2020
The State of Pulmonary Health in New York City

Listening to Your Voice.
Fighting for Your Every Breath.
The Fund for Trust, Access, and Equity.
New York City faces a pulmonary health crisis.

Despite its prominence as a center for superior medical facilities, the city is also home to pronounced wealth gaps. These have led to dramatic health disparities. The city needs collaboratively created solutions to address the widening disparity and to improve the health of all its residents.

Many chronic lung diseases are incurable; however, several tools are available to treat symptoms and delay its progression. Chronic lung disease plagues an estimated 12 percent of adults in the city, which underestimates prevalence among underserved communities with access barriers to timely diagnosis. Chronic obstructive pulmonary disease (COPD), asthma, and other pulmonary conditions often go undiagnosed, especially by those without easy access to health care. In New York, that describes more people than it should, in part because poverty levels and the percentage of people without health insurance are double the national average according to recent U.S. Census estimates.

The intense, early outbreak of COVID-19 in New York City exacerbated the problem. The disease added more patients to the roster of those needing lung care because of the lasting complications from COVID-19 infection. The pandemic has also deepened social divides, sunk many people into economic distress, and strained our health systems. This is especially true for Hispanic and Black communities. These communities saw more cases and severe outcomes of COVID-19 infection, as well as more job losses among its community.

Both long-suffering chronic lung disease patients and those who developed lung disease post-COVID have one commonality—they are disproportionately made up of our most vulnerable populations.

New York City is part of a coast-to-coast search for answers.

We aim to learn how we can work together with local communities, policy-makers, and providers to identify and implement feasible and long-lasting solutions to health and health care disparity.

The first step in this endeavor was a nationwide listening tour which brought together civic leaders, clinicians, and specialists. It provided a platform for patients who have fought for access to care and have faced other barriers in treating their lung disease, to share their stories.

This summary includes concepts discussed during the CHEST Foundation New York Listening Tour call and explains specifics to be addressed by a newly launched CHEST Foundation fund that will directly support those who need help most.

The pandemic introduced changes to countless aspects of our lives, most of which were unwelcome. Through this new initiative, and an increased awareness of lung health, we can introduce change that is desperately needed. In the absence of a cure for lung disease, the ability to treat everyone, regardless of who they are, would be a victory.
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About the Study

**People battling lung disease fight for every breath.** For many of them, the struggles aren't isolated to the physical limits of their lungs. They search for answers and struggle to validate their diagnosis. They try to find a health care provider who takes their form of payment and insurance, and who they can trust. Getting the appropriate medications and medical equipment strains their resources or, in some cases, is beyond their ability.

Meanwhile, doctors struggle to establish relationships with patients due to limited time. They need patients' trust in order to give them the crucial information they need and for them to understand the contributing factors that impede their health. Educating patients on complicated health issues can take years. They don't always know how to help patients navigate social assistance programs or which ones might be appropriate for their patient's needs. Treatment plans must consider patients' circumstances. Providers need community partners who can help patients follow medical advice.

On October 27, 2020, the CHEST Foundation hosted a virtual event in New York City as part of a national listening tour focusing on lung health care. The conversation brought together patients, health care providers, and community organizations. It was the second event of its kind, with more planned across the country in cities identified for their incidence of lung disease, racial disparities, and COVID-19 infection rates.

People in New York City suffer from both low overall lung health and are more likely than the average American to be uninsured and in poverty. Studies estimate 12 percent of the city suffers from chronic lung disease. The city has documented persistently worse conditions for people of color and those living in low-income neighborhoods, where death rates are 30 percent higher for virtually every health condition. This trend extended to deaths caused by COVID-19 infections, in which the city saw Black and Brown people nearly twice as likely to die from the disease as their White neighbors.

The discussion focused on identifying barriers to accessing medical care, breakdowns in trust between patients and caregivers, and how to reach equity in treatment for people of color and disenfranchised communities. Providers shared what resources they need to properly treat patients and the logistical roadblocks to providing the best care.

The listening tour was launched to prepare communities nationwide for more patients with chronic lung issues. Both Americans living with chronic lung disease and those diagnosed with COVID-19 are disproportionately made up of vulnerable populations, who often do not have resources to seek medical treatment or can afford necessary medical devices and medication.

