



Unidos Hablemos: Engaging Hispanics/Latinos in Asthma Research

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Outline

Asthma in Hispanic/ Latino
Children

Asthma in Hispanic/Latino
Adults

Asthma Disparities in the
Hispanic/Latino communities

Unidos Hablemos...

Asthma Prevalence in the Hispanic/Latino Community

- ▶ In 2018, 2.3 million Hispanics/Latinos reported having asthma
- ▶ Prevalence of asthma is 100 % higher in Hispanics/ Latinos as compared to caucasians.
- ▶ In the Hispanic/Latino community, 6.4% of adults have asthma. Of this group, 15% are from Puerto Rico and 5% from Mexico.
- ▶ Prevalence rates are increasing, in particular, in underserved areas or with difficulty accessing medical resources

Asthma Prevalence in Children

- ▶ Among children under 18 years, 8% of all Hispanic are affected by asthma
- ▶ Of this group, 17% are from Puerto Rico and 7% from Mexico
- ▶ Asthma cases in Puerto Rico represent twice as many asthma cases compared to other Hispanics
- ▶ Children of Puerto Rican origin suffer from asthma three times more than white children of non-Hispanic origin



Data table for Figure 10. Current asthma among children under age 18 years, by age and race and Hispanic origin: United States, 2008–2018

Excel and PowerPoint: <https://www.cdc.gov/nchs/hus/contents2019.htm#Figure-010>

Current asthma among children under age 18 years, by age: 2008–2018

Year	Total		Under 5 years		5–17 years	
	Percent	SE	Percent	SE	Percent	SE
2008.....	9.4	0.4	6.2	0.6	10.7	0.5
2009.....	9.6	0.4	6.3	0.6	11.0	0.5
2010.....	9.4	0.3	6.0	0.5	10.7	0.4
2011.....	9.5	0.3	6.9	0.5	10.6	0.4
2012.....	9.3	0.3	5.4	0.5	10.7	0.4
2013.....	8.3	0.3	4.2	0.4	9.9	0.4
2014.....	8.6	0.3	4.3	0.5	10.2	0.4
2015.....	8.4	0.3	4.7	0.5	9.8	0.4
2016.....	8.3	0.3	3.8	0.5	10.0	0.4
2017.....	8.4	0.4	4.4	0.6	9.9	0.5
2018.....	7.5	0.4	3.8	0.5	8.9	0.5

