this exclusion is rooted in traditional research methodologies that disproportionately impact some groups, rather than intentional discrimination by investigators. For example, randomized clinical trials (RCTs) are the gold standard of research, but they have limitations that may reduce the applicability of their findings in the real world. RCTs are typically conducted in academic settings and have highly exclusionary criteria for participation. These factors can decrease diverse participation by limiting access to research sites or by disqualifying medically complex subjects.

In addition, even when research includes diverse populations, reports of results may not reflect that. RCTs and other research, like observational research, report aggregated outcomes,<sup>25,26</sup> which may mask medically important variations along racial and ethnic (and potentially other) lines that would be uncovered by stratifying results. For example, Latinos in aggregate have the lowest asthma prevalence, but stratifying the data by subgroup reveals that Puerto Ricans have the highest asthma rates among all ethnic and racial groups.<sup>27</sup>

Apart from the evidence base limitations rooted in inadequate representation, a different factor that limits the usefulness of the current evidence base is the dearth of patient-centered outcomes research (PCOR). Patients' priorities in terms of outcomes that are most important to them may differ significantly from the research questions that scientists and clinicians focus on. For instance, the outcomes most important to asthma patients and their families may be the number of nights of uninterrupted sleep or of missed work or school days, rather than the function of a particular protein on airway white cells or other biomedical findings that scientists want to know.<sup>28</sup> Patient-centered outcomes research can generate findings that are far more relevant to people's needs and daily functioning.

As a response to these shortcomings, scientists have adopted new approaches in recent years to strengthen and improve the evidence base. These include comparative effectiveness research (CER) and PCOR. CER

## Evidence for Equity Initiative

Families USA launched the **Evidence for Equity Initiative** to promote the need for representative and transparent evidence to help decision makers implement health system transformation policies that advance health equity instead of making inequities worse. The Initiative will synthesize, translate, and disseminate research findings of particular relevance to addressing disparities, with a special focus on patient-centered outcomes research and comparative effectiveness research.

compares the benefits and harms of existing treatments, interventions, and therapies to improve health care delivery. It conducts research in real-world settings, making sites accessible and participation inclusionary.<sup>29</sup> Significantly, CER is particularly interested in the variability of treatments across subgroups, including communities that are absent from the evidence base.<sup>30</sup> PCOR is CER with a patient perspective. PCOR compares existing interventions to assess their harms and benefits, but also prioritizes patient outcomes by meaningfully including patients throughout all research stages. No longer just research end points, patients have significant influence over the direction of the research (including implementation, analysis, and dissemination) that can improve the relevance and quality of the evidence. The combination of CER, which emphasizes inclusion of subgroups, with patient involvement increases diverse participation and makes evidence more representative and transparent. As a result, PCOR is a research practice that can advance health equity.

The United States government, by far the world's largest public funder of biomedical research,<sup>31</sup> has enacted multiple pieces of legislation to improve our evidence

base.<sup>32</sup> In 2010, Congress created the Patient-Centered Outcomes Research Institute (PCORI) to advance the quality and relevance of evidence available to inform health care decision-making centered on patients and subgroups.<sup>33</sup> PCORI funds projects that conduct PCOR across a number of research portfolios to inform the development and implementation of delivery and payment reform policies. These projects also emphasize particular populations, including racial and ethnic minorities, low-income communities, women, older adults, those with multiple chronic conditions, and children.<sup>34</sup>

This report synthesizes available findings from PCORI's asthma portfolio and translates them into health equity-focused policy recommendations. This is the second report in a four-part series for Families USA's Evidence for Equity Initiative, a project of our Center for Health Equity Action for System Transformation. The first report in the series is a foundational, in-depth explanation of the limitations of our current evidence base and how PCOR can help advance health equity. This and forthcoming reports will be available at [familiesusa.org/initiatives/evidence-equity-initiative](http://familiesusa.org/initiatives/evidence-equity-initiative).