The COVID-19 pandemic pushed more people into poverty. A disproportionate amount —68 percent— of job losses were among people of color in New York City. The time to find solutions is now.
### Participants

A total of 14 people participated in the virtual event. They included:

#### PHYSICIANS & PROVIDERS

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<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Joan Reibman, MD, FCCP</td>
<td>NYU Grossman School of Medicine, World Trade Center Environmental Health Center, New York University/Bellevue Asthma Airways Environment Program</td>
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<tr>
<td>Doreen Addrizzo-Harris, MD, FCCP</td>
<td>NYU Grossman School of Medicine, President-Designate of CHEST, Past President of the CHEST Foundation</td>
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<tr>
<td>Negin Hajizadeh, MD, MPH</td>
<td>The Feinstein Institute of Health Innovations &amp; Outcomes Research at Northwell Health, The Donald and Barbara Zucker School of Medicine at Hofstra/Northwell</td>
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<tr>
<td>Achala Talati, MD, DO, MS, MPH</td>
<td>New York City Department of Health and Mental Hygiene</td>
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<tr>
<td>Odai Sinokrot, MD</td>
<td>Sunset Park Family Health Center at NYU Langone, Brooklyn</td>
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<tr>
<td>Jorge M. Mercado, MD</td>
<td>NYU Langone Health, Brooklyn</td>
</tr>
<tr>
<td>Mangala Narasimhan, DO, FCCP</td>
<td>Northwell Health</td>
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#### PATIENTS & INTERPRETER

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<tr>
<th>Name</th>
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<tr>
<td>Elizabeth Ortiz</td>
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<td>Maria del Carmen Agudelo</td>
<td>Patient</td>
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<td>Sonny Amaya</td>
<td>Patient Language Interpreter</td>
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#### COMMUNITY LEADERS

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<tr>
<td>Clara Londoño</td>
<td>Urban Health Plan Plaza del Sol Family Health Center</td>
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<tr>
<td>Udai Tambar</td>
<td>Northwell Health</td>
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<tr>
<td>Amanda Dunker</td>
<td>Community Service Society New York</td>
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<tr>
<td>Emily Blank</td>
<td>Local Initiatives Support Corporation</td>
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Patients with lung conditions face an uphill battle to understand their condition, receive treatment, and maintain a supply of medication or equipment. When they are uninsured, have language barriers, or have limited incomes, they often struggle to get an appointment with a specialist. Many, instead, rely on emergency departments or public health clinics, where immediate problems are treated only with temporary fixes.

Once patients make it to a doctor's office, a new concern emerges. Providers can destroy any chance of trust if they fail to give patients an opportunity to express all concerns or act dismissive of both social and medical difficulties, fail to explain diagnoses clearly, or treat low-income patients with biased behaviors.

Maintaining lung health once diagnosed has its own barriers. New York City's network of hospitals don't share information, and established patients with lifelong illnesses may not be recognized as diagnosed from one hospital system if their previous treatment came from another.

The struggles lung patients face are part of a larger puzzle with complex, moving parts. Poverty, systemic racism and toxic stress compounds the troubles patients face accessing quality health care. Patchwork solutions address some issues, but there is a lack of awareness on what resources are available. Doctors don't have an easily accessible roadmap and are often as overwhelmed as their patients when it comes to navigating the system.

Looking forward, New York City needs increased public awareness about indications of serious lung disease so patients understand when to seek out a specialist, and how to access care that they can afford. Clinicians need awareness about tactics to establish and build trust, training on addressing medication access with patients, and readily available access to community partnerships that can help to reliably implement treatment plans. Low-cost health care shouldn't be low quality, and treatments that are prescribed but impossible to fill do not help patients and lead to frustration and despair.
Patients and caregivers expressed the most difficulties with accessing health care. Obstacles blocked their access when they needed to see doctors and specialists and obtain medication. Some barriers are logistical. Not all practices accept low-income insurance or have providers that speak their language, so finding a provider and getting an appointment can be difficult. Not all patients recognize signs of lung disease and know they need to see a specialist, such as a pulmonologist for adequate diagnosis and treatment.

Lack of resources prevents other patients from accessing health care. Despite existing social programs that help patients with costs, knowing which programs help which patients can be a maze for providers as well as patients. Many facilities don’t have social workers to assist with the untangling of that web and the social workers available are often overwhelmed.

Patients don’t always recognize the signs indicating that a serious lung problem is emerging until their lung health has already dramatically deteriorated. Likewise, even if they believe their lung conditions are severe, the nurses and clinicians at public health clinics and emergency departments may not recognize the indicators.

Identified barriers included:

- Cost of medication and/or treatment
- Lack of awareness of programs that help patients with costs
- Patients do not have a pulmonologist treating their chronic condition, due to factors like cost, insurance issues, lack of knowledge or diagnosis, and reliance on emergency medicine or urgent care providers instead
- Patients do not have access to a pulmonologist who speaks their language fluently to prevent gaps in conversation and frustration with communication
- Patients do not have access to pulmonologists who they perceive as being able to relate to their culture and lived experiences
- Patients’ conditions are dismissed as minor, leading to worsening lung health and delayed attention
- Inability for uninsured patients to see specialists
- Digital divide creates a health disparity as more providers shift to telemedicine

FIGHT FOR ACCESS

Some people, deterred by costs, delay treatment for many years. Once their conditions worsen, their lung health has deteriorated. If they aren’t assertive or have an advocate fighting for them, they may suffer with their symptoms on their own.