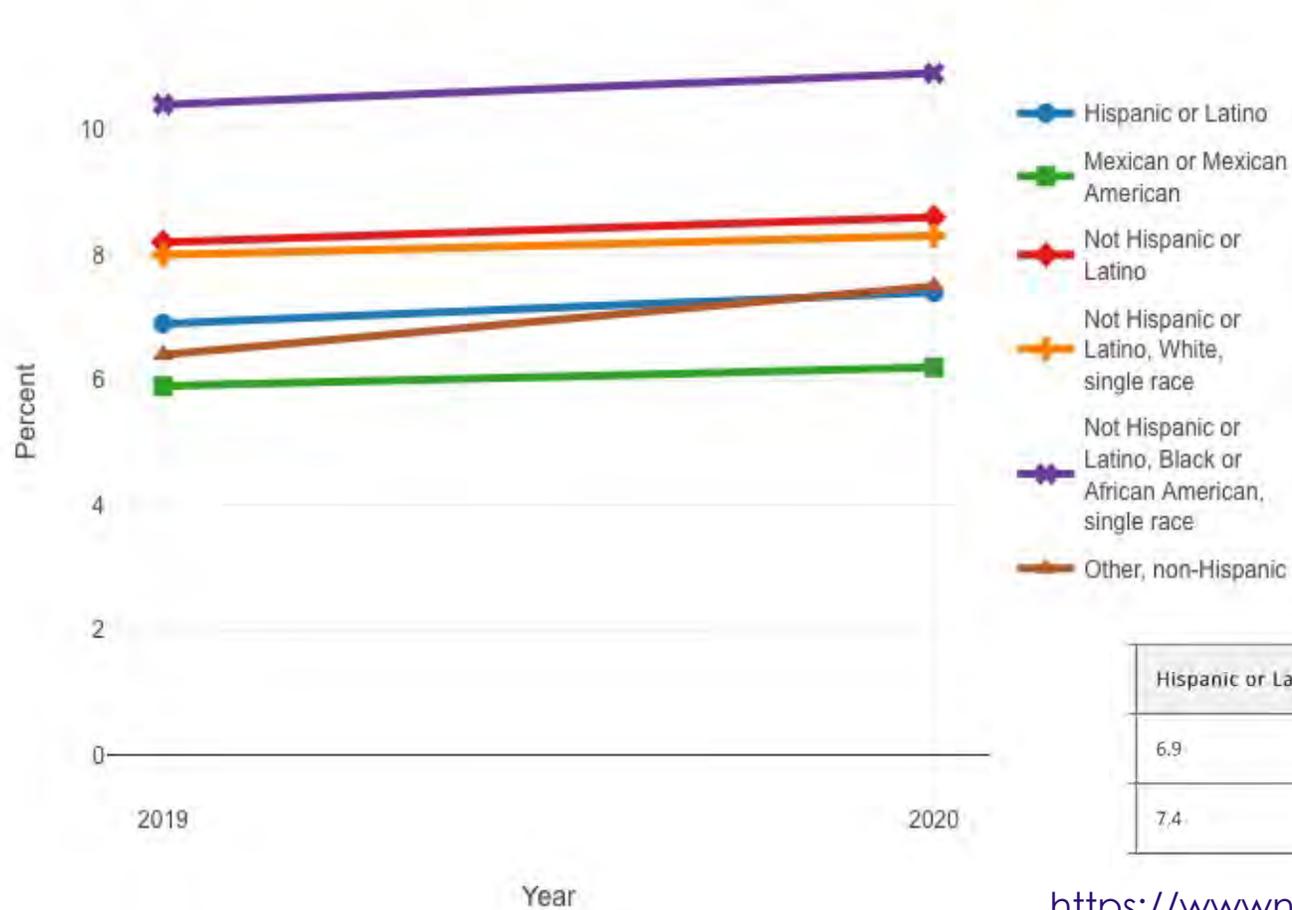
Current asthma among children under age 18 years, by race and Hispanic origin: 2018

Year	Not Hispanic or Latino							
	Hispanic		White		Black		Asian	
	Percent	SE	Percent	SE	Percent	SE	Percent	SE
2018.....	8.0	0.8	5.6	0.4	14.3	1.5	3.6	0.9

NOTES: SE is standard error. Data are for the civilian noninstitutionalized population. Based on a parent or knowledgeable adult responding yes to both questions, “Has a doctor or other health professional ever told you that your child had asthma?” and “Does your child still have asthma?” Children of Hispanic origin may be of any race. Race-specific estimates are tabulated according to the 1997 “Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity.” See [Appendix II](#), Hispanic origin; Race.

SOURCE: NCHS, National Health Interview Survey. See [Appendix I](#), National Health Interview Survey (NHIS).

Percentage of current asthma for adults aged 18 and over, United States, 2019—2020



Hispanic or Latino	Mexican or Mexican American	Not Hispanic or Latino	Not Hispanic or Latino
6.9	5.9	8.2	8.0
7.4	6.2	8.6	8.3

https://wwwn.cdc.gov/NHISDataQueryTool/SHS_adult/index.html

Asthma Prevalence in Adults

AsthmaStats

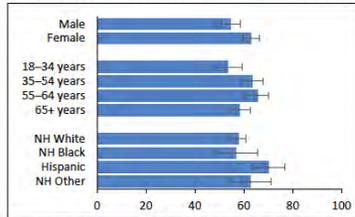
Uncontrolled Asthma Among Adults, 2019

Sixty Percent of Adults with Current Asthma had Uncontrolled Asthma

Uncontrolled asthma is associated with significant health and economic costs because of frequent and intense episodes of symptoms that may increase risk of emergency department visits, hospitalizations, and work and school absenteeism. Asthma control status was classified as well-controlled or uncontrolled asthma based on the national asthma guidelines.*

60.1% of adults with current asthma[†] had uncontrolled asthma. Percentage of uncontrolled asthma was higher among females (63.1%) than males (54.7%), Hispanics (70.1%) than non-Hispanic White adults (58.0%), and ages 55–64 years (65.5%) than ages 18–34 years (53.3%). No other significant differences were observed by demographic characteristics. The percentage of adults with uncontrolled asthma varies by state but does not seem to follow a specific geographic pattern. The percentage ranged from 41.7% in New Jersey to 72.4% in Missouri and Utah (see table).

