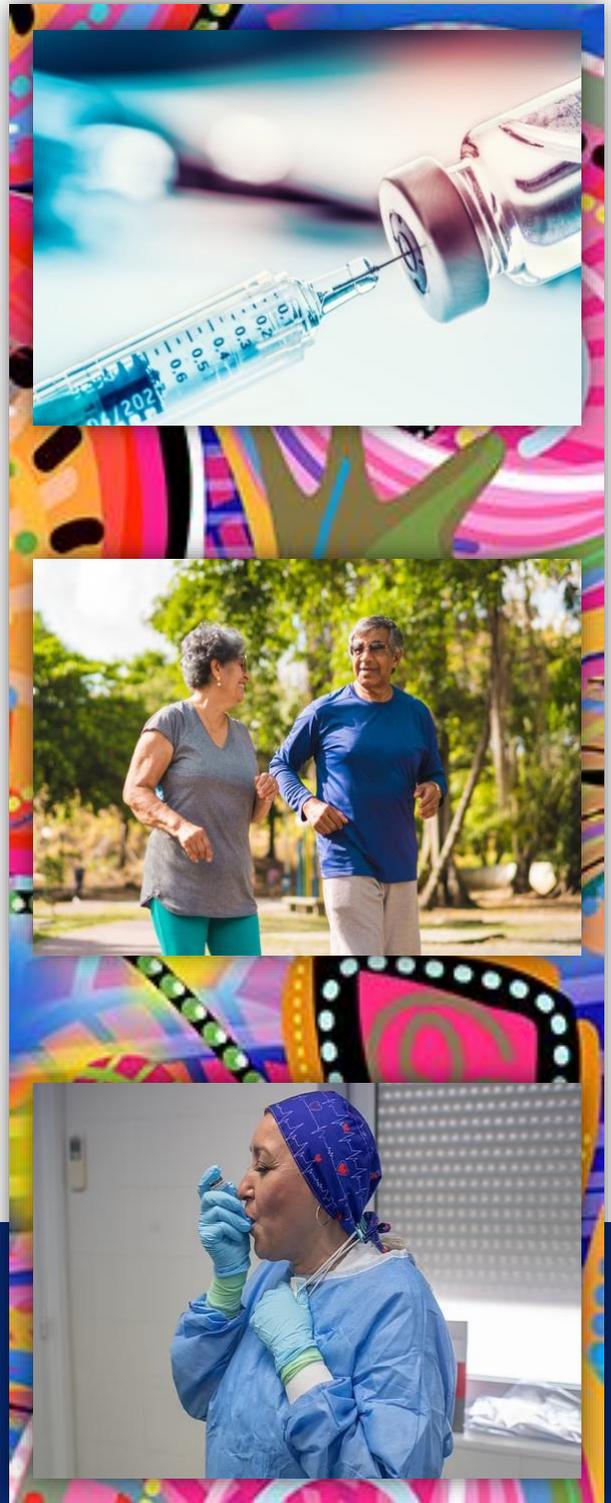


# 2022 Status of Hispanic Older Adults Annual Report: Insights from the Field - Working for Health Equity in a Pandemic

**September 20, 2022**

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National Hispanic Council on Aging



**Chronic Condition** /'kränik kən'diSH(ə)n /

A chronic condition is a health condition or disease that is persistent or otherwise long-lasting in its effects or a disease that comes with time. The term chronic is often applied when the course of the disease lasts for more than three months. Obesity and asthma are chronic conditions.

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Note: Throughout this report, we use the terms Hispanic and Latino interchangeably.

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# Acknowledgements

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A special thanks is extended to those who participated in our focus groups and surveys. These participants included older adults, caregivers and service providers who gave their time, shared their personal stories and perceptions, and provided recommendations.

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Christine Perez, Christina M. Pacheco, and Ivonne Rivera drafted the report, while the entire NHCOA team participated in editing the report. The implementation of the study and production of the report was directed by President and CEO, Dr. Yanira Cruz.

Finally, we would like to express our deepest gratitude to our sponsors, who, with their generous contributions, allowed us to conduct the focus groups that this report is generated from. Through these focus groups and surveys, we had the opportunity to learn from Hispanic older adults, their families and caregivers and engage them in discussions that contributed greatly to the recommendations included in the report. These sponsors are Amgen, Biogen, Campaign for Tobacco Free Kids, Eli Lilly, Abbott, AstraZeneca and Novo Nordisk funding supported the work.

# Policy Recommendations

**B**uilding on the findings presented in this report, NHCOA has developed a number of recommendations for local, state and national leaders. We also advance specific recommendations from Hispanic community members, community-based organizations and grassroots leaders. NHCOA forwards the following recommendations to help address health equity and chronic conditions during a pandemic:

- 1. Expand telehealth access infrastructure and support telehealth policies through CMS and state Medicaid plans that improve asthma and obesity outcomes and maintain access to telehealth services post COVID-19.**

Ensuring that all Americans have access to telehealth services established during the public health emergency will require legislative action to establish payment parity, ensure all can access services from home or other setting of choice and their provider has flexibility of where their providing the service (originating and distance site issues), can use audio devices and personal devices to access telehealth services. CMS should ensure telehealth covers services for obesity and asthma. Such services should be available in Spanish and other languages.

- 2. Direct funds using a broad interpretation of “health” that includes social determinants of health and considers health equity.**

Legislators must consider the definition of “health” to include all aspects of the social determinants of health (conditions in the places where people live, learn, work, and play that affect a wide range of health risks and outcomes) and allocate those funds accordingly. Additionally, health equity should be a primary consideration in the distribution of funds.

- 3. Encourage government policies and enact legislation that requires bias and equity analysis of policy decisions and legislation at all levels.**

Similar to the process of informing policymakers about the financial impact of proposed legislation, or requesting economic impact statements on relevant bills, the legislature should adopt a procedure for developing and considering equity analysis and impacts of any policy change.

- 4. Improve language access and interpretation services in the healthcare field.**

The United States is truly greater for its diversity. However, navigating healthcare services is even more difficult for individuals who are most comfortable using a language other than English. Governments need to enhance language access. Training and development of healthcare interpreters needs to happen early on, and legislators should invest in pipelines for translators.

- 5. Reinstate the regulation to implement the Executive Order on Access to Affordable Life-Saving Medications.**

HHS rescinded the 2020 Rule due to the excessive administrative costs and burdens that implementation would have imposed on health centers. We acknowledge that the Rule imposed a significant burden to health centers as written. However, rather than rescind the rule, HHS should reduce the administrative burden related to verifying financial eligibility by setting price caps on these medications for EVERYONE.

