Long COVID Patients Are Frustrated That Federal Research Hasn't Found New Treatments

Without clinical trials, physicians specializing in treating long COVID must rely on hunches to guide their clinical decisions.

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Erica Hayes, 40, has not felt healthy since November 2020 when she first fell ill with COVID.

Hayes is too sick to work, so she has spent much of the last four years sitting on her beige couch, often curled up under an electric blanket.

"My blood flow now sucks, so my hands and my feet are freezing. Even if I'm sweating, my toes are cold," said Hayes, who lives in Western Pennsylvania. She misses feeling well enough to play with her 9-year-old son or attend her 17-year-old son's baseball games.

Along with claiming the lives of 1.2 million Americans, the COVID-19 pandemic has been described as a mass disabling event. Hayes is one of millions of Americans who suffer from long COVID. Depending on the patient, the condition can rob someone of energy, scramble the autonomic nervous system, or fog their memory, among many other symptoms.

In addition to the brain fog and chronic fatigue, Hayes' constellation of symptoms includes frequent hives and migraines. Also, her tongue is constantly swollen and dry.

"I've had multiple doctors look at it and tell me they don't know what's going on," Hayes said about her tongue.

Estimates of prevalence range considerably, depending on how researchers define long COVID in a given study, but the Centers for Disease Control and Prevention puts it at 17 million adults.

Despite long COVID's vast reach, the federal government's investment in researching the disease — to the tune of $1.15 billion as of December — has so far failed to bring any new treatments to market.

This disappoints and angers the patient community, who say the National Institutes of Health

should focus on ways to stop their suffering instead of simply trying to understand why they're suffering.

"It's unconscionable that more than four years since this began, we still don't have one FDA-approved drug," said Meighan Stone, executive director of the Long COVID Campaign, a patient-led advocacy organization. Stone was among several people with long covid who spoke at a workshop hosted by the NIH in September where patients, clinicians, and researchers discussed their priorities and frustrations around the agency's approach to long COVID research.

Some doctors and researchers are also critical of the agency's research initiative, called RECOVER, or Researching COVID to Enhance Recovery. Without clinical trials, physicians specializing in treating long COVID must rely on hunches to guide their clinical decisions, said Ziyad Al-Aly, chief of research and development with the VA St Louis Healthcare System.

"What [RECOVER] lacks, really, is clarity of vision and clarity of purpose," said Al-Aly, saying he agrees that the NIH has had enough time and money to produce more meaningful progress.

Now the NIH is starting to determine how to allocate an additional $662 million of funding for long COVID research, $300 million of which is earmarked for clinical trials. These funds will be allocated over the next four years.

At the end of October, RECOVER issued a request for clinical trial ideas that look at potential therapies, including medications, saying its goal is "to work rapidly, collaboratively, and transparently to advance treatments for long COVID."

This turn suggests the NIH has begun to respond to patients. This has stirred cautious optimism among those who say that the agency's approach to long COVID has lacked urgency in the search for effective treatments.

Stone calls this $300 million a down payment. She warns it's going to take a lot more money to help people like Hayes regain some degree of health.

"There really is a burden to make up this lost time now," Stone said.

The NIH told KFF Health News and NPR via email that it recognizes the urgency in finding treatments. But to do that, there needs to be an understanding of the biological mechanisms that are making people sick, which is difficult to do with post-infectious conditions.

That's why it has funded research into how long COVID affects lung function, or trying to understand why only some people are afflicted with the condition.

Good Science Takes Time

In December 2020, Congress appropriated $1.15 billion for the NIH to launch RECOVER, raising

hopes in the long COVID patient community.

Then-NIH Director Francis Collins explained that RECOVER's goal was to better understand long COVID as a disease and that clinical trials of potential treatments would come later.

According to RECOVER's website, it has funded eight clinical trials to test the safety and effectiveness of an experimental treatment or intervention. Just one of those trials has published results.

On the other hand, RECOVER has supported more than 200 observational studies, such as research on how long covid affects pulmonary function and on which symptoms are most common. And the initiative has funded more than 40 pathobiology studies, which focus on the basic cellular and molecular mechanisms of long COVID.

RECOVER's website says this research has led to crucial insights on the risk factors for developing long COVID and on understanding how the disease interacts with preexisting conditions.

It notes that observational studies are important in helping scientists to design and launch evidence-based clinical trials.

Good science takes time, said Leora Horwitz, the co-principal investigator for the RECOVER-Adult Observational Cohort at New York University. And long COVID is an "exceedingly complicated" illness that appears to affect nearly every organ system, she said.

This makes it more difficult to study than many other diseases. Because long COVID harms the body in so many ways, with widely variable symptoms, it's harder to identify precise targets for treatment.

"I also will remind you that we're only three, four years into this pandemic for most people," Horwitz said. "We've been spending much more money than this, yearly, for 30, 40 years on other conditions."

