

Want to Enroll in a Long COVID Clinical Trial? This New Project Helps Track Them.

While there are over 100 trials recruiting patients for interventional studies, many of those are not testing novel drugs.

April 10, 2024 By Betsy Ladyzhets and The Sick Times

A new long COVID project makes information about clinical trials more accessible to people who may want to participate in research while showing gaps in the current search for meaningful treatments. Patient-researcher Ezra Spier developed the new project, called [Long COVID Studies](#). As of its launch on March 26, the site includes details of about 550 trials in the U.S. and 54 other countries.

“Clinical trials are the currency in research that pushes things forward. Trials are how consensus is built within medicine,” Spier said. He was inspired to develop Long COVID Studies after participating in a long COVID trial at Stanford University and seeing discussions from people with long COVID who wanted to learn about new trials, he told The Sick Times.

To build the new website, Spier used data from [ClinicalTrials.gov](#), a database run by the National Institutes of Health (NIH) that lists registered trials in the U.S. and elsewhere in the world. Researchers interested in submitting their products for approval from the Food and Drug Administration, as well as those who have received NIH funding, must register their trials in the database.

While ClinicalTrials.gov offers a comprehensive list of ongoing trials, it’s “designed for regulators and researchers” who are familiar with how these trials work, Spier said. He explained that many people with long COVID may not know how to navigate the website — since most people don’t have a biomedical background — and may have limited time and energy to learn its infrastructure.

To create a more accessible site, Spier designed Long COVID Studies to highlight details about clinical trials that are most important to people interested in participating, such as where a study is taking place and which treatments it’s testing. The site automatically shows studies currently recruiting in the country where a user is located, based on users’ IP addresses, he said. But users can also use filters to find other types of trials.

Long COVID Studies is a great tool to “make it easier for people [with long COVID] to consume information and get involved in clinical trials,” said David Putrino, PhD, who leads a long COVID clinic and trials at the Mount Sinai Health System in New York City. He agreed that ClinicalTrials.gov is not very accessible to patients; for example, it takes several steps to find contact information for researchers running trials that a user may be interested in, he said.

“The clinical trial landscape is so opaque to so many patients, and it’s hard to know what to plug into,” said patient advocate Charlie McCone. The Long COVID Studies site may demystify that landscape, particularly for those who aren’t already closely following research on social media, he said.

While developing the new site, Spier also spent time analyzing the ClinicalTrials.gov database to better understand the current landscape of long COVID trials. His analysis found that, while there are over 100 trials labeled as recruiting patients for interventional studies as of March 2024, many of those studies are not testing novel drugs or following rigorous research practices that scientists and doctors consider important for demonstrating a treatment’s effectiveness.

Clinical trials for long COVID and related chronic diseases have moved slowly, said Karyn Bishof, founder of the [COVID-19 Longhailer Advocacy Project](#), in an email after reviewing Spier’s analysis. For this reason, “I think we are in really bad shape when it comes to finding treatments or a cure any time soon,” she said.

More clinical trials are starting, but quality concerns abound

While the ClinicalTrials.gov database is designed for clinical trials, which test whether a potential treatment helps patients with a particular disease, the site also lists studies that are simply observing patients and collecting data, called observational studies. These observational studies may inform later clinical trials, but they are less helpful for demonstrating whether a treatment is successful.

Spier’s analysis included 485 trials listed for the condition long COVID, as of mid-March. It didn’t include other trials in the broader category of “post-COVID conditions” that are less relevant to people with long COVID. Out of those trials, 191 are observational studies and 294 are actual clinical trials, called interventional studies. Among those 294 trials, 108 are currently recruiting patients.

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The number of trials testing drugs is higher now than in August 2023, when The Lancet Infectious Diseases [published an editorial](#) calling attention to slow progress on long COVID trials. At that time, out of 94 interventional trials on ClinicalTrials.gov, only 12 tested pharmaceutical treatments. As of March 2024, current research includes more than 100 studies involving pharmaceutical treatments, though Spier cautions that his analysis double-counts trials that include multiple drugs.