**6. Provide tax incentives for grocery stores to build in food desserts. States that impose sales taxes on groceries should eliminate them.**

Thirteen of the 45 states with sales tax still impose it on groceries. Of those, ten offer a lower tax rate for groceries than the general sales tax rate or provide a tax credit to offset some or all the sales tax on groceries. Only Alabama, Mississippi, and South Dakota still tax groceries at the full state sales tax rate. Sales taxes on groceries have an especially harmful impact on income and racial inequities since low-income families tend to spend a larger share of their income on groceries.

**7. The FDA should enhance regulations on hormones and other food additives that have been shown to contribute to weight gain and other health issues and improve labeling to better allow the public to make informed choices.**

Focus group participants specifically requested regulations to protect them from harmful additives in food and labeling to aid in making informed choices. The “chemical obesogen” hypothesis posits that synthetic, environmental contaminants are contributing to the global epidemic of obesity. In fact, intentional food additives (e.g., artificial sweeteners and colors, emulsifiers) and unintentional compounds (e.g., bisphenol A, pesticides) are largely unstudied regarding their effects on the metabolism. Many of these additives and contaminants have been found to dysregulate endocrine function, insulin signaling, and/or adipocyte function. We urge the government to invest more funds in studying chemical obesogen to better understand the role these additives play in the obesity epidemic and to learn about how to prevent or even reverse their effects.

**8. Create more financial support for programs that are community-based and that are culturally and linguistically appropriate.**

The National Institutes of Health and other federal granting agencies should strongly encourage partnerships with community-based organizations in implementation and dissemination grants.

**9. All levels of government should support infrastructure that promotes physical activity, particularly in areas of high social vulnerability.**

Physical inactivity is an important contributor to most of the leading chronic diseases and an independent primary risk factor for cardiovascular diseases, like smoking and hyperlipidemia in

importance. Not only will this require a change in many built environments, such as implementing complete streets, but will also require an investment in changing systems infrastructure.

**10. CMS should work on reimbursement models to support community health workers (CHWs) who can aid with providing trainings and seminars about asthma, triggers and symptoms.**

Asthma is a health problem that can make it hard for people to breathe. People who have low incomes and who are African American or Hispanic are more likely to have asthma than other adults. Removing or reducing things that can trigger asthma symptoms at patients' homes, like pollen or dust, can help control symptoms. Studies have shown that CHWs can be effective at helping patients have more days without asthma symptoms and fewer missed work or school days.

**11. Access to Continuum Obesity Care for Medicare Patients**

Obesity is a major driver of health care costs, and more effective treatment can yield savings for the health care system. Obesity is a treatable disease through behavioral therapy, bariatric surgery, and now pharmacotherapy. Successful treatment of obesity involves both weight reduction and improvements in related comorbidities. The anti-obesity medications (AOMs) are an important component of the continuum of care to help reduce risk of heart disease, diabetes, osteoarthritis, and other complications. Due to outdated regulations, Medicare does not provide access to the full continuum of obesity care available to patients. Current CMS guidance does not permit coverage for drugs that treat obesity under Medicare Part D, on the grounds that such drugs are excluded under the Medicare Part D statute as agents "used for anorexia, weight loss, or weight gain." CMS has held this policy for almost two decades, and in the meantime our scientific understanding of obesity and how to treat it have evolved substantially. CMS' current Part D policy denying coverage of AOMs has the unintended effect of creating and perpetuating an unnecessary gap in access to an important standard of care. Medicare is the only federal health program that does not allow for coverage of AOMs. Congress should pass legislation to establish Part D coverage and ensure access to the continuum of care.

COVID-19 Specific Recommendations

**12. Provide grants to trusted partners and community-based organizations that can educate people about the importance of data collection and collect data at vaccination sites.**

Collecting and reporting disaggregated data is the only way we will know if vaccine distribution is equitable, and we know who is getting vaccinated. However, data collection can create barriers for individuals who fear misuse of that data, particularly those of differing immigration statuses. Federal agencies should work with community partners to ensure that data collection is implemented in a way that does not create unintended barriers.

**13. Utilize culturally competent messaging about vaccine efficacy, availability, and boosters. Make sure materials and communications are available in a variety of languages.**

Communication from local, state and the federal governments about vaccines and vaccine availability should be clear, timely and culturally competent. In relation to the COVID-19 vaccine, messages should also highlight that the vaccines are safe, effective, and free, and that individuals who refuse to share personal data will not be turned away from getting a vaccine. Use a variety of media, including social media, ethnic media, traditional media, and mainstream media. Provide grants to trusted partners and CBOs to employ phone banking, door-to-door canvassing, and texting campaigns.

**14. Work with states and national leaders to identify strategies to distribute vaccines to the most impacted communities.**

Partner with states and national leaders, such as NHCOA, to develop innovative distribution models to distribute vaccines and boosters to the most impacted communities. Historically resilient communities have been disproportionately impacted by the pandemic and utilizing local clinics and mobile clinics as well as culturally competent providers, like community health workers, to reach these communities should be a priority.

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# COVID-19 and Latino Americans

Based on evolving data, it is evident that the COVID-19 pandemic has and continues to dramatically impact Latino communities and some of our most vulnerable, including isolated seniors, immigrant communities, Latino families and single-parent households living paycheck to paycheck, and small Latino owned businesses. Even more than 2 years post the start of the COVID-19 pandemic, Latinos and other people of color continue to be disproportionately affected.

Today, Latinos make up 18.5% of the US population. According to the CDC, Latinos currently comprise 24.8% of COVID-19 cases in the United States, second only to Whites (53.4%) (data from Aug. 23, 2022). Race/ethnicity data is available for only 65% of the nation's COVID-19 cases. We see these disparities by state also:

- Utah is 14% Latino, but Latinos make up 17.6% of COVID-19 cases (Aug. 14, 2022).
- Washington is 13% Latino, but Latinos make up 18% of COVID-19 cases (Aug. 21, 2022).
- California is 39.3% Latino, but Latinos make up 45.4% of COVID-19 cases (Aug. 19, 2022).

Of the US COVID-19 deaths, Latinos account for 15.8% according to a new CDC data. When using weighted population distributions, the death rate is 33.3%. This is important because weighted population distributions ensure that the population estimates, and percentages of COVID-19 deaths represent comparable geographic areas and gives insight into whether certain racial and ethnic subgroups are experiencing a disproportionate burden of COVID-19 mortality.

With regards to the COVID-19 vaccines, between July and September 2021, the data shows that more and more Latinos are getting vaccinated, surpassing the number for Black and white people, according to data from the Kaiser Family Foundation. Yet there are still disparities by state. Latinos also seem to be getting boosted at lower rates compared to their white counterparts. As of July 8, 2022, 27 states and Washington DC were reporting vaccination booster data by race/ethnicity. Among these states, the share of Black and Hispanic people who had received a booster shot was lower compared to White people.