## Children and Communities of Color Are Disproportionately Harmed by Asthma

Asthma is a serious chronic lung disease and the most common disease of childhood, affecting 6 million children and 19 million adults in the United States.<sup>35</sup> The direct cause of asthma is unknown. However, multiple factors play a significant part in the development of the disease, including genetics, the environment, allergies, and respiratory infections.<sup>36</sup> Race<sup>i</sup> and psychosocial stress are increasingly considered additional drivers of asthma, a consideration that may better explain the uneven distribution of the disease among children of color.<sup>37</sup>

### Asthma Inequities Among Children of Color

Asthma is known as the disease of the young and the poor because children and people with incomes below the poverty line are most commonly and severely affected by the disease. Communities of color experience both poverty and asthma at higher rates than whites, but asthma inequities can be significantly wider than the disparities in poverty rates. While 8 percent of whites have incomes below the poverty line, 22 percent of American Indians and Alaska Natives, 20 percent of Blacks, and 16 percent of Latinos do.<sup>38</sup> Asthma rates among American Indians and Alaska Natives are significantly higher compared to whites — 27 percent for adults and 58 percent for children — and the overall death rate from asthma for these groups is 22 percent higher.<sup>39</sup> Overall, Blacks are 40 percent

more likely than whites to have asthma and nearly three times as likely to die from the disease.<sup>40</sup> Puerto Ricans have the highest rate of the illness of any group, nearly 75 percent higher than whites.<sup>41</sup> Black and Puerto Rican children and adolescents between 5 and 14 years old have asthma at 2.5 times the rate of whites.<sup>42</sup>

### Exposure to Environmental Contaminants and Environmental Racism as Asthma Risk Factors for Communities of Color

Where we live plays a significant role in determining our health, and the prevalence of asthma among communities and children of color exemplifies this fact. The role of poor air quality and exposure to contaminants in triggering asthma is well documented.<sup>43</sup> Air pollution is pervasive in places where people of color lead their lives and is associated with worsening asthma symptoms, attacks, and hospitalizations.<sup>44</sup> Communities of color are more likely to live in polluted neighborhoods with less green space.<sup>45</sup> A recent study examining exposure to a traffic-related pollutant across the United States found that people of color were exposed to 37 percent more pollution than whites.<sup>46</sup> Further, schools in large cities across the country with majority Black student populations are 18 percent more likely to be located near a major roadway — and to traffic-related contaminants.<sup>47</sup> This is also true for Latino children in California, who are 1.5 times more likely to live near both a major freeway and a roadway than whites.<sup>48</sup>

<sup>i</sup>Historically, health disparity research and literature focusing on racial and ethnic inequities have considered “race” a risk factor for a variety of conditions and outcomes. Although advances in genomics have identified some genetic variations associated with race, it is important to clarify that in most cases, the primary driver of these inequities is not one’s “race” or “ethnicity” per se, but racism. Asthma is one example where systemic, structural, and interpersonal racism (major contributors to toxic stress) influence health outcomes as well as some specific genetic variations that may be prevalent among particular races or ethnicities.

**Stressors that are prevalent in communities where low-income families live increase the risk of adverse childhood experiences (ACEs) such as family dysfunction, family separation, and violence.**

Higher exposure to asthma-triggering air pollutants for communities of color is not accidental. Rather, it is the result of decades of public policies and private decision-making about where to locate health risks in relation to specific communities, or vice versa. Environmental racism, or the impact of discrimination on the environments where low-income and minority communities live, is one of the drivers of this increased environmental exposure risk.<sup>49, 50</sup> Environmental racism includes the frequent placement of environmentally hazardous industries near communities of color, or the forced placement of these communities on undesirable lands through historical segregation and housing policies.<sup>51</sup>

While poverty is a significant contributor to a community's risk of exposure to pollutants, researchers have also documented the impact of structural racism. Recent research by the Environmental Protection Agency that examined exposure to particulate matter concluded that majority Black communities are 54 percent more likely to breathe in polluted air than majority white neighborhoods.<sup>52</sup> The research found these inequities markedly more significant than disparities based on poverty alone. Given the role of environmental factors in the development and exacerbation of asthma, the inequitable exposure of air pollutants in communities of color that results in the geographic concentration of health risk must be understood as a fundamental driver of asthma inequities for children and families of color.

### **Psychosocial Stressors as Asthma Risk Factors for Children and Communities of Color**

Stress has long been recognized as a significant contributor to asthma.<sup>53</sup> Children of color experience higher asthma rates even when they live in the same neighborhoods as white children. One factor that may contribute to these deep inequities is increased exposure to a number of psychosocial stressors.<sup>54</sup> Children of color are more likely to live in poverty and are more vulnerable to stressors such as food insecurity and crowded or unstable housing.<sup>55</sup> Children exposed to these stressors have higher rates of poor adult outcomes in health, educational achievement, and economic status.<sup>56</sup> Moreover, living in chronic poverty is a stressor for parents as well as their children, and parental stress has been shown to negatively impact child health outcomes.<sup>57</sup>

