Written Testimony before the U.S. Senate, Health, Education, Labor and Pensions Committee

Hearing Entitled
"Addressing Long COVID: Advancing Research and Improving Patient Care"

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Thursday January 18, 2024

Good Morning--Chairman Sanders, Ranking Member Cassidy and distinguished Members of the Committee, my name is Michelle Harkins and I am a pulmonary and critical physician from the University of New Mexico in Albuquerque, NM.

I am honored to appear before you today to talk about the impact Long Covid is having on patients and provide some recommendations based on my work as a clinical researcher, a clinician, and an educator on how I believe this committee and the federal government can make a huge difference on the day to day lives of Americans suffering with Long Covid.

My background:

As an ICU doctor at a busy urban medical center, I was in the trenches with critically ill patients dying of Covid-19. I very quickly became part of exciting networks of researchers—public, private, and everything in between—who came together with the singular goal of understanding this new disease. I was our lead investigator for many Covid clinical studies at University of New Mexico, first to study therapeutics for the acute disease and then the long-term effects of Covid-19.

I will share a story of a woman in the middle of career as a primary care provider in rural New Mexico. After serving her community and treating patients for years, she herself became infected with Covid-19 and then months later presented with signs of Long Covid including brain fog, and difficulty breathing during even short periods of exercise. She came to see me for these persistent symptoms. All of her diagnostic tests were essentially normal.

Two years later, she still is active and goes on walks but has to stop several times to catch her breath. These symptoms so impacted this patient, that she eventually decided to leave her work, unable to maintain the mental recall needed to do her job.

I was fortunate to participate in the NIH Adaptive Covid Treatment Trials (ACTT) and Accelerating Covid-19 Therapeutic Intervention and Vaccines (ACTIV) trial networks that provided randomized control trial evidence of medications that worked and those that did not in acute Covid.

I am currently a Co-Investigator for the adult cohort of the NIH Recover study and we are now enrolling for the RECOVER VITAL study, a treatment trial with Paxlovid for Long Covid, and hope to participate in the other sub studies.

The NIH Recover Research Program is poised to systematically study risk factors and clinical symptoms that lead to Long Covid and ultimately to treatments that are individualized to certain clinical subsets of patients. This network has relied on extreme collaboration between scientists, clinicians, patients and advocates to inform the study design and processes that has never before been seen. Thank you for all this committee has done to fund this important initiative as the research and clinical needs are still ongoing.

In addition to research and seeing patients, I also have a passion for sharing emerging new knowledge with my peers and learning from them about the challenges they face in their environment. When the pandemic began, I worked closely with Project ECHO, leader of the ECHO model, an innovative method of creating virtual communities of practice to help accelerate peer-to-peer knowledge in a trusted community. We set up a virtual ECHO network to support the hundreds of health care providers across the state who were struggling to treat critically ill Covid-19 patients in their hospitals and clinics.

When the initial waves of the pandemic slowed, we then set up a parallel program for primary care providers struggling to identify and treat Long Covid patients which was funded by the Health Resources and Services Administration (HRSA) Telehealth Technology-Enabled Learning Program (TTELP) initiative. Through this program my team and I have helped train over 800 local providers across the United States on how best to identify and support patients with Long Covid.

The problem:

The CDC previously estimated that 1 in 5 adults and 1 in 4 children will experience some form of Long Covid. There are over 1.1 million deaths due to Covid and now CDC data mark more than 5000 deaths from Long Covid. These Long Covid death rates varied by race and ethnicity, from a high of 14.1 cases per million among American Indian/Alaska Natives, 6.7 cases per million for White, 6.4 cases per million for Black and 4.7 cases per million for Hispanic to a low of 1.5 cases per million among Asian. These numbers are likely underestimated for a variety of reasons; increased mortality from Covid-19 in some racial and ethnic groups resulting in lower numbers to develop of Long Covid, lack of access to health care or to providers that could diagnose them, or patient deaths were attributed to other causes.

Symptoms of long covid can be wide ranging and difficult to diagnose. For a primary care practitioner in a small community for example who doesn't see many cases, it may be difficult for that provider to differentiate long covid from symptoms of existing illnesses a patient may have or would develop.

We are learning every day about the potentially debilitating and life altering effects of this disease.

Recommendations:

Based on my experience as a clinician, researcher, and educator, I suggest a few ways in which I believe the federal government and this committee in particular can help support patients with Long Covid and the providers and care teams working to help these patients.

A. The need for continued investment in ongoing research

We need to continue funding research in Long Covid. We are learning more each day about this complex disease and its mechanisms which will translate into treatment plans for patients to improve their quality of life and their ability to manage their disease more effectively.