# Obesity Among Latino Americans

## Introduction

In the midst of the COVID-19 pandemic, Latinos are also suffering from the obesity epidemic, which has been shown to exacerbate the severity of illness among those infected with the COVID-19 virus. Latino Americans not only have a disproportionate burden of morbidity and mortality when it comes to COVID-19, but they also carry a disproportionate burden with regards to obesity.

According to the Office of Minority Health, almost 80% of Latino American women are classified as overweight or obese, compared to 64% of non-Hispanic white women. In 2018, Latino Americans were 1.2 times more likely to be obese than non-Hispanic whites. We see similar trends among youth, with Latino American youth roughly 1.8 times more likely to be obese when compared to non-Hispanic white youth. It is no surprise that people who are overweight and obese are more likely to suffer from high blood pressure, high levels of blood fats, diabetes and LDL cholesterol – all risk factors for heart disease and stroke.

Racial and ethnic minority groups have historically not had broad opportunities for economic, physical, and emotional health, and these inequities have increased the risk of getting sick and dying from COVID-19, especially among Latino Americans. Many of these same factors are contributing to the higher levels of obesity among Latino Americans. To understand Latinos' knowledge, attitudes, beliefs and behaviors regarding obesity and its subsequent health issues, NHCOA held a series of virtual focus groups in Spanish.

We stratified focus groups by age and gender. We ran 7 focus groups with each focus group having 6-10 participants in it. Focus groups lasted 90 minutes. Recruitment occurred in New York, Florida, California, Texas, New Mexico, Washington DC, Maryland and Virginia (DMV), and Puerto Rico. We had a total of 60 participants, 63% of participants were female and 37% were male. All of our participants were over the age of 18, and the average age of participants was 52.7 years of age (min. 18 years of age, max. 80 years of age) and all of the participants in our Washington, DC focus group were 65 years of age or older (n=7). The largest subgroups were from Central America, Mexico and Puerto Rico. With regards to education, 14% had some high school or less, 33% had graduated from high school, 19% had some college, 30% had graduated from college and 4% had received their graduate degree. 16% of participants had a diagnosis of diabetes and 28% had a diagnosis of high blood pressure. Recruitment occurred via social media, word of mouth and through our strong network of community-based organizations and to focus groups were conducted via zoom.

The data were analyzed following a grounded theory approach, in which concepts emerge and are linked to formal theories, allowing us to develop a more accurate model of behavior. The analysis include three coders and two reviewers; scientists and community members serve as both. Coders inductively determine topic areas from transcripts to develop a codebook and deductively code using the codebook. Coders then came up with ideas for thematic statements, drafted by the primary (Dr. Cruz) and secondary (community) coders. Coders reach consensus before sending statements to emic “insider” and etic

“outsider” reviewers, who finalize and bring them to the full team for consensus. This process allowed NHCOA to ensure representation of both insider and outsider points of view.

## Personal Stories of Weight Management

Most focus group participants had experiences with various methods of dieting during different points in life. Motivation for weight control was came from an effort to either prevent a health concern or as a solution to a health concern. Some participants expressed being motivated by a desire to feel good about their physical appearance. Health concerns that were expressed included knee and joint pain, high blood pressure and cholesterol, a fear of having to permanently rely on medications, wanting to be healthy in the aging process, and as precaution when they had family history of obesity and associated health issues like diabetes and hypertension. Other participants mentioned children as their motivators, whether it was because of weight gained during pregnancy or because as parents they have less energy and are less able to play with their children when overweight, or because they want to set a good example for them.



***“I have a chronic condition and I am always taking care of my diet to manage my condition and through a better diet I did improve a lot. I am not overweight thankfully. Exercise and diet are very important.”***

California Participant

***“In my case, it was seeing the obesity. When a man starts seeing his belly grow that creates a discomfort and desire to look good. But in the last two years I also had problems with my blood pressure and my doctor recommended [me] to reduce salt, carbohydrates and that motivated me to start a different lifestyle in terms of nutrition”***

New York Participant

The pandemic was a motivator for some participants and a deterrent for others. For some, it helped them ***“get it together because [they] saw that the health state of a person impacted whether a person got the virus or not, and many people who died from it was also because of their obesity and the state of their health.”*** (Texas Participant) For others, the COVID-19 pandemic was the perfect storm that led to less activity and higher quantities of food intake.

For a minority of participants weight management was not a concern, as some of these participants shared, they ***“have always been thin”***, were athletes, or very active throughout their youth or have always had a healthy relationship with food.

## Successes

Participants who had dieted reported moderate success with their diets. Those who reported success shared that weight loss was not sustained and weight was gained back with some reporting gaining even more weight than was initially lost. Participants who reported weight loss, shared losses between 15-40 lbs., and successful techniques included dietary restrictions or dietary guidance. Exercise was also mentioned in most focus groups but less frequently than nutritional changes. Factors that contributed to success included:

- Strict nutrition plans removed a need for decision-making,
- Strong mental health and discipline,
- Having support systems in place, and
- Celebrating victories, such as changes in appearance.

***“It was very helpful when I had a friend who had the same goal and one day, she would call me out of my laziness and the next time I would call her”***

DMV Participant

## Challenges

The main challenge put forward by participants was that of maintenance of weight loss and diet. Participants generally likened their relationships with weight to a rollercoaster. Challenges with weight loss and maintenance included genetics, personal and cultural eating habits, lack of discipline, the pandemic, and work/finances. Several participants mentioned they come from families in which many of their relatives struggled with weight. Some participants had trouble trying to break dietary habits such as consuming diets high in carbohydrates, sugar and fat, which some participants related to a cultural or family-sourced love of

***“I have always been heavier since I can remember. My whole family we all have thick bones, and a lot of my family members also struggle with weight.”***

Puerto Rican Participant

***“During the pandemic we were stuck at home eating all the time and snacking with the kids, not being able to go to the gym or anything.”***

DMV Participant

food. Participants shared that these factors were harder to overcome during the pandemic.

***“For me it isn’t really the unhealthy eating or lack of activity, it is more the case of stress or emotional eating and then the negative cycle of overeating. Seeing the physical impact, clothes don’t fit, I don’t feel good about myself, then I am less productive and even more stressed and so on.”***

Texas Participant

For many participants, the main difficulty of managing their weight was the personal struggle of having enough willpower and discipline to do it. Mental health and financial ability were also considered important factors that contribute to weight gain. For instance, one participant shared, ***“Overeating is a***

*conscious choice. I know it is not good for me, but it does not only come from a physical issue but also a mental one. Many people overeat for emotional reasons or as an escape.”*

## Knowledge, Attitudes and Beliefs and Obesity

Focus group participants generally agreed that obesity is a growing problem for Latinos, especially children. Obesity was attributed to a sedentary lifestyle, which many acknowledged was exacerbated during the pandemic, and the general trend of people moving less and spending more time in front of screens. Some participants expressed that obesity is treatable and is largely caused by a lack of awareness and education.