Percentage With Uncontrolled Asthma by Demographics



Abbreviation: NH, Non-Hispanic; SE, Standard error; CI, confidence interval

Characteristic	Percent	95% CI	SE	y-error bar
Male	54.7	50.7–58.6	2.03	4.0
Female	63.1	59.8–66.2	1.65	3.2
18–34 years	53.3	47.4–59.2	3.00	5.9
35–54 years	63.4	59.0–67.6	2.19	4.3
55–64 years	65.5	60.8–69.9	2.34	4.6
65+ years	58.4	54.1–62.6	2.16	4.2
NH White	58.0	55.0–60.9	1.51	3.0
NH Black	56.9	48.1–65.3	4.42	8.7
Hispanic	70.1	63.2–76.2	3.32	6.5
NH Other	62.7	53.8–70.8	4.36	8.5

CDC's National Asthma Control Program (NACP) was created in 1999 to help the millions of people with asthma in the United States gain control over their disease. The NACP conducts national asthma surveillance and funds states to help them improve their asthma surveillance and to focus efforts and resources where they are needed.

STATE	Adults with Current [†] and Uncontrolled Asthma ^{**}	
	%	% 95% CI
Total ^{††}	60.1	57.5–62.6
AZ	57.9	45.6–69.3
CA	61.1	53.4–68.3
CT	54.7	44.2–64.8
FL	67.8	58.6–75.8
GA	71.0	56.9–82.0
HI	49.6	40.1–59.1
IL	52.8	44.0–61.4
IN	62.5	54.0–70.3
IA	54.4	46.0–62.5
KS	60.4	51.8–68.4
KY	71.0	60.2–79.8
ME	60.0	51.3–68.0
MA	42.7	34.4–51.4
MI	60.7	54.0–67.1
MN	61.9	56.6–67.0
MO	72.4	63.5–79.9
MT	59.6	51.5–67.2
NE	58.6	50.9–66.0
NV	70.0	58.3–79.6
NH	55.9	47.8–63.6
NJ	41.7 ^{†††}	20.3–66.9
NM	66.6	54.2–77.1
NY	61.4	48.8–72.6
OH	62.3	54.2–69.7
OR	59.3	51.8–66.4
PA	55.0	46.0–63.6
RI	53.2	41.4–64.7
TX	60.8	49.0–71.5
UT	72.4	66.1–77.9
VT	54.3	43.5–64.7
WI	58.5	48.3–68.1
PR	58.8	49.5–67.4

Source: Behavioral Risk Factors Surveillance System (BRFSS)—Adult Asthma Call-back Survey Data, 2019

Note: data not available for (AL, AK, AR, CO, DC, DE, ID, LA, MD, MS, NC, ND, OK, SC, SD, TN, VA, WA, WV, WY)

*National Asthma Education and Prevention Program Expert panel report 3: Guidelines for the Diagnosis and Management of Asthma, 2007. Available at: https://www.ncbi.nlm.nih.gov/books/NBK7232/pdf/Bookshelf_NBK7232.pdf

[†]Includes persons who answered "yes" to the questions: "Have you ever been told by a doctor, nurse, or other health professional that you had asthma?"

and "Do you still have asthma?"

^{**}Includes listed states and Puerto Rico.

^{††}Unreliable estimate, RSE > 30

- ▶ 60.1% of adults with current asthma had uncontrolled asthma.
- ▶ Percentage of uncontrolled asthma was higher among females (63.1%) than males (54.7%), **Hispanics (70.1%) than non-Hispanic White adults (58.0%)**, and ages 55–64 years (65.5%) than ages 18–34 years (53.3%).
- ▶ Prevalence of asthma varies by state

https://www.cdc.gov/asthma/asthma_stats/documents/AsthmaStats_Uncontrolled-Asthma_Adults_2019-p.pdf

Importance of adequate asthma control- mortality

- ▶ Mortality from asthma is higher among Latinos, especially from origin of Puerto Rico
- ▶ The death rates from asthma in Puerto Rican patients is 75% to 200% higher than in Caucasians
- ▶ Studies show that in Latino school-age children - from Puerto Rico, Mexico and Central / South America - use of quick relief medications is greater than in other groups
- ▶ Hispanic/Latino children have a 40% higher risk of dying from asthma compared to non-Hispanic whites