To be most effective, we need to ensure that a research network is able to share data on all levels (public health, community, federal and state) among researchers, that transparency of the results of research is valued. We also need to improve access for all subjects to participate in research studies on Long Covid no matter where they live or what other social determinants of health impact them. We must be sure subjects enrolled reflect all of our population and especially those that are disproportionately affected by the disease. These efforts will help us better understand the parameters of this disease and the range of ways it is affecting our diverse populations. Long Covid syndromes and symptoms are varied, and multiple cell types and organ systems are involved and so answers to therapy are complex and will take time.

B. Making Access to Clinical Care Easier for Patients

Very few Long Covid clinics exist nationwide. If they do exist, they are in bigger academic centers in big cities. In New Mexico for example, we have one Long Covid clinic at UNM run by my Project Echo co-medical director Dr. Alisha Parada, a general internist.

What we need are multidisciplinary clinics to address the myriad of symptom complexes that these patients face. For example, we need a pulmonologist, a cardiologist, a neurologist or psychologist, physical therapy, occupational and speech therapy and social workers to be in one location so that the patients can be seen by whomever they need.

Long Covid patients tend to be sicker and use the health care system more regularly. Multidisciplinary clinics can ultimately help reduce these costs on the healthcare system.

To make this vision possible, we need to figure out how to reimburse providers in a multidisciplinary Long Covid clinic for seeing patients with the same diagnosis on the same day. A Long Covid patient might come to a multidisciplinary clinic and need to see a neurologist, a cardiologist, and an internist, all for the same diagnosis of Long Covid. This committee should ask CMS to look into ways that it could provide guidance on the billing codes, reimbursements for Long Covid, and how this code can be best used for the multidisciplinary care many Long Covid patients need.

This committee should also encourage insurers and CMS to support evaluations for Long Covid. Evaluations for Long Covid are complicated and can involve a broad group of signs and symptoms.   There is no one blood test for diagnosis. Without insurance coverage and access to these clinics, many patients will not get the evaluation and assessment tools they need.

C. Helping to prevent the occurrence of Long Covid in the future

There is yet another surge in acute Covid-19 infections across the country. With the end of the public health emergency for Covid-19, it is harder for patients, especially in rural settings or from marginalized communities, to get access to vaccines. Reducing cost barriers will improve the ability to deliver vaccines in rural clinics, institutions and in all populations.

In many areas, the cost for medical centers to give the vaccine is more than their reimbursement rate for the visit, making it difficult for many clinics to provide them.

D. Supporting clinicians across the country to have access to the most up-to-date best practices in trusted communities of practice

We can do a much better job with educating the public and providers regarding Covid and Long Covid.   As an example, the ECHO model has been shown to be a cost-effective, and efficient way to support local providers to learn new information as a disease is changing and evolving.

When the pandemic hit, Project ECHO, funded by the Agency for Healthcare Research and Quality (AHRQ), created a national network of state and regional virtual communities of practice designed to support nursing homes to train their staff on infection control and prevention just as nursing home staff and residents were being hit hard by the disease. This initiative proved the ability to create a nation-wide network of regional communities of practice, all sharing evolving best practices and taking in new information each week and each month about what clinicians were seeing in their own community as they see patients. Creating a national network of regional communities of practice that meet virtually would also help to share and disseminate evolving research findings and new treatment options.

Once the pandemic is truly over, we need the necessary skills and network to be ready for the next pandemic or health emergency that arises.

The HRSA TTELP Initiative provides an early example. Expanded investment in the development of a national network for telementoring would make a huge difference. This national network of local providers and regional and national experts, once created, would then be available to help respond to the next pandemic or health emergency as it arises. This is telementoring for providers but in theory this model could be created as regional Long Covid Clinics where the experts actually consult with the patients.

Thank you again for the opportunity to testify on Long Covid. It is real. It affects many Americans and we need continued funding for research in hopes to find treatments for patients, and to educate providers.

The patient I mentioned at the beginning of my remarks has stepped away from her career as a primary care physician serving her community in rural New Mexico. Your investments today can help increase the chances that we will find treatments for Long Covid and ensure that these patients such as mine don't lose years of their life to this disease, but instead can be as active and productive members of society as possible.

I am happy to answer any questions you may have.

References:

CDC - NCHS - National Center for Health Statistics

Nearly One in Five American Adults Who Have Had COVID-19 Still Have "Long COVID" (cdc.gov)

NCHS Data Brief, Number 479, September 2023 (cdc.gov)