When asked about causes, medical causes such as hormonal imbalances and genetic predispositions were raised. Other contributing factors included food quality, negative lifestyle changes, stress and loneliness, particularly for immigrants, mental health, financial considerations, cultural practices, and a lack of education and tools for better health management. Most participants noted that while it used to be the case that they would walk more and play outside as children, now life is very sedentary

for adults and children. People also cook much less and eat out, and busy schedules make it hard to dedicate the time to healthy habits. Portion sizes in the United States are also larger than in some Latin American countries.

***“Children spend all their time in front of screens and don’t play anymore. And everyone goes by car everywhere instead of walking.”***

Florida Participant

***“There is a lack of education about obesity in our community and it is growing.”***

New Mexico Participant

***“It is not knowing how to balance meals. Instead of eating more times a day in lesser quantities as doctors recommend for diabetics, people want to lose weight and won’t eat anything for some time and then next time eat twice as much. Healthy food and healthy eating habits are the most important.”***

California Participant

***“There’s a lack of education and lack of awareness. We think the more we eat, the healthier we are, the more our children eat the better. We have to learn that it is not about quantity but quality. Also, we need programs for exercise specifically for Latinos and specifically for children.”***

New York Participant

## Cultural Impacts

Cultural differences in the way obesity is viewed were raised regarding food, lifestyle in the US, and exercise. Additionally, participants shared that in Latin America the main worry “is having enough to eat”, rather than the quality of those foods.

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***“We tell our kids they have to eat everything on their plate...and say the chubbier they are the cuter they are. We have a bad relationship with food because in our culture if you celebrate you go out to eat, and if something bad happened you go out to eat.”***

DMV Participant

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***“It's a cultural thing... here in the US everything has hormones and is processed, because in [our home countries] we eat the same but now there's diabetes, hypertension, thyroid issues.”***

Texas Participant

***“Our culture of internal tourism or “chinchorro” culture means social and family life revolve around restaurants and bars where the food and drink is not so good and there is a lot of it.”***

Puerto Rican Participant

### Cultural Facilitators to Healthy Lifestyles

Participants mentioned that an affinity for community gatherings, more nature-based traditions, a less individualistic culture, as well as outdoor activities and dancing as part of Latin American culture that contribute to healthy habits. Participants shared that the love of dancing in Latino culture can be a way to improve health, ***“We like dancing. When people say let's go work out you can say no but if they say let's go dance that is better and you can burn some calories.”***



Participants mentioned the need to give people better options to incorporate healthy choices and habits into their life, through awareness and education that is community oriented, a Latino preference, according to participants. They also suggested reclaiming pride in Latin American foods that are high quality and are commonly used in the US such as quinoa or chia, etc. Simple small changes to foods that are part of the traditions can make the transition more sustainable. Participants also suggested focusing on cultural significance of foods that are given to children. Educating children requires educating parents and grandparents to spread awareness and lead to more cohesive prevention efforts. One participant shared, ***“We need to do more family cooking. We should spend more time cooking at home and do it for***

***two or three days ahead. It should include the children, so they start knowing the names of vegetables and fruits instead of the variety of sweets and junk food.”***

### Cultural Barriers to Healthy Lifestyles

Participants shared that many of the features of Latino culture that promote healthy habits have disappeared because of acculturation, societal trends, the pandemic, and lifestyle changes related to immigrating to the US. Participants mentioned the cultural misconceptions of “healthy weight” and the actual ingredients of Hispanic diets were additional obstacles. One participant shared that in Honduras, “junk food” was a luxury, ***“and then when people come [to the US], they can access it then they overdo it.”***

### Definition of Obesity

When it came to defining obesity, participants differed a bit. Some groups focused on the cultural differences of how “obesity” is defined in Latin American countries vs the United States.

***“In our countries maybe, we care a bit less, but here if you are 10 lbs. over you are obese. It felt like a slap in the face when my doctor told me I was obese. For me obese is someone who weighs 200 lbs. and I do not feel obese.”***

DMV Participant

### Immigrant Experiences with Weight Maintenance

Participants shared that the immigrant experience made weight maintenance more difficult in the United States. One participant shared that immigrants, ***“usually don’t have the luxury of choosing the organic foods that are so much more expensive.”*** Another commented on how inactivity is encouraged in the US, ***“It is too easy to be inactive in the US, it is encouraged even.... There are places in Europe and South America where bikes and walking are more common forms of transportation.”***

## **How Community Organizations Can Help**

Participants suggested ways that community-based organizations (CBOs) can work to address healthy behaviors and obesity in their communities. Suggestions included holding small focus groups in communities, especially low-income communities, to understand and identify community driven strategies to address obesity. Another suggestion was for CBOs to launch educational campaigns and distribute booklets, conduct seminars and host small group discussions.



Participants also mentioned massive campaigns like the cancer awareness campaign and

providing guidance from professionals on healthy habits. Beyond raising awareness, participants want CBOs to work towards increasing access to high quality foods, creating safe access to exercise and to provide support for health initiatives targeting obesity. One participant shared that CBOs ***“are very good health fairs, but they will take the [blood] pressure and weigh an obese person and tell them you’re overweight, but it ends there. They should follow up with those people.”***

Participants stressed the importance of group and community efforts to raise awareness about obesity. For some, this meant removing the stigma of being overweight or obese. A lot of emphasis was placed in creating awareness and support from early ages so truly create lasting impact.

***“They should approach obesity positively because there is a stigma against obesity, and it should be supporting instead of discouraging. Instead of saying ‘don’t be obese’ saying ‘be healthier’, or ‘let’s all be healthier.’”***

DMV Participant

## Government Responsibility to aid with Healthy Lifestyles



Puerto Rican participants highlighted the efforts of the Department of Health and local municipalities to set up group activities and repair public structures for physical activity that were damaged by Hurricane Maria. However, they and participants in all the groups generally do not believe that the government prioritizes

obesity prevention, especially for Latinos. In many cases, participants thought the government contributes to the growing issues with weight and obesity in the United States, and the few efforts and programs that are being implemented are not reaching the most vulnerable communities.

Participants suggested that healthy foods and healthy options should be more affordable and accessible to vulnerable groups and those with lower financial ability. They also mentioned the need to better regulate the quality of food and prohibit the harmful hormones, additives and ingredients that contribute to weight gain and health issues. Participants also felt that the government could do a better job regulating advertising for unhealthy foods and products, and to take a more preventative approach to obesity versus the palliative approach. Access to insurance and better health care are also needed for many Latinos and other racial/ethnic groups. Participants requested more financial support for programs that are community based and embedded in communities and that are culturally and linguistically appropriate. There was also strong support for infrastructure that promotes physical activity. Participants stressed that particular attention needs to be paid to children and school settings.