ASTHMA HEALTH DISPARITIES

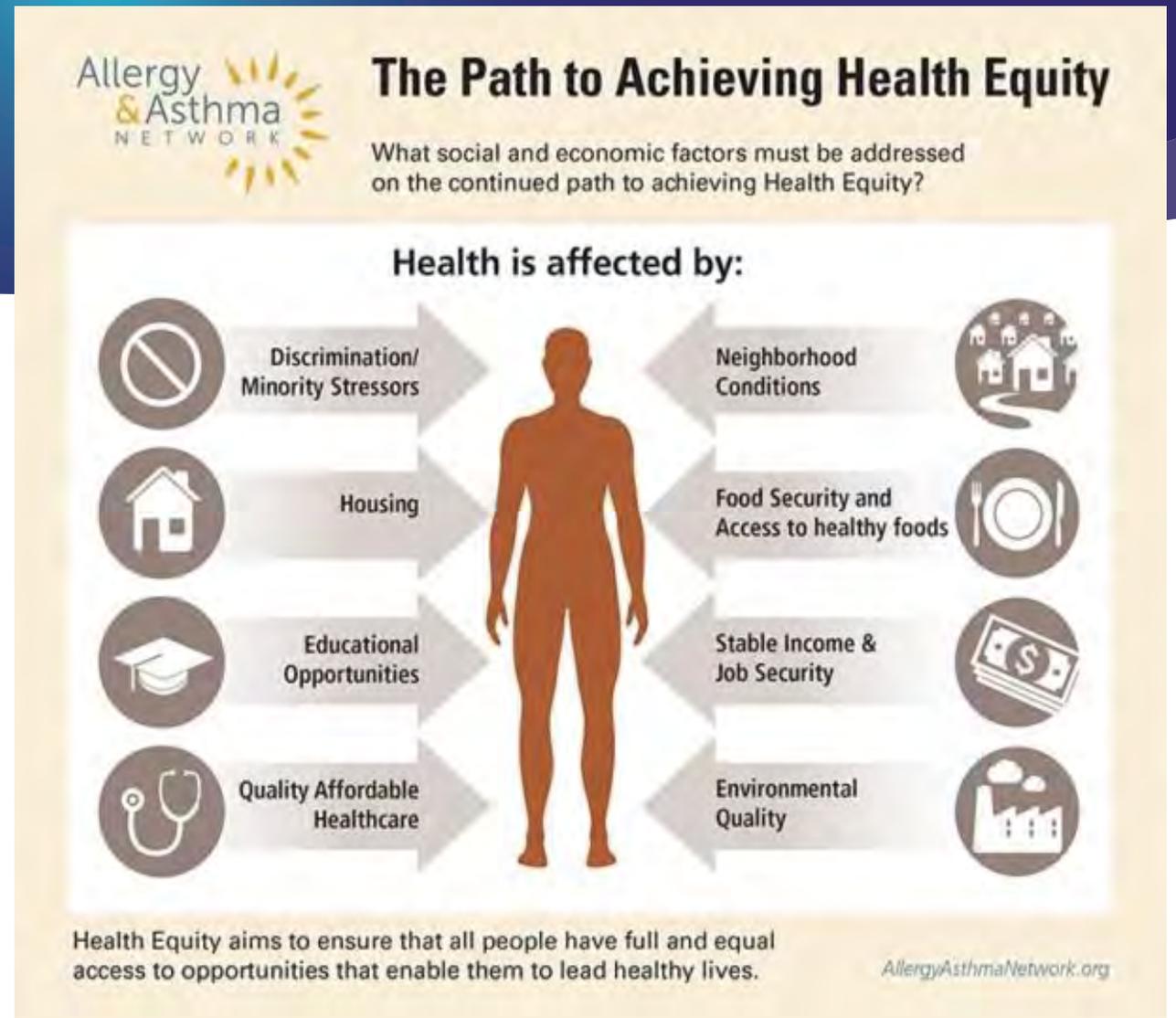
Asthma crosses all racial, ethnic and socioeconomic groups. It is more common among African-American, Hispanic and Native American populations, particularly those living in poor urban areas.