Public health facilities don’t ensure immediate help and awaiting care can cost patients wages and time.

The expense of repeat doctor visits accumulates, especially for uninsured people. Without a consistent insurance plan, establishing a long-term relationship with a primary provider can be difficult to maintain, and the cost for seeing a specialist may be even more prohibitive. Many of the more difficult to control lung diseases require sub-specialist care.

A shift toward telemedicine in response to the COVID-19 epidemic can paradoxically hurt marginalized communities. Many low-income, Hispanic, Black, and older patients don’t have access to consistent broadband internet access. If web-conferencing can be established, pulse oximetry and basic vital sign measurement tools are necessary for many of these remote visits—which is an impossibility for many patients.
Nearly every person in Elizabeth Ortiz’s family has asthma. She was diagnosed as an infant, but she didn’t struggle with the disease herself until pregnancy triggered more severe symptoms. Her health took a turn for the worse in 1996. When she ended up in an emergency room during a severe outbreak, the medical staff wouldn’t give her prednisone because that hospital system didn’t have documentation of the diagnosis she’d had since infancy.

She suffered through the weekend while awaiting an appointment at Bellevue Hospital Chest & Asthma Clinic. But when she showed up for her appointment, she was nearly turned away because they didn’t have documentation of the appointment scheduled from the emergency department referral.

“I was extremely upset. I couldn’t breathe. I didn’t feel well and the nurses told me I’m not going to be seen,” she said.

She grew angry and distraught and demanded to be seen. The outburst eventually prompted a doctor to come to the waiting room to see what the disruption was about. The doctor arranged for her to be treated—and it created a path toward better health.

Elizabeth still struggles with her asthma. She is self-employed and uninsured, so she’s had access struggles in the past. But those problems don’t exist at the asthma clinic. “You can walk in, and you’re always seen. That’s major,” she said.

The clinic also has its own pharmacy that offers low-cost medication, which is essential for Ortiz. Without it, her monthly prescriptions would likely be close to $300.
New York City is sharply divided between who can afford health care and those who cannot. Systemic racism prevents some people from achieving good health. The problems are admittedly complex in an enormous city with deeply rooted and tangled barriers. Perceptions that providers treat low-income patients differently prevail. A lack of education about health care terms and serious lung disease symptoms causes some patients to be unaware of the severity of their condition. Without the benefit of a health advocate or proficiency in health issues, patients may not have the ability to seek care or maintain treatment. Education is a small piece of the solution. We can teach, and prescribe, but 'adherence' will require communities to collaborate on how to enable reliable access.

Barriers include:

- Deepening of wealth disparities because of COVID-19 economic fallout, which disproportionately affects Black and Hispanic people
- Lack of in-depth knowledge in health areas
- Low-cost health care is often low-quality, with daylong wait times, and only gives temporary relief for chronic conditions
- Patients may need to advocate for themselves and their families, often loudly and adamantly. Many are not empowered to demand better care
- Cost prohibitive medication leads low-income patients to rely on temporary solutions and emergency department treatment
- Undocumented immigrants fear legal ramifications because of their status, so they avoid doctor visits, withdraw from public insurance programs, and/or aren't eligible for other assistance programs

"We thought that we figured it out if we gave them medications...but there's so much else that's going on in their home, in the workplace."
—Dr. Negin Hajizadeh

New York Residents Living in Poverty

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<th>New York Residents</th>
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<td>National Average</td>
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Maria has struggled to breathe for 50 years. It took over 40 years for her to learn why.

She'd seen many doctors, most who told her she had asthma or chronic lung disease. They prescribed medications that didn't fully treat her condition. One medication she was prescribed helped to alleviate her symptoms, but was unaffordable. Only by chance was she able to fill the prescription. She won a contest with a $300 prize and used most of her winnings to buy it.

"I gave thanks to God that day, because I was able to buy that medication," she said.

It wasn't until she got health insurance in 2011 that she had a CT scan of her lungs. Then, doctors were able to confirm what she had been living with since childhood. Maria has bronchiectasis, a condition where the bronchial tubes of the lungs are permanently damaged, widened, and thickened. The damaged air passages allow bacteria and mucus to build up and pool in the lungs.

By the time she was diagnosed, her lung function was so poor, she needed supplemental oxygen even while sleeping. She relies on a collection of medical equipment to help her breathe. The medications she takes are so strong, they've damaged her heart and kidneys.

But there are other problems now that she's diagnosed. It's difficult to travel on public transportation with her oxygen machines, which are sensitive and easily recalibrated. She also needs comprehensive medical advice on nutrition, therapy, and exercise to manage her disease.