*“Latinos don’t have access to social security or medical insurance and so they can be fooled by tricks and medicines on TV that we don’t know the side effects of. Credibility has been lost because all those harmful things are supposed to be regulated by the government but have no positive effect.”*

DMV Participant

*It’s not about curing obesity but prevent it. Sometimes I have to travel two hours for dance classes for my daughters. We need more local programs and personalized attention and accessible to our budgets.”*

NY Participant

*“The [government] needs to support the organizations that are serving the community because resources do not always go to organizations that really approach the community and are interested in the people as if they were family. A lot of the time the information is not always in the language we need, we had that issue all through covid, and that’s how it happens often, the information does not reach the community.”*

New Mexico Participant

*“The [government] needs to be more strict with fast food restaurants. People will always look for the lowest prices and if a lot of people don’t have the means to reach higher then that’s where they will go to eat. Make healthier foods more accessible and cheaper foods more nutritious.”*

DMV Participant



*“Create government initiatives like bike lanes and programs of accessible prices and hire personnel that are culturally competent to address this challenge for Latinos. Create dancing programs for Latinos with Latino music and provide food that we use and that is healthy like in our countries.”* NY

# Asthma among Hispanics

## Introduction

According to the Office of Minority Health, more than 2.3 million Hispanics in the United States reported having a current diagnosis of asthma. In 2018, Puerto Ricans had twice the rate of asthma rate when compared to the overall Hispanic population. Furthermore, Hispanics are twice as likely to visit the emergency department for their asthma, versus non-Hispanic whites. Hispanic children are 40 percent more likely to die from asthma, as compared to non-Hispanic whites. While all the causes of asthma remain unclear, children exposed to secondhand tobacco smoke exposure are at increased risk for acute lower respiratory tract infections, such as bronchitis. One study found that acculturation was associated with diagnosed asthma and pulmonary function in Latino children.

## Asthma Knowledge, Attitudes, Beliefs and Behaviors Survey

NHCOA conducted a national survey of Hispanic adults to ascertain their knowledge, attitudes, and beliefs about asthma. Asthma is a common disease and is prevalent in people over age 65. Asthma in older adults can cause serious health problems if not treated properly. While asthma is a common disease, many people still do not know much about it and myths persist. One of the most common myths is that asthma is a childhood disease. Most people with asthma experience their first symptoms at a young age, but it can develop for anyone, at any age. It is not uncommon for adults in their 70s or 80s to develop asthma symptoms for the first time. When asthma does occur at a later age, the symptoms are much like those experienced by anyone else. The most common causes of an asthma flare up are a respiratory infection or virus, exercise, allergens, and air pollution (an irritant). Allergens and irritants are substances found in our everyday environment. People who have asthma may experience wheezing, cough, shortness of breath, and chest tightness.

Asthma creates a much greater risk for older adults because they are more likely to develop respiratory failure because of the asthma, even during mild episodes of symptoms. Our survey provides insight into knowledge, attitudes, and beliefs about asthma among Hispanic adults, as well as provides information about screening rates and engagement in preventive measures.

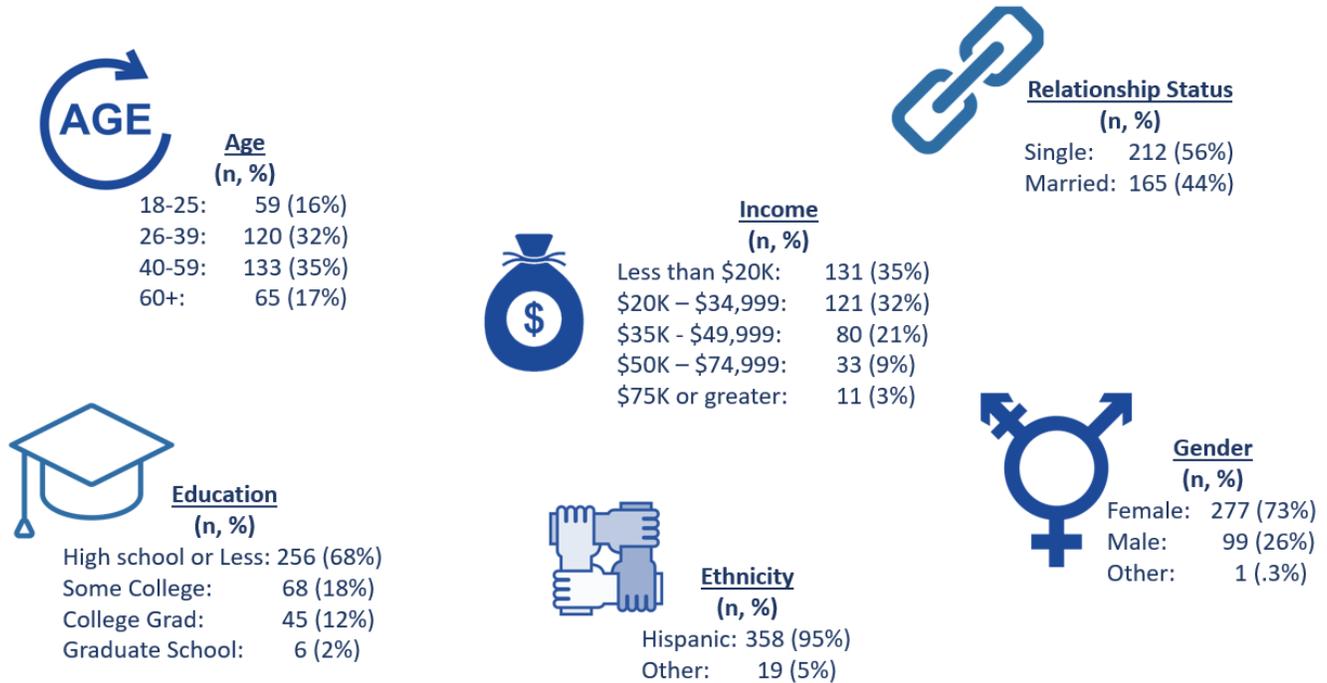


## Demographics

NHCOA surveyed 377 Hispanics/Latinos across the United States. Most survey takers identified as Hispanic/Latino (95%), female (73%) and had attained high school graduation or less education (68%). Most participants fell into the age ranges of 26-39 years of age (32%) and 40-59 years of age (35%). Just

over half of survey participants were single (56%). Roughly a third of participants had an annual income less than \$20,000 (35%), and another third had an annual salary of \$20,000 to \$34,999 (32%).