NYU received nearly $470 million of RECOVER funds in 2021, which the institution is using to spearhead the collection of data and biospecimens from up to 40,000 patients. Horwitz said nearly 30,000 are enrolled so far.

This vast repository, Horwitz said, supports ongoing observational research, allowing scientists to understand what is happening biologically to people who don't recover after an initial infection — and that will help determine which clinical trials for treatments are worth undertaking.

"Simply trying treatments because they are available without any evidence about whether or why they may be effective reduces the likelihood of successful trials and may put patients at risk of harm," she said.

Delayed Hopes or Incremental Progress?

The NIH told KFF Health News and NPR that patients and caregivers have been central to RECOVER from the beginning, “playing critical roles in designing studies and clinical trials, responding to surveys, serving on governance and publication groups, and guiding the initiative.”

But the consensus from patient advocacy groups is that RECOVER should have done more to prioritize clinical trials from the outset. Patients also say RECOVER leadership ignored their priorities and experiences when determining which studies to fund.

RECOVER has scored some gains, said JD Davids, co-director of Long COVID Justice. This includes findings on differences in long COVID between adults and kids.

But Davids said the NIH shouldn’t have named the initiative “RECOVER,” since it wasn’t designed as a streamlined effort to develop treatments.

“The name’s a little cruel and misleading,” he said.

RECOVER’s initial allocation of $1.15 billion probably wasn’t enough to develop a new medication to treat long COVID, said Ezekiel J. Emanuel, co-director of the University of Pennsylvania’s Healthcare Transformation Institute.

But, he said, the results of preliminary clinical trials could have spurred pharmaceutical companies to fund more studies on drug development and test how existing drugs influence a patient’s immune response.

Emanuel is one of the authors of a March 2022 COVID roadmap report. He notes that RECOVER’s lack of focus on new treatments was a problem. “Only 15% of the budget is for clinical studies. That is a failure in itself — a failure of having the right priorities,” he told KFF Health News and NPR via email.

And though the NYU biobank has been impactful, Emanuel said there needs to be more focus on how existing drugs influence immune response.

He said some clinical trials that RECOVER has funded are “ridiculous,” because they’ve focused on symptom amelioration, for example to study the benefits of over-the-counter medication to improve sleep. Other studies looked at non-pharmacological interventions, such as exercise and “brain training” to help with cognitive fog.

People with long COVID say this type of clinical research contributes to what many describe as the “gaslighting” they experience from doctors, who sometimes blame a patient’s symptoms on anxiety or depression, rather than acknowledging long COVID as a real illness with a physiological basis.

“I’m just disgusted,” said long COVID patient Hayes. “You wouldn’t tell somebody with diabetes to breathe through it.”

Chimére L. Sweeney, director and founder of the Black Long COVID Experience, said she's even taken breaks from seeking treatment after getting fed up with being told that her symptoms were due to her diet or mental health.

"You're at the whim of somebody who may not even understand the spectrum of long COVID," Sweeney said.

Insurance Battles Over Experimental Treatments

Since there are still no long COVID treatments approved by the Food and Drug Administration, anything a physician prescribes is classified as either experimental — for unproven treatments — or an off-label use of a drug approved for other conditions. This means patients can struggle to get insurance to cover prescriptions.

Michael Brode, medical director for UT Health Austin's Post-COVID-19 Program — said he writes many appeal letters. And some people pay for their own treatment.

For example, intravenous immunoglobulin therapy, low-dose naltrexone, and hyperbaric oxygen therapy are all promising treatments, he said.

For hyperbaric oxygen, two small, randomized controlled studies show improvements for the chronic fatigue and brain fog that often plague long COVID patients. The theory is that higher oxygen concentration and increased air pressure can help heal tissues that were damaged during a COVID infection.

However, the out-of-pocket cost for a series of sessions in a hyperbaric chamber can run as much as $8,000, Brode said.

"Am I going to look a patient in the eye and say, 'You need to spend that money for an unproven treatment'?" he said. "I don't want to hype up a treatment that is still experimental. But I also don't want to hide it."

There's a host of pharmaceuticals that have promising off-label uses for long COVID, said microbiologist Amy Proal, president and chief scientific officer at the Massachusetts-based PolyBio Research Foundation. For instance, she's collaborating on a clinical study that repurposes two HIV drugs to treat long COVID.

Proal said research on treatments can move forward based on what's already understood about the disease. For instance, she said that scientists have evidence — partly due to RECOVER research — that some patients continue to harbor small amounts of viral material after a COVID infection. She has not received RECOVER funds but is researching antivirals.

But to vet a range of possible treatments for the millions suffering now — and to develop new drugs specifically targeting long COVID — clinical trials are needed. And that requires money.

Hayes said she would definitely volunteer for an experimental drug trial. For now, though, “in order to not be absolutely miserable,” she said she focuses on what she can do, like having dinner with her family.

At the same time, Hayes doesn’t want to spend the rest of her life on a beige couch.

RECOVER’s deadline to submit research proposals for potential long COVID treatments is February 1.

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