Maria was born in Colombia and doesn't speak English, so during most of her treatment in the United States she relied on translators. Details got lost in translation and made her hesitant to ask questions.

Recently, she found a Spanish-speaking pulmonologist.

"He has explained my condition to me, I have had translators and doctors who have treated me but communication is not good when it is not in your same language and it is a great barrier to understanding and asking questions confidently," she said.
Trust

Providers must establish trust by showing patients their concern for them is beyond their health issues. Training is needed to ensure physicians help patients understand diagnoses and address any barriers the patients may encounter carrying out recommended treatment.

Identified barriers included:

• Technical medical language used by physicians can intimidate patients and make them reluctant to ask questions
• Providers don’t recognize or have access to past diagnoses and patient’s treatment successes and failures, requiring both sides to repeat tests and failed treatments
• Clinicians may be unaware of the obstacles that patients face affording medication, returning for follow-up visits or factors that interfere with following treatment plan
• Ideology that patients must follow doctors’ orders doesn’t address roadblocks patients face carrying out health plans
• Patients perceive dismissive attitudes and/or mistreatment based on their race, income level, lack of insurance, or use of state-funded insurance

“I don’t have to be wheezing to have asthma, or an asthma attack. I’m coughing horribly. And that can be really frightening. If I don’t feel like I’m being heard, it creates even more anxiety, and I get upset, and…there goes my chest getting tighter. So it’s really frightening.”
—Elizabeth Ortiz, Patient

Demographics of New York City

32 percent Non-Hispanic White
29 percent Hispanic
24 percent Black
14 percent Asian
1 percent Other

“I am a clinician, but obviously, as a person, I’m also a patient. It’s very, very difficult to navigate the health system in New York City. So, to me, it’s very important to find people that can help you navigate that system. And I feel like sometimes patients get lost in that maze.”
—Dr. Jorge Mercado
Recommendations

The problems surrounding trust, access and equity can't be eradicated until the community acknowledges them and works together toward a solution. Health care expenses, even for the insured, can deter treatment. Providers must be a partner in assisting patients with accessing their medication and be sensitive to perceptions of unequal treatment. They can help recognize those who need community assistance. Patients need education and engagement from their medical team. Physicians need partners in their fight to provide better care.

ACCESS
• Advocate for additional funding for programs that offer low-cost and free medication
• Develop, share and drive awareness of a comprehensive listing of social programs that offer cost assistance
• Build and model effective partnerships between clinicians, social workers, and community resources that can help identify available assistance for patients
• Advocate Training for clinicians to identify and understand barriers to access and reasons prescribed medication or treatment plans may go unfollowed
• Educate the patients, caregivers and the public about the signs of serious lung problems that necessitate specialist/pulmonologist care
• Advocate the care and support of all patients including undocumented immigrants
• Support telehealth options available to all patients who need it regardless of internet accessibility

TRUST
• Foster creative ways to ensure patient intake that assists doctors in discovering what barriers patients face
• Drive efforts to gain meaningful, relevant qualitative information about patients that fosters relationships between providers and the communities they serve

EQUITY
• Resource list for patients who speak other languages to find providers who speak their language
• Share meaningful resources that support front-line providers in their ability to identify and effectively treat on types of lung-related health conditions
• Advocate and support quality low-cost health care and emphasis at public health clinics on treatment plans for chronic lung conditions
• Patient education strategies to help bridge the education gap between patients and their providers

"You often don't know, and understand what the environment is that your patient is living in. All these things that are really, really important and are part of the whole holistic care of a patient."
—Dr. Joan Reibman

"The physicians don't know where to go to help their patients, we're often lost. All the insurances are so different. All the patient needs are so different...it's piecemeal in thousands of places."
—Dr. Doreen Addrizzo-Harris
About the CHEST Foundation
The CHEST Foundation, the charitable arm of the American College of Chest Physicians, champions lung health by supporting clinical research, community service, and patient education. Through CHEST Foundation-supported programs, CHEST’s 19,000+ members engage in advancing the lung health of millions of patients in local communities around the world. More than 95 cents of every dollar raised goes toward advancing the foundation’s mission-based programming. Since its inception, the foundation has provided more than $10 million in funding for clinical research and community service, with a reach that spans more than 60 countries. For more information about the CHEST Foundation, visit chestfoundation.org.

About the Erin Popovich Endowment
The Erin Popovich Endowment, established with the CHEST Foundation, is changing what it means to live with ILD by increasing access to information and treatment, improving patient independence and supporting clinical research. The mission of the Erin Popovich Endowment focuses on improving the quality of life of patients with ILD and their families through education, becoming a facilitator between clinicians and patients for the myriad of burdens that patients and families encounter from their initial diagnosis to their end of life. To learn more about the Erin Popovich Endowment, visit chestfoundation.org/popovich.

To learn more about the Listening Tour, visit chestfoundation.org/tour