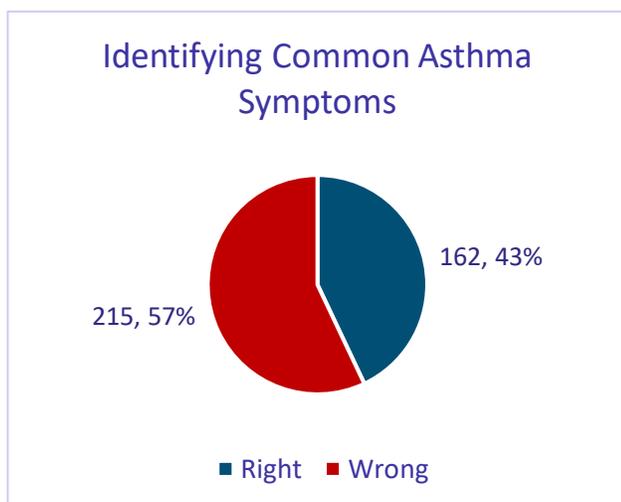
One hundred and twenty (120) survey takers reported having a diagnosis of asthma (32%). According to the CDC 2018 National Health Interview Survey Data, 6.4% of all Hispanics over the age of 18 had a diagnosis of asthma. Of our survey takers with asthma, 70% were between the ages of 26 and 59 years old. We asked survey takers how old they were when they were first diagnosed with asthma, the average age was 16 years old with a minimum of 1 year of age and a maximum of 62 years of age when first diagnosed.



### Knowledge

To gain an understanding of Hispanic adults’ knowledge of asthma, we asked a series of 9 knowledge questions that focused on symptoms and treatments. Nearly half (51%) of survey takers scored 78% or greater on the knowledge test, meaning they missed 3 questions or less. Almost all (94%) of our

participants correctly acknowledged that, “**medicines exist to treat asthma.**” Participants had a harder time with the following questions, “Identify which of the following symptoms is NOT a common asthma symptom.”



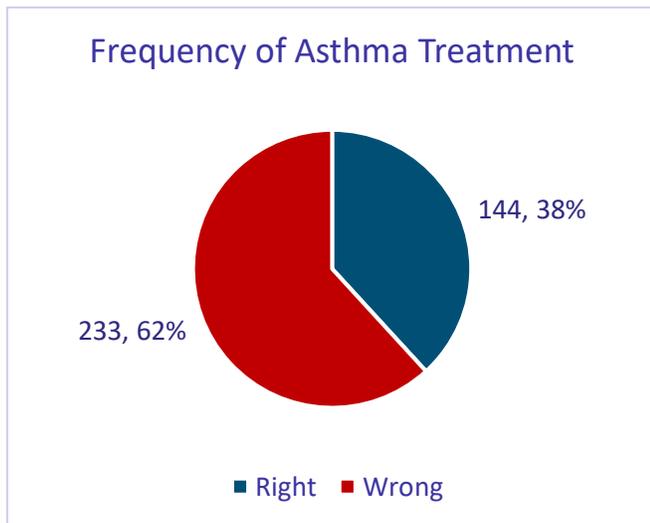
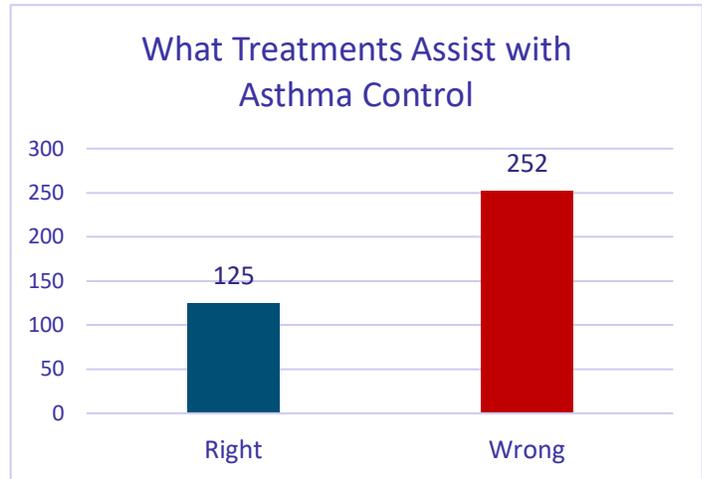
- Sore, dry throat
- coughing
- chest tightness
- wheezing
- headache
- shortness of breath

All the above are common asthma symptoms except for headaches.

Participants were asked to, “Identify which of the following assist with controlling asthma”

- Identifying and avoiding triggers
- Daily inhaled or oral controller medication
- Quick-relief inhaler
- Biologics
- All the above

The correct answer is “All the above” assist with controlling asthma.

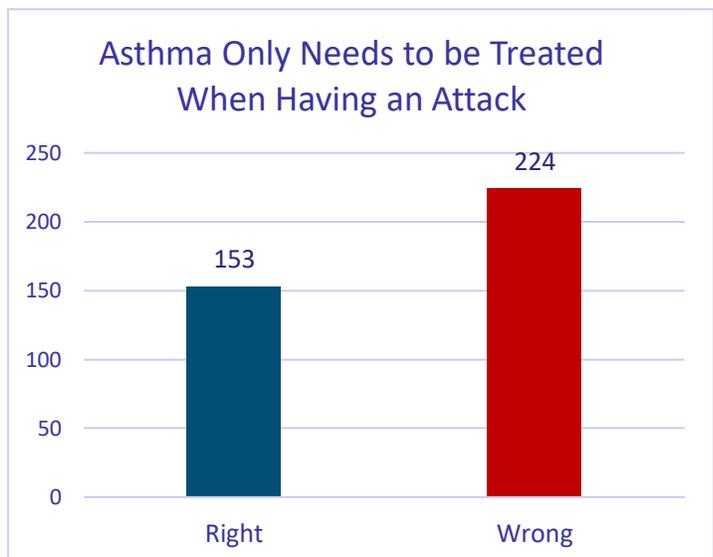


Participants were asked, “does asthma needed to be treated on a daily basis?” 62% of participants answered yes. However, asthma does **NOT** always need to be treated daily.

If a person’s symptoms are minor and infrequent or if they have exercise-induced asthma, they might be able to manage their symptoms with only a quick relief medication, which are NOT for daily use. with one of these medications alone. However, most people with persistent asthma also need an inhaled corticosteroid or other long-term control

medication.

We asked participants if asthma only needed to be treated when a person is having an asthma attack. Nearly 41% of survey takers got this question wrong by selecting true. The correct answer is no. Proper ongoing treatment makes a big difference in preventing both short-term and long-term complications caused by asthma. Asthma is an ongoing condition that needs regular monitoring and treatment.



## Attitudes

We asked Latino adults with asthma a series of questions about how they feel about their asthma diagnosis and medication options. In response to the statement, *“I am not worried when others come to know that I have asthma,”* 99 survey takers with asthma (83%) strongly agreed/agreed with that statement. Twenty survey takers with asthma (17%) strongly disagreed/disagreed with this statement.