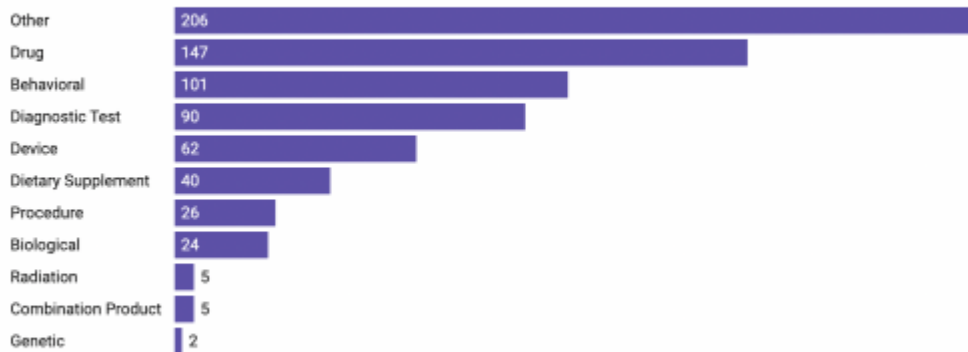
It's "encouraging that overall numbers are higher than when I last checked," said Ursula Hofer, author of the August 2023 editorial, in an email. But Hofer still noticed "some of the same shortcomings" in the research, including many observational studies and that "many of the interventional trials are only supportive (e.g., coping) or target lifestyle factors, none of which I

expect to lead to a substantial improvement in most participants.”

Putrino similarly noted that the trials listed are heavily skewed toward behavioral interventions, which test symptom management strategies like pacing and cognitive training rather than drugs. According to Spier’s analysis, current research includes about 100 behavioral interventions (some of which could be in the same trials, as with the drugs).

Long Covid trials, intervention type

Researchers are testing drugs, behavioral interventions, and other potential treatments. Note that ClinicalTrials.gov asks studies to list every intervention used separately, so some studies are represented multiple times.



Trials registered as of March 2024.

Chart: Betsy Ladyzhets • Source: Ezra Spier/ClinicalTrials.gov • Get the data • Embed • Created with Datawrapper

Some of these behavioral strategies can be very helpful for patients, Putrino said. However, these strategies “are not likely to do much better after a \$5 million clinical trial,” as such a trial would only reaffirm what people with long COVID already know based on their personal experience. He’d prefer to see research institutions instead devote funding to developing novel drugs and repurposing drugs from other conditions for long COVID.

Spier searched for common keywords across researchers’ descriptions of the interventions they were testing, finding that “training” and “exercise” were among the most popular terms used. Exercise trials, in particular, [aren’t a great use of funding](#) as extensive research has shown that exercise can worsen symptoms for many people with long COVID and related diseases, such as myalgic encephalomyelitis (ME), said Stephen Smith, who tracks clinical trials on the Twitter/X account [Post-Viral Trials News](#).

“There’s a time and a place for exercise trials, and I think almost none of them are appropriate,” Smith said. Testing exercise as a treatment for people with disabling forms of long COVID is like testing smoking as a treatment for lung disease, he said.

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Smith also expressed concern that many of the long COVID trials listed in ClinicalTrials.gov are not blinded, meaning that people involved with the studies will know which participants in a trial receive treatment and which participants receive placebos. Scientists consider blinding to be an important aspect of rigorous clinical trials, as this practice reduces the risk of patients and researchers believing a drug is helpful when it has limited impact.

Among the interventional Long Covid trials, 113 have no blinding and 55 have only a single level of blinding, meaning the patients may not know whether they receive a drug or placebo but researchers still know and can bias results. People who work in fields like long COVID and ME “have huge biases, they really want their drug or therapy to work,” Smith said. He warned that without double- or higher-level blinding, trial results may not be reliable.

As with options for long COVID medical care, clinical trials tend to be clustered in urban areas where large research centers are located, Spier’s analysis found. For example, there are 15 trials clustered in Southern California and none in more rural states like Idaho and Wyoming. Trials are also much more common in the U.S. and Europe than in other countries, though those data are likely skewed because ClinicalTrials.gov is a U.S. registry.

“I am not surprised to see a significant lack of access to clinical trials in rural areas,” Bishof said. “This has been an issue highlighted by so many in our community when it comes to seeking and obtaining care for acute COVID and long COVID.”

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Improving access to clinical trials

Scientists and patient advocates agree that more funding is needed to speed up long COVID research — and that funding should be spent wisely, on the most promising treatments rather than behavioral interventions. Advocacy groups like [Long COVID Moonshot](#) and [Long COVID Action Project](#) focus on research funding as a key demand for the federal government.

“My dream scenario would be to see large platform trials like we had for acute COVID-19 treatment for long COVID; the piecemeal approach that predominates at the moment with relatively many small trials looking at supportive care/lifestyle is wasting resources,” Hofer said.

Hofer recommended that people with long COVID should be involved in designing and planning trials, as one way to ensure that research is prioritizing the most promising treatments and to improve patient confidence in studies. Bishof agreed, writing, “Every single clinical trial should be