RATE OF ASTHMA-RELATED ER VISITS AND DEATHS COMPARED WITH CAUCASIANS

	ER VISITS	DEATHS
African-American children:	4.5X HIGHER	7X HIGHER
African-American adults:	2.8X HIGHER	3X HIGHER
Hispanic children:	2.1X HIGHER	2X HIGHER

Health disparities in the Hispanic/Latino community

- ▶ Latinos who prefer to communicate in Spanish received fewer asthma diagnoses in community health centers in the United States compared to Latino patients who prefer to communicate in English
- ▶ Latinos received a diagnosis of asthma less frequently the first day they presented with symptoms compared to white non-Latino patients



Factors affecting the Latino community

Respiratory infections during the first two years of life increase the risk of developing asthma in Puerto Rican patients

In the National Health Survey (NHIS) of Children, more visits to the Emergency Room among Asthma Patients from Puerto Rico and Mexico / Americans. ER visits and hospitalizations related to asthma in Hispanics/LatinX and African Americans are double those in caucasians and numbers of rehospitalization are 50% higher

Among obese children, the risk of oral steroid use increases by 15%- can have long-term side effects if used over time

FACTORS THAT CAN LEAD TO ASTHMA DISPARITIES



• **ACCESS TO CARE** – Limited or lack of transportation can result in patients missing or rescheduling doctor appointments and forgoing or delaying medication use.



• **INCOME** – Poverty can affect access to healthcare and health insurance, forcing low-income patients to skimp on medical care, including preventive medications.



• **ENVIRONMENTAL ALLERGENS AND IRRITANTS** – People with asthma who live in urban areas with substandard housing are exposed to more asthma triggers, including mold, dust mites, cockroaches and mice, cigarette smoke and vehicular exhaust from nearby highways.



• **EDUCATION INEQUALITY** – A lack of knowledge and understanding of the disease can lead to problems such as using asthma inhalers incorrectly or not following through on treatment.



• **LANGUAGE AND CULTURAL DIFFERENCES** – People with asthma who speak Spanish as a primary language may struggle to get appropriate health services.

Trends in Poor Health Indicators

- ▶ Hispanic/Latino adults ranked worst across all racial/ethnic groups for access to health care during the 20-year period. Despite experiencing a lower chronic disease burden than Black/African American adults, Hispanic/Latino men and women of all ages reported the worst perceptions of their general health of all groups.
- ▶ Higher mental health challenges, suboptimal insurance coverage, physical inactivity and other factors including self-management of chronic diseases are likely involved.

How can we address these disparities?

Advancing the patient voice and engagement in research to reflect the full community, addressing barriers, misinformation and diverse cultural backgrounds to ensure all those living with allergies, asthma and related conditions have the same opportunities to make informed healthcare decisions and improve healthcare delivery and outcomes.

Resulting in long term positive outcomes that make a difference in health care, healthcare decisions and better asthma outcomes in this population.

How can we address these disparities?

Efforts to increase participation levels of minority patients in research need to include patient engagement programs that address the many barriers:

- ▶ Distrust
- ▶ Fear of influencing immigration status
- ▶ Education
- ▶ Language barriers

Patients as Partners in Research

- ▶ There are only few models to train patients as partners to engage in research or researcher-patient collaborations specific to asthma
- ▶ In 2021, Allergy & Asthma Network proposed to build an infrastructure with the capacity to grow productive collaborations between patient partners from medically underrepresented communities
- ▶ Preparing patients to be experts in research requires an investment in their education about research, from the questions developed through outcome adoption
- ▶ Involving patients from these communities result in stronger relevant studies with meaningful outcomes and lead to better acceptance by the communities at large

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United, Let's talk about...

- ▶ Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award #EAIN 21130- Allergy & Asthma Network (May 2021-May 2022)
- ▶ The Network was awarded two Engagement Awards (EW), (#EAIN-00134 & #EAIN-21130), to engage patients in PCOR/CER.
- ▶ The first award engaged the Black/African American community and the second, the Hispanic/Latino community – Unidos Hablemos...United Let's Talk About.





Unidos hablemos...
United, Let's talk about...

Goal:

To bring the patient voice into research and clinical trials, establishing trust and removing barriers to participation by developing culturally and linguistically appropriate education and diminishing biases and stereotypes that impact health care decisions and patient mistrust

To increase trust in medicine and research with the result leading to people in these communities having a desire to further learn about PCOR/CER



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- ▶ The program was designed to increase the number of people from this community that feel confident to participate in all phases and types of research, from the development of the research questions, protocol development, to participating in the clinical trial or focus group providing expert opinion.
- ▶ Engagement, trust and patient partner participation in all aspects of the program was the foundation to the project approach





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Key stakeholders and faith leaders worked together to establish trust within the Hispanic/Latino community and to engage the community in Patient Centered Outcomes Research and clinical effectiveness research (PCOR/CER)

The project convened Hispanic people with asthma, patient advocates, patients, researchers, leaders in the Hispanic community to develop a robust agenda to participate in a series of virtual, live sessions to introduce the attendees to PCOR/CER and share the needs of researchers and patients, their caregivers who have asthma and/or COVID



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- ▶ A Project Advisory Group (PAG) was comprised of 6 Latino patients diagnosed with COVID-19 and/or asthma, a faith-based leader, healthcare providers, researchers and program evaluator
- ▶ The group of patients were tasked with identifying the appropriate platform for hosting the virtual series, identified the theme of the virtual series, determined the agendas, selection of presenters, review of objectives, and developed titles of the sessions





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United, Let's talk about...

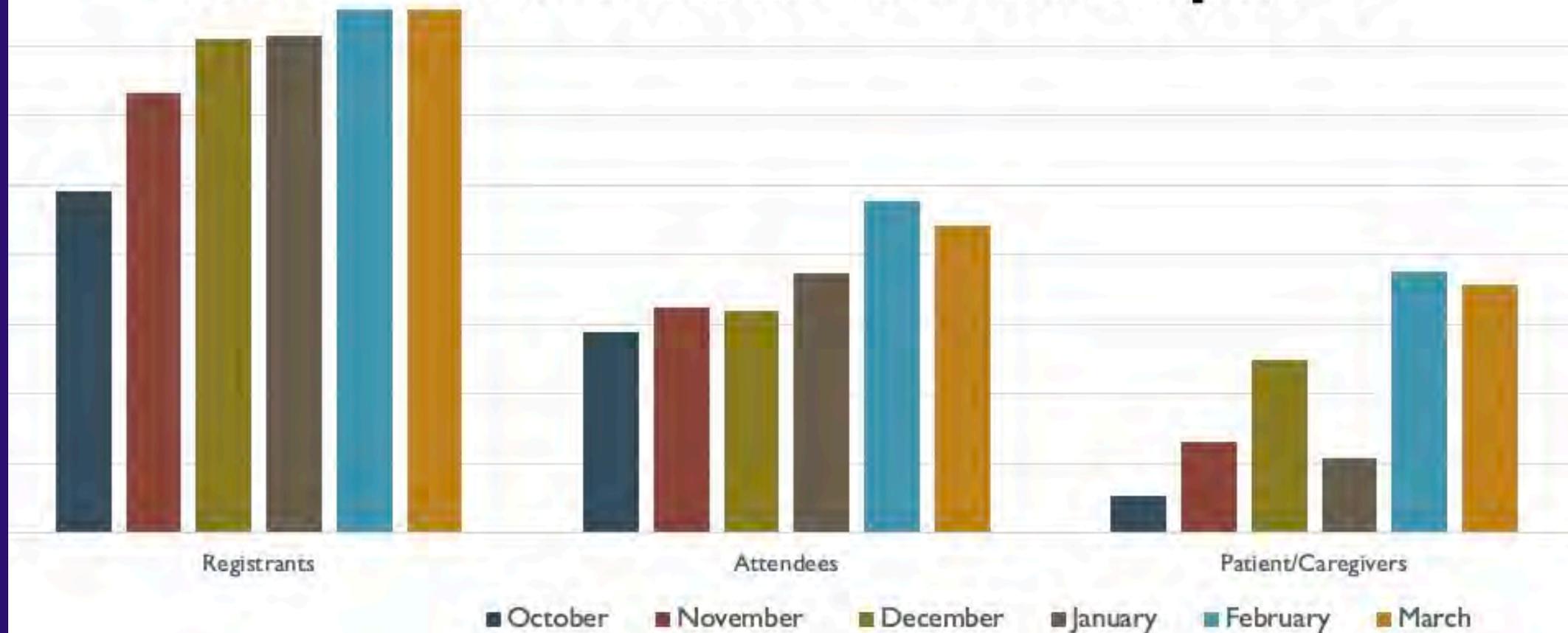
All sessions were delivered using the Zoom™ Language Interpretation feature so attendees could choose to hear the presentation in either English or Spanish