Next, we asked survey takers with asthma if they were embarrassed to take their asthma meds in public. The vast majority (84%) reported they were NOT embarrassed to take their asthma medications in public, while 16% indicated some level of embarrassment when taking asthma medications in public.

We also asked Latino survey takers with asthma if they would consider using a biologic therapy. Biologic drugs are human-made proteins that are designed to zero in on parts of the immune system that trigger inflammation. They come from a living source (a human or animal) or its products. Seventy-seven percent (77%) of survey takers with asthma indicated that they would consider taking a biologic while 23% indicated that they would not consider taking a biologic to treat their asthma.

## Beliefs

To understand Latino adults’ beliefs about asthma, we asked a series of true and false questions about different asthma topics. We asked if asthma was a childhood illness and while most survey takers correctly identified that asthma is not a childhood illness (55%), a good percentage incorrectly thought it was (44%). While asthma is the most common chronic illness among children, it is important to note that asthma is a long-term condition that affects children and adults.

We asked if asthma could be cured, and most survey takers (60%) incorrectly believed that it could be cured. In fact, according to the Mayo Clinic, asthma cannot be cured, but its symptoms can be controlled. Majority of survey takers (63%) incorrectly believed that people with asthma are not able to exercise or play vigorous sports. However, when people with asthma follow their asthma action plan, they can play sports and they can be good at them. In fact, many elite athletes have asthma.

### *JD Martinez, Professional Baseball Player*

JD Martinez is an American professional baseball outfielder and designated hitter who played for the Boston Red Sox of Major League Baseball. He made his MLB debut in 2011 for the Houston Astros and has also played for the Detroit Tigers and Arizona Diamondbacks. Martinez announced his asthma diagnosis in the 2020 MLB season. Martinez is one of the most feared bats in the American League. A four-time All Star, three-time Silver Slugger, and 2018 World Series Champion.



Most survey takers also incorrectly believed that asthma medications can be addictive (62%).

Questions that most survey takers got **correct** included:

- 92% identified that tobacco smoke can make asthma worse
- 63% identified that children with asthma tend to be less adventurous than other children
- 77% identified that some people have asthma and do not know it
- 76% identified that asthma care is expensive
- 78% identified that asthma is a serious health problem for Latinos
- 85% identified that asthma is NOT contagious.

### Behaviors

We asked survey takers with asthma (N=120) about some of their behaviors:

- 57 survey takers with asthma have smoked at some point in their lives (47.5%)
- 70 survey takers with asthma have taken a long-term steroid medication such as prednisone or cortisone (58%)
- 40 survey takers with asthma reported exercising regularly (33%)



### Information about Survey Takers with Asthma

Thirty-two percent (n=120) of our survey takers shared that they had received a diagnosis of asthma. We asked a series of questions to survey takers who had asthma. First, we asked if participants were taking their medications as prescribed, 56% of survey takers with asthma reported that they did NOT take their asthma medications everyday as prescribed. Some of the reasons for not taking their medications included:

- Lack of health insurance
- Limited symptoms
- Their asthma is well controlled
- Only use inhaler when needed
- Sometimes they forgot

When asked if a doctor had ever told them that their asthma has evolved in severity, 27% reported that their asthma has evolved in severity. Almost half of participants with asthma had received medications prescribed for severe asthma. Sixty-two percent of participants with asthma reported that they had gone to the emergency room for an asthma attack. However, 92% of participants stated that they can recognize changes before an asthma attack begins.

## Focus Groups

To understand Latinos' knowledge, attitudes, beliefs and behaviors regarding asthma and its subsequent health issues among Latinos, NHCOA staff held a series of 8 focus groups in English and Spanish. We ran 8 focus groups with each focus group having 6-10 participants in it. Focus groups lasted 90 minutes. Recruitment occurred in New York, Texas, Washington DC, Maryland and Virginia (DMV), and Puerto Rico. Recruitment occurred via social media, word of mouth and through our strong network of community-based organizations and to focus groups were conducted via zoom. The data were analyzed following a grounded theory approach, in which concepts emerge and are linked to formal theories, allowing us to develop a more accurate model of behavior. The analysis included three coders and two reviewers; scientists and community members serve as both. Coders inductively determine topic areas from transcripts to develop a codebook and deductively code using the codebook. Coders then came up with ideas for thematic statements, drafted by the primary (Dr. Cruz) and secondary (community) coders. Coders reach consensus before sending statements to emic "insider" and etic "outsider" reviewers, who finalize and bring them to the full team for consensus. This process allowed NHCOA to ensure representation of both insider and outsider points of view.

### Asthma Identification

Participants described asthma as a respiratory ailment that affects a person's ability to breathe in their daily life and during physical activity. Participants identified that asthma can be exacerbated by many triggers like dust, weather changes, chemical products, complications in minor colds, allergies, stress etc. Both genetic and environmental factors were mentioned as probable causes of asthma. Asthma was also linked to other comorbidities like obesity, mental health issues and sleep disorders that can cause and/or worsen the condition. Though many participants reported experiencing improvement in their own or their relatives' condition through time and into adulthood, most participants (especially those who have had asthma for a long period of time or developed it in adulthood) considered it an incurable disease that can only be managed and controlled with the right prevention and treatment.

***"It is a respiratory issue. There is no cure, but it can be controlled."***

Texas Participant

### Personal & Family Histories

Many participants reported currently or previously dealing with asthma themselves or have at least one close family member or acquaintance who has it. Cases reported range from mild to chronic and most participants reported active management strategies with medications and home remedies either for prevention or rescue treatment. Parents reported high incidence of cases among children at early ages (0-8 yrs.) many with hospitalizations and ER visits, and most saw decreased severity and frequency of asthmatic episodes as they moved into adulthood.

***Mine was active during my teenage years but it usually comes seasonally, and it gets worse at night."***

California Participant

Participants overwhelmingly reported being diagnosed with asthma during childhood; with a small number receiving their diagnosis during adulthood. Some adults diagnosed later in life report they only found out through diagnoses of other medical issues like sleep apnea, lupus, and allergies. One Puerto Rican participant shared, ***“I have sleep apnea, but it had not affected me before. One day I had a cough and wheezing, and the doctor said I have asthma now.”***

Participants mostly reported that their own and their families’ cases were first diagnosed after their first asthmatic episode, which for many took place during early childhood. Participants reported that they relied on primary care providers or their pediatricians to manage their asthma. Referrals to allergists and pneumologists were mentioned by a few participants but did not appear to be the norm. Many participants sought medical attention at hospitals and emergency rooms during severe asthmatic episodes especially at the start of their condition when they were first learning to control their asthma.