Stressors that are prevalent in communities where low-income families live increase the risk of adverse childhood experiences (ACEs) such as family dysfunction, family separation, and violence.<sup>58</sup> Experiencing adverse events in childhood has been linked to increased risk of substance abuse, cardiovascular disease, diabetes, and asthma in adulthood.<sup>59</sup> Moreover, there is a dose-response relationship between the number of ACEs a person experiences and increased health risks — the higher the number of ACEs, the higher the risks. All communities experience ACEs, but socioeconomic status and race and ethnicity intersect to compound



vulnerability to ACEs for children of color. Across racial and ethnic groups, 61 percent of Black children and 51 percent of Latino children have two or more ACEs compared to 40 percent of white children.<sup>60</sup> For asthma, having just one ACE increases the odds of developing the disease by 28 percent; having four ACEs increases the odds to 73 percent.<sup>61</sup>

### **Initial Learnings to Inform a Patient-Centered Strategy to Address Asthma Inequities**

The causes of asthma inequities among children and families of color are complex and intersectional, and they extend well beyond individual biology into myriad environmental, geographic, and social factors. Therefore, solving these inequities requires a deliberate focus on those whom current medical science leaves behind. A foundational step in addressing asthma inequities is implementing research practices that produce representative evidence based on the real-world experiences of children and families, and that is reported with the greatest transparency. Recent asthma research funded by PCORI shows the potential for a patient-centered CER strategy that focuses on care delivery and non-traditional provider interventions to discover and disseminate clinical approaches that can improve health equity. An important aspect of these studies is that they respond to known research priorities for addressing asthma inequities, with some promising outcomes as well as some important limited findings. For example, children's health equity experts agree that an important priority is including clinical multi-generational approaches that support parents, children, and their caretakers directly. The expanded

use of CHWs is a high-priority issue among health equity advocates. However, the limitations of these studies also underscore the need for an explicit focus on equity that includes stratified outcomes data as a central research objective.

### **Overview of Six Patient-Centered Outcomes Research Studies on Asthma**

This report covers six PCOR studies from the PCORI asthma portfolio that had publically available findings at the time of writing. All six used CER techniques that compare the effectiveness of one or many interventions against a control. Patients and/or providers participated in each study. The six studies measured the interventions' effects on asthma-related health and quality of life outcomes, management and treatment of asthma, and patients' involvement in their treatment. Many of the interventions tested in these research studies resulted in positive patient-centered outcomes, and most of the studies focused on patients of color and low-income patients. However, data on the effectiveness of the interventions used in the studies have not been stratified by race or ethnicity, so the effectiveness of the interventions for specific ethnic groups remains unknown.

PCORI awarded funding for these six research studies in 2013 and 2014. Abstracts detailing the studies participants, interventions, and measured outcomes are available. Five of the six studies have completed their research, four have completed their peer reviews, and two have published results. Final research reports for many of the studies are expected to be released later this year. Families USA will update this report as additional information becomes available.

**The tables below summarize key information on the six PCORI research studies.**

For more detailed information on the studies, we recommend visiting the links in the Availability of Results column.

<b>1. Does a Stress Management Program for African-American Parents Increase Asthma Symptom-Free Days for Their Children? — The BEAMS Study</b>				
Participants	Interventions Tested	Outcomes Measured	Limitations	Availability of Results
<p>African American parent-child pairs from Washington, D.C.</p> <p>Children had asthma, were 4 to 12 years old, and were enrolled in public insurance.</p>	<p>Group 1: Parents participated in a stress management program.</p> <p>Group 2: Usual care. (Did not participate in the program.)</p>	<p>Number of days without asthma symptoms.</p>	<p>Although children whose parents participated in stress management classes had reduced asthma symptoms, there was no direct evidence of a relationship between parent stress level and child asthma symptoms.<sup>ii</sup></p> <p>Evidence of intervention effectiveness limited to African Americans.</p>	<p>Research project completed January 2019.</p> <p>Abstracts and peer review summary are available at <a href="http://www.pcori.org/Teach190">www.pcori.org/Teach190</a>.</p> <p>Final research report is expected to be available by October 2019.</p>

<sup>ii</sup> Although children of parents who participated in stress management program had more days without asthma symptoms, parents' stress levels or ability to manage stress were not measured, so there is no definitive evidence that reducing or managing stress in parents can reduce asthma symptoms in their children.

## 2. Comparing Three Ways to Prepare Children and Caregivers to Manage Asthma after an Emergency Room Visit — The CHICAGO Plan

Participants	Interventions Tested	Outcomes Measured	Limitations	Availability of Results
<p>Children between 5 and 11 years old with asthma from six hospitals in Chicago.</p> <p>64% Black, 31% Hispanic or Latino.</p>	<p>Group 1: Parents given a paper decision support tool in the emergency room to help providers communicate instructions and recommendations for asthma treatment after leaving the emergency room.</p> <p>Group 2: Parents received the decision-support tool in the emergency room plus home visits from a CHW.</p> <p>Group 3: Usual care.</p>	<p>Survey responses from patients on how asthma affected their lives.</p> <p>Use of asthma medicine at home.</p> <p>Likelihood of filling asthma prescriptions.</p> <p>Likelihood of scheduling and attending office visits.</p>	<p>Fewer children participated in the study than the researchers anticipated.</p> <p>Due to its modest size, the study did not measure the interventions' impacts on clinical outcomes or utilization of the emergency room.</p>	<p>Research project completed October 2018.</p> <p>Abstracts and peer review summary are available at <a href="http://www.pcori.org/Krishnan184">www.pcori.org/Krishnan184</a>.</p> <p>Final research report is expected to be available by October 2019.</p>

### 3. Guidelines to Practice (G2P): Reducing Asthma Health Disparities through Guideline Implementation

Participants	Interventions Tested	Outcomes Measured	Limitations	Availability of Results
<p>Low-income patients from 5 to 75 years old with uncontrolled asthma from six community health centers in Seattle and King County, WA.</p> <p>Patients were from various ethnic backgrounds.</p>	<p>Group 1: Patients or parents received CHW home visits, were treated by providers implementing clinic improvements; and received health plan interventions, and provider education.</p> <p>Group 2: Patients or parents received CHW home visits, health plan interventions, and provider education.</p> <p>Group 3: Patients were treated by providers implementing clinic improvements, and received health plan intervention, and provider education.</p> <p>Group 4: Patients or parents received health plan intervention and provider education.</p>	<p>Asthma Control Test.</p> <p>Asthma Quality of Life Questionnaire.</p> <p>Number of days without asthma symptoms.</p> <p>Missed work or school days.</p> <p>Lung function.</p> <p>Lung inflammation.</p> <p>Oral steroid use.</p> <p>Asthma-related hospitalization and emergency department visits.</p> <p>Urgent care utilization.</p> <p>Nocturnal awakenings.</p> <p>Patient-provider communication.</p> <p>Patient satisfaction with care.</p>	<p>Data on effectiveness of interventions are not stratified by patients' race or ethnicity.</p>	<p>Research project completed December 2018.</p> <p>Currently in PCORI peer-review process.</p> <p>Abstract is available at <a href="https://www.pcori.org/research-results/2013/guidelines-practice-g2p-reducing-asthma-health-disparities-through-guideline">https://www.pcori.org/research-results/2013/guidelines-practice-g2p-reducing-asthma-health-disparities-through-guideline</a>.</p>

#### 4. Using a Home- or Clinic-Based Program to Help Older Adults Manage Their Asthma — The SAMBA Study

Participants	Interventions Tested	Outcomes Measured	Limitations	Availability of Results
<p>Adults ages 60 and older from nine clinics in New York City.</p> <p>Patients were 57% Hispanic, 30% Black, 7% white, and 85% women.</p>	<p>The Supporting Asthma Management Behavior in Aging Adults (SAMBA) study consists of meetings with trained coaches, creation of a care plan, and follow-up meetings over the course of 1 year.</p> <p>Group 1: Patients received the SAMBA asthma self-management program at home through CHWs.</p> <p>Group 2: Patients received SAMBA asthma self-management program at a clinic through Asthma Care Coaches (ACCs).</p> <p>Group 3: Usual care.</p>	<p>Asthma Control Test.</p> <p>Asthma Quality of Life Questionnaire.</p> <p>Medicine adherence.</p> <p>Correct usage of metered dose inhaler.</p> <p>Correct use of dry powder inhaler.</p>	<p>Four different organizations, with distinct hiring, supervision, and procedure documentation processes, assigned patients trained ACCs or CHWs based on geographic proximity.</p> <p>The lack of comparable criteria for selecting and training ACCs and CHWs limited understanding of what characteristics made them more or less effective for specific populations.</p>	<p>Research project completed January 2019.</p> <p>Abstracts and peer-review summary are available at <a href="http://www.pcori.org/Federman201">www.pcori.org/Federman201</a>.</p> <p>Final research report is expected to be available by November 2019.</p>

5. Improving Youth Question-Asking and Provider Education During Pediatric Asthma Visits				
Participants	Interventions Tested	Outcomes Measured	Limitations	Availability of Results
<p>Youth ages 11 through 17 from four pediatric practices in North Carolina.</p> <p>Patients were from various ethnic backgrounds and spoke English or Spanish at home.</p>	<p>Group 1: Patients watched a short educational video and completed an asthma question prompt list.</p> <p>Group 2: Usual care.</p>	<p>Number of questions youth asked related to asthma medications, asthma triggers, and environmental control.</p> <p>Whether providers educated youth on asthma medications, asthma triggers, and environmental control during visit.</p>	<p>Published results do not include data related to health outcomes.</p> <p>Data on effectiveness of intervention is not stratified by patients' race or ethnicity.</p>	<p>Research project will be completed May 2019.</p> <p>Currently in PCORI peer-review process.</p> <p>Summary and published results are available at <a href="http://www.pcori.org/research-results/2014/using-question-prompt-lists-during-pediatric-asthma-visits-increase-adolescent">www.pcori.org/research-results/2014/using-question-prompt-lists-during-pediatric-asthma-visits-increase-adolescent</a>.</p>

## 6. Training Staff at Doctors' Offices to Use Shared Decision Making with Patients Choosing Asthma Treatments

Participants	Interventions Tested	Outcomes Measured	Limitations	Availability of Results
Primary care practices with at least 75 Medicaid patients over 2 years old with asthma in North Carolina.	<p>Group 1: Primary care practices participated in a 12-week, facilitator-led shared decision-making (SDM) training program that was customized for each doctor's office.</p> <p>Group 2: Primary care practices participated in a single 1-hour SDM training program that was not customized for each doctor's office.</p> <p>Group 3: Primary care practices did not participate in an SDM training program.</p>	<p>Survey responses from patients on their perceptions of shared decision-making in their treatment.</p> <p>Asthma-related hospitalizations and emergency department visits.</p> <p>Oral steroid prescription orders.</p>	Data on effectiveness of intervention is not stratified by patients' race or ethnicity.	<p>Research project completed July 2018.</p> <p>Abstracts, peer-review summary, and published results are available at <a href="http://www.pcori.org/Tapp165">www.pcori.org/Tapp165</a>.</p> <p>Final research report is expected to be available by July 2019.</p>

## Results and Policy Implications

As indicated in the table above, publicly available information on the results of these six PCOR studies is currently limited. Nevertheless, available findings provide valuable evidence to support policies that address asthma-related health inequities.

### **1. Does a Stress Management Program for Black Parents Increase Asthma Symptom-Free Days for Their Children? – The BEAMS Study**

#### **Inequities Addressed**

The BEAMS Study addressed Black children’s asthma inequities and the impact of parental stress on asthma symptoms. Black children are twice as likely to have asthma compared to their white counterparts.<sup>62</sup> Early childhood caregiver stress has been linked to asthma symptoms.<sup>63</sup>

#### **Results of Study**

The BEAMS Study shows that stress management classes for Black parents of children with asthma can reduce their children’s asthma symptoms after 12 months. However, stress management classes had no effect on children’s asthma symptoms after 6 months.

This study focused exclusively on Black parents and children. It provides clear evidence of the intervention’s effect on Black patients without the need to stratify data from multiple ethnic groups.

#### **Policy Implications**

This research study demonstrates the effectiveness of long-term and multi-generational interventions in managing asthma in children. Key policy implications include:

- » Providers and health systems must commit to investing at least 12 months in this type of parental support.

- » Parental stress management programs should be part of a longer-term asthma management plan that includes treatment or intervention with more immediate results.
- » Because the parents and children who participated in this study were enrolled in public insurance,<sup>64</sup> advocates and policymakers who want to sustainably fund and implement this intervention should consider pursuing Medicaid waivers or demonstration projects such as those proposed in the Trauma-Informed Care for Children and Families Act of 2017.

### **2. Comparing Three Ways to Prepare Children and Caregivers to Manage Asthma After an Emergency Room Visit – The Chicago Plan**

#### **Inequities Addressed**

The Chicago Plan focused on Black and Latino childhood asthma inequities. Along with Black children, Puerto Rican children are twice as likely to have asthma compared to their white counterparts.<sup>65</sup> Asthma among Black and Latino children is also more likely to be uncontrolled. Black and Latino children are less likely to receive and refill prescriptions and use controller medications.<sup>66</sup> In 2015, Black children were 10 times more likely to die from asthma compared to non-Hispanic white children, and Latino children were twice as likely to die from asthma compared to non-Hispanic white children.<sup>67, 68</sup> Asthma-related hospital admissions and emergency room visits are higher for Black and Latino children, who are more likely to visit the emergency room for a potentially preventable asthma crisis.<sup>69, 70, 71</sup>



## Results of Study

The literacy level-appropriate and culturally tailored decision support tool used in this study helped Black and Latino children and their caregivers better manage their asthma symptoms. The decision support tool was especially effective when combined with home visits from CHWs.

Children who received the decision support tool in the emergency room were more likely than children who received the usual care provided in the emergency room to use asthma medicine such as steroids, inhaler medicine, and rescue medicine at home and were more likely to schedule an office visit.

Among children who received the decision support tool, those who also received home visits from CHWs were also more likely to attend their scheduled office visits and were more likely to fill and renew their prescriptions.

Stratifying results by race revealed no significant differences between Black and non-Black children.

## Policy Implications

- » Emergency departments should implement a culturally tailored and literacy level-appropriate decision support tool to help Black and Latino children and their caregivers improve management of their condition.
- » A majority<sup>72</sup> of the children who benefited from this study's CHW interventions had public insurance, so advocates and policymakers who are interested in establishing more sustainable funding for CHW interventions should consider Medicaid reimbursement.

## 3. Guidelines to Practice (G2P): Reducing Asthma Health Disparities Through Guideline Implementation

### Inequities Addressed

The G2P Study addressed inequities in patients' asthma-related quality of life outcomes. One measure of asthma-related quality of life is missed days of work or school due to asthma. As many as 14 million days of work and 14 million days of school are reportedly lost each year due to asthma symptoms.<sup>73</sup> Another measure is quality of sleep among patients with asthma. Black patients report more nights with disrupted sleep compared to their white counterparts.

### Results of Study

Although the research is currently in scientific review, the preliminary results suggest that home-based interventions from CHWs can increase the number of patients' asthma symptom-free days and reduce the number of nights of waking up due to asthma symptoms, trips to urgent care, missed days of work or school, and use of oral steroids. Integration of CHWs into clinics and provider teams in Seattle and King County, Washington, has resulted in improved quality of care. However, the results of the study are limited in that the available data on the effectiveness of the interventions are not stratified by race or ethnicity.

### Policy Implications

Because of the G2P study's preliminary successes, efforts are already underway to scale up these interventions to communities throughout Washington. The researchers and their partners have received additional funding from PCORI to disseminate and implement their results.<sup>74</sup> The goals of this new dissemination and implementation project are to:

## Evidence Spurs Action

### Community Health Workers in Washington's Accountable Communities of Health

The G2P Study's successful CHW interventions are an example of how patient-centered outcomes research is informing one state's efforts to transform its health care system to better address health inequities. Washington is now working on expanding this intervention throughout the state via Accountable Communities of Health (ACH).

In January 2017, The Centers for Medicare and Medicaid Services approved Washington's Medicaid Transformation Project Section 1115 waiver. Through this waiver, the state intends to transform its health care delivery system through ACHs with the ultimate goal of advancing health equity and eliminating health disparities.<sup>75</sup> Washington's ACHs are nine regional partnerships among community-based organizations, including health care providers, insurance companies, public health agencies, local government agencies, non-profit social service agencies, legal services organizations, school districts, and tribes. The 1115 waiver makes federal funds available to ACHs to make performance-based payments to participating providers. These payments are intended to incentivize the provision of high-quality health care instead of paying based on the quantity of services provided.

Washington's Medicaid Transformation Project incentivizes ACHs to implement the G2P research project's successful CHW interventions because they have been shown to improve health outcomes and address inequities, which in turn generates greater performance-based payments for ACH providers.

- » Expand the CHW home visit program to four regions of Washington. The CHW home visit program is expected to affect 1,700 people in the two years that PCORI will fund this program.
- » Implement a training program for CHW mentors and managers, along with an online tutorial and hands-on training for asthma-focused CHWs.
- » Evaluate the dissemination and implementation project.

The dissemination and implementation program could be replicated outside Washington. In other states, health systems, clinics, and CHW organizations can implement the training program to build CHWs' skills in treating asthma. Using various funding strategies, such as Medicaid reimbursement (as outlined for the Chicago Plan), other states could begin to implement the CHW home visit program.

Additional evidence to support the replication of these interventions will be available after the review of the preliminary research and evaluation of the dissemination and implementation project are completed.

#### ***4. Using a Home- or Clinic-Based Program to Help Older Adults Manage Their Asthma — The SAMBA Study***

##### **Inequities Addressed**

The SAMBA Study focused on asthma inequities among older Black and Latino adults. Black older adults are about 35 percent more likely to have asthma compared to their white counterparts.<sup>76</sup>

##### **Results of Study**

The SAMBA asthma self-management program can improve quality of life, asthma control, medicine adherence, and correct inhaler use for Black and Latino adults over the age of 60.

Older adults who received the SAMBA asthma self-management program had better asthma control and improved quality of life after 6 months. SAMBA also resulted in better medication adherence and correct use of a metered dose inhaler after 6 months and 1 year.

After 1 year, asthma management improved for patients who received SAMBA at home, as well as patients who received the SAMBA asthma self-management program at a clinic.

Stratified results showed no significant difference in effectiveness between Black and Latino patients.

One important limitation is that there is no evidence in the study that the SAMBA program was more effective than usual care in reducing hospital stays or emergency room visits.

##### **Policy Implications**

- » The inclusion of CHWs and asthma care coaches in this model for improving asthma management and medication adherence further support the value of face to face support by non-clinical staff in addressing this chronic disease. This suggests

that decision makers should increase resources for establishing and maintaining these kinds of services.

- » Both the home- and clinic-based interventions were roughly equally successful, in the specific context of New York City. Decision makers should evaluate whether to provide SAMBA in either a home- or clinic-based setting, taking into consideration relevant factors in their particular geography, given that some barriers, like distance and transportation, may vary greatly. That said, a strongly patient-centered approach would make room for both and allow patients to elect the setting in which they would prefer to receive services.

#### ***5. Improving Youth Question-Asking and Provider Education During Pediatric Asthma Visits***

##### **Inequities Addressed**

The Question-Asking Study focused on inequities related to patient engagement in doctors' offices. Historically, patients of color have been left out of the decision-making process for treating their asthma and other health conditions. When patients are more engaged in their treatment, they are better able to take steps to improve their health.

##### **Results of Study**

Completing a question prompt list and watching an educational video prior to receiving treatment can make patients more likely to ask questions and be educated by their providers about asthma medications, asthma triggers, and environmental control. However, the study did not evaluate the impact on health outcomes or the effectiveness of this intervention in addressing asthma-related health inequities.

The report on this research study includes demographic data which show that white, Black, Latino, and American Indian patients participated in this research. The demographic data also show that the language that participants spoke at home was either English or Spanish. However, the results of the study are limited in that data on the likelihood of youth question-asking and the likelihood of provider education are not stratified by race or ethnicity, or by the language spoken at home. It is particularly unfortunate that no stratified data are available on the effectiveness of this communication-based intervention, because it is possible that patients' primary language and ethnic background influenced the questions they asked and the education they received from providers.

Without these stratified data, the likelihood that patients of certain ethnic or linguistic backgrounds will ask questions and receive provider education, both with and without the intervention, remains unknown. Therefore, it also remains unknown whether the intervention was any more or less effective for patients of certain ethnic or linguistic backgrounds.

### **Policy Implications**

- » This study did not directly assess impact on health outcomes. Generally, increasing patient activation and engagement is considered a positive process outcome, and the potential life course impact of encouraging youth to engage more actively in their health care may have long-term benefits. However, this study illustrates the need to measure patient-centered health outcomes more concretely.
- » This study exemplifies a larger challenge in research and health equity generally—the dearth of data that is stratified by demographic characteristics, even when subjects are diverse.

Without stratified data on the effects of a treatment intervention, it is impossible to know how any given intervention affects patients from specific communities likely to experience inequities. Even if the study had demonstrated success as a whole, these aggregated results could mask inequities. Without stratified data we cannot know whether the intervention was less successful for patients from specific communities. To avoid masking or exacerbating health inequities, a new standard must be set for all health care research to require that results be stratified by race, ethnicity, and gender, at a minimum.

### ***6. Training Staff at Doctors' Offices to Use Shared Decision-Making with Patients Choosing Asthma Treatments – The SDM Study***

#### **Inequities Addressed**

The Shared Decision-Making (SDM) study focused on addressing disparities in patients' involvement in treatment decision-making by focusing on provider behavior.

#### **Results of Study**

Practice facilitation, in the form of a customized 12-week, facilitator-led training in doctors' offices, is an effective strategy for successfully implementing SDM in primary care practices. However, despite the success in implementing SDM in doctors' offices, the researchers reported “no significant difference in health outcomes” between patients whose providers participated in SDM training programs and patients whose providers did not.<sup>77</sup> The results of the study are limited in that the available data on the effectiveness of the interventions are not stratified by race or ethnicity.

#### **Policy Implications**

- » While this study does not provide evidence that implementing SDM improves outcomes or

addresses inequities in asthma-related emergency room utilization, hospitalization, or oral steroid prescriptions, the implementation strategy for SDM could be adopted to implement interventions that have been proven to address inequities.

For example, in the Chicago Plan, doctors in the emergency room used a decision-support tool to help families manage asthma after leaving the emergency room. Ongoing, customized, facilitator-led dissemination, as was used in the SDM study, could be a successful strategy for implementing decision-support tools in emergency rooms.

## Key Overarching Policy Recommendations

The synthesis of the available findings from the six studies reviewed in this report suggests that there are at least three key issues that are ripe for policy solutions. We propose the recommendations below.

### 1. **Researchers should be required to stratify the results of their studies by race, ethnicity, and gender—at a minimum.**

Aggregated research results continue to be an impediment to identifying health inequities that require tailored attention, developing effective solutions to solve them, and tracking progress. With the exception of research designed for a specific group experiencing inequities, such as the BEAMs study that focused on African Americans, data that is not stratified will be of very limited use in health inequity reduction policy development and implementation.

### 2. **CHW interventions continue to show success in addressing inequities and improving outcomes, so these services should be funded as valuable health interventions, particularly in Medicaid, which covers a large proportion of children and adults of color.**

Three of the research projects discussed in this paper tested home-based interventions by CHWs. In the Chicago Plan and the G2P Study, CHWs visited patients in their homes, and were especially successful in improving outcomes. In the Chicago Plan, families who received home visits from CHWs after visiting the emergency room took more steps to manage their children's asthma. In the G2P Study, home visits from CHWs reduced asthma symptoms and improved patients' quality of life in every outcome measured.

The SAMBA study also tested a home-based intervention in which CHWs provided patients with SAMBA in the home and compared this intervention with one where coaches provided patients with SAMBA in a clinic setting. The SAMBA program was effective in helping patients manage their asthma and control symptoms, with similar results regardless of setting.

### 3. **Research on children of color needs to include qualitative data from parents.**

Two of the research projects discussed in this paper focused specifically on managing and reducing asthma symptoms in children of color. The BEAMs Study found that stress management classes for Black parents reduced their children's asthma symptoms after 12 months. In the Chicago

## Sustainably Funding CHWs through Medicaid

Given that the evidence demonstrating the value of CHWs in reducing health inequities continues to grow, including in addressing asthma inequities, decision makers should focus on securing sustainable funding for their valuable services. Considering Medicaid's critical role in providing care for people of color, and especially for children of color, obtaining Medicaid funding support should be a top priority.

There are several ways that states can fund CHWs through Medicaid. These include:

- » State plan amendments for reimbursing preventive services.
- » State legislation and state plan amendments for broader Medicaid reimbursement.
- » Defined reimbursement through Section 1115 waivers.
- » Reimbursement through managed care contracts.
- » Funding through other health system transformation efforts.

The source of funding has important implications for the breadth and depth of specific CHW programs. As part of its Community Health Worker Sustainability Collaborative, Families USA has published resources that provide information on pathways for sustainably funding CHWs through Medicaid.<sup>78</sup>

Plan, the use of a decision support tool and home visits from CHWs had no measurable effect on children's trouble breathing or on caregivers missing work due to a child's asthma symptoms.

However, the Chicago Plan does demonstrate that a decision support tool, especially when combined with home visits from CHWs, was successful in helping families manage asthma symptoms outside the emergency room. These interventions made patients more likely to schedule and attend doctor's office visits, use asthma medications, and

renew prescriptions. Even if these interventions are successful in helping children and their parents manage asthma, patients did not recognize their value in reducing day-to-day asthma symptoms. The BEAMS study did not collect qualitative data from parents on whether they believed their participation in stress management classes was effective in reducing their child's asthma symptoms. It is important that providers recognize the discrepancy between the demonstrated effectiveness of interventions and their perceived effectiveness among patients.

## Conclusion

The six patient-centered outcomes research studies discussed in this report constitute an evidence base for policies and clinical approaches that address inequities in asthma-related health and quality of life, management and treatment of asthma, and patients' involvement in their treatment. In particular, the SAMBA program for older adults, a decision support tool in the emergency room, and CHW interventions were especially successful in improving asthma-related health outcomes. These successful interventions can be implemented at the state level through Medicaid state plan amendments and

demonstration projects, and at the health system level through practice facilitation.

The successes of these research studies in addressing health inequities are tempered by their limitations. Primarily, the lack of available stratified data in the research studies resulted in a lack of evidence on how their interventions addressed specific inequities. The limitations of these studies also demonstrate the need for an explicit focus on equity that includes stratified outcomes data as a central research objective. As the results of these studies are made available later in the year, we hope to learn more about these interventions' effectiveness for patients of color.

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