All attendees were offered the following in English or Spanish: pre and post knowledge surveys, polling questions during each session and session evaluations

Each PAG member, the faith leader, guest presenters and consultants and 100 patients or caregivers were compensated after each session



Table I. Characteristics of Participants



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Results

- ▶ On average 700 registered and 382 unique people attended the sessions between October 2021– March 2022.
- ▶ Between October and January there was a 6% increase in attendees identifying as Hispanic patients or caregivers, and a 20% increase in the attendees requesting the handouts in Spanish.



Results

- ▶ When asked if whether they would be willing to be a research subject in an asthma study, 66.4% agreed, while 15.6% did not agree and 18% would depend on whether their doctor thought it was a good idea.

- ▶ We found 77.6% would be willing to be a patient partner/advisor for an asthma study while only 3.2% did not agree and the remaining 20% were either unsure or participation would depend on whether their doctor thought it was a good idea.

What is Next...

Capacity Building - Research Ambassadors

- ▶ **ADDITIONAL FUNDING-** For capacity building to draw upon those who demonstrate interest in becoming research advisors- and to develop Patient Research Experts or Ambassadors who are provided with education about all aspects of research, from developing a research question, to being involved in research as a subject or advisor to the project
- ▶ This will prepare them to become trainers in their communities, leading to further engagement based on trust
- ▶ Anticipate sharing with researchers about the “pool” of future patient experts and encourage them to involve these new patient experts to participate in their research programs

Summary slide

- ▶ Increasing participation in research/clinical trials from people from Hispanic/Latino and other medical underserved communities can help to eliminate health disparities in asthma and other related conditions
- ▶ There is a need to include ALL patient voices in research and clinical trials
- ▶ People from Hispanic/Latino are interested in furthering their involvement in research opportunities with more training

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Resources

- Asthma and Allergy Network website:
<https://www.allergyasthmanetwork.org/>
- Updated resources in Spanish and English are available to patients with asthma and families of people with asthma
- Communication with the medical team is very important

Asthma Action Plan for Home & School Allergy & Asthma NETWORK

Name: _____ Birthdate: _____

Asthma Severity: Intermittent Mild Persistent Moderate Persistent Severe Persistent
 He/she has had many or severe asthma attacks/exacerbations

Green Zone Have the child take these medicines every day, even when the child feels well.

Always use a spacer with inhalers as directed.

Controller Medicine(s): _____

Controller Medicine(s) Given in School: _____

Rescue Medicine: Albuterol/Levalbuterol _____ puffs every four hours as needed

Exercise Medicine: Albuterol/Levalbuterol _____ puffs 15 minutes before activity as needed

Yellow Zone Begin the sick treatment plan if the child has a cough, wheeze, shortness of breath, or tight chest. Have the child take all of these medicines when sick.

Rescue Medicine: Albuterol/Levalbuterol _____ puffs every 4 hours as needed

Controller Medicine(s): _____

Continue Green Zone medicines: _____

Add: _____

Change: _____

If the child is in the yellow zone more than 24 hours or is getting worse, follow red zone and call the doctor right away!

Red Zone If breathing is hard and fast, ribs sticking out, trouble walking, talking, or sleeping.
Get Help Now

Take rescue medicine(s) now

Rescue Medicine: Albuterol/Levalbuterol _____ puffs every _____

Take: _____

If the child is not better right away, call 911
Please call the doctor any time the child is in the red zone.

Hispanic Resources

Our online store includes Spanish-language print resources and digital downloads for use by patients and caregivers and as educational materials for the health professional offices. Find educational handouts, guides and more.

[Visit Our Online Store](#)



Acknowledgment

- ▶ Allergy and Asthma Network for the use of slides and graphics
- ▶ Eugene Washington Engagement Award- Engaging Hispanic Asthma Patients in PCOR/CER Nationwide- PCORI grant
- ▶ Thank you for your attention