### Information Seeking Behaviors

The most frequent resources participants relied on for asthma information were the internet (via Google), their primary care providers and pediatricians, and friends and family with firsthand experience. Doctors sometimes referred participants to specialists and specific trainings for management of asthma, but this was not common. For older adult participants, books were also important resources, but they have also transitioned gradually to the internet, ***“I used to look in books or would ask my child’s pediatrician, but now it would probably be google and the internet.”*** A significant number of participants (especially those who had asthma for a long time) reported not doing much research into their illness. These participants shared that they learned how to manage their asthma through trial and error and experience.

### Asthma Management

Participants defined good asthma control as staying on top of taking medicines that improve the condition or prevent attacks. Others defined asthma control as a combination of awareness of triggers and effective prevention and management of exposure and episodes through life circumstances changes and following the doctor’s orders properly to avoid severe episodes. Participants stressed the importance of having access to health care services and providers who not only speak Spanish but treat Latinos with respect.

Asthma management was discussed as being twofold, requiring lifestyle changes to reduce exposure to triggers, as well as taking the necessary preventative steps to avoid serious asthma flare-ups. Those exposed at work or in specific trigger environments take measures to cover nose and mouths. Many people redesign their home removing rugs, curtains, books etc., and installed air conditioning, air purifiers and humidifiers. They also had to adapt the way they dress, pick new detergents and cleaning products, and hypoallergenic makeup. For prevention, people engage in deep breathing exercises and relaxation techniques, attend therapy, work on reducing their weight, and use the inhaler or nebulizer before any physical activity. One



participant shared, ***“Allergic asthma is hard because it is always there, so I try to manage the environment, take care of my colds, work on my emotions and my weight to be as healthy as possible.”***

### *Decision Making*

Many focus group participants shared that doctors and healthcare providers influence their asthma treatment decisions; however, the experience and input of family and friends who have asthma is also significant, especially with regards to natural remedies. One participant expanded, ***“[the] doctor’s recommendations can be a guide, but we investigate at home and do our own research.”*** Another participant shared a strong reliance on their parent’s advice, ***“I follow my dad’s advice on how he has managed asthma with home remedies and medicines since his must be similar.”***

### *Traditional Treatments*

Participants shared that the most typical asthma treatments that they use are inhalers, nebulizers, and daily asthma management pills. Participants knew of many types of pharmaceuticals to treat asthma like steroid injections, steroid inhalers, albuterol, alvesco, montelukast, wixela, pulmicort, prednisone, Advair, breo, symbicort, singular, and Ventolin. All forms were considered to be effective in treating asthma with individual preferences. Participants reported a preference for preventative measures to manage asthma rather than relying on rescue treatments. Many participants voiced concerns about potential long-term effects, dependency, and side effects (e.g., increased heart rate, anxiety, weight gain and acne). Participants also shared that if they were uninsured, they had trouble accessing the medications due to and the high cost of these medicines.

Home remedies were also popular among participants and many report these being successful in helping them manage their asthma along with the medicines. These include steam baths, oils and/or teas with eucalyptus, pineapple, mango, cinnamon, cod liver oil, aloe, figs, white onions, chicken grease etc.



### *Treatments – Biologics*

When asked about biologics as an asthma treatment, focus group participants had not heard of them. In fact, some participants thought they might be like vaccinations and antibiotics which they understood as introducing organisms into the body. One participant expanded, ***“Hearing about living organisms is scary but it is just shock at the novelty. But asthmatic people are very sensitive so it would require getting a lot more information.”*** Some participants expressed curiosity about biologics as a treatment option and stated that natural medicines are more appealing than chemical ones. ***“It’s good that they find alternatives to chemical treatments which have more side effects,”*** shared a participant from the DC Metro Area. However, participants were confused and concerned about the



thought of “living organisms” and were not sure if it meant the medicine comes from animals or is tested on animals, and whether it might cause infections in the body or lead to a poor reaction in asthmatic people who are already sensitive to a lot of natural triggers. ***“I would not take anything coming from an animal, unless they didn’t tell me, and it was used to save me,”*** added a participant from Texas.

Many participants disclosed that they might be persuaded to try biologics medication if given enough information about the benefits, side effects, ingredients, results of clinical trials, FDA approval, and clearance and recommendation by their primary care providers for their specific cases. Participants in general expressed a desire for more information about biologics specifically, participants wanted more information on the ingredients, how this type of medicine differs from regular chemical treatments, how it is administered, and its interaction with other medications. There was uncertainty about if biologics were a preventive measure, such as a vaccine, or if they are a treatment, after diagnosis, or even if it would be a cure.

***“I don’t understand how it works, how is it different from regular medicines? Would it be like probiotics?”***

California Participant

***“I would want to know its effectiveness. If it controls asthma faster or better maybe I would use it”***

Puerto Rican Participant

***“Inhalers cause a lot of problems and give me anxiety and steroids make me gain weight. More natural could be good”***

California Participant

### Latinos & Asthma

All participants agreed that Latinos have a high incidence of asthma and found it to be a significant health concern. However, participants had mixed opinions on whether asthma was an issue that affected Latinos more than other ethnic groups. ***“It affects a lot of Latinos, but it is not specific to Latinos more than other races. Minorities in general have higher exposure to triggers,”*** provided one participant from the DC Metro Area. Participants felt that life conditions and circumstances in the US make Latinos more likely to be exposed to environmental triggers and harder to manage than other groups. One participant shared, ***“We, Latinos do not have the luxury of prevention; we just end up curing during crisis and self-medicating. We don’t have time and money for the doctor.”***

### Next Steps

Participants suggested that medical providers should make the terminology used around asthma easier to understand for an average person because the foreign symptom and treatment names make it harder to understand. There was a desire for community-based organizations to provide more education and support for individuals with asthma. Participants suggested that community health workers offer trainings and seminars at community center about asthma, triggers and symptoms. Written asthma education should be more visible and accessible at community centers or places where community members frequent, such as post offices, grocery stores, etc. One participant stressed the importance of making

information available in school settings, ***“More education about the seriousness of asthma at schools is needed because teachers can often brush it off and don’t know the statistics of the likelihood of dying from an asthma attack.”***

Participants shared that educational campaigns should provide information about new and low-cost medicines, preventative methods other than inhalers and good asthma management strategies for the asthma patients and raise awareness and empathy in the community to ensure the necessary services are provided and to promote inclusion rather than discrimination (e.g., smoking in public areas, pets). One suggestion that emerged was creating a bilingual hotline for asthma patients and families to receive timely information about triggers, what to do during an asthma attack, etc. Another suggestion offered was creating support groups where patients can share experiences and not feel isolated in their conditions. Participants stressed the need to increase access to medication by advocating for lower costs and broader coverage by insurance companies. Finally, some participants recommended having a “reserve or bank” of emergency asthma treatment medications within the community for those who cannot afford medications or do not have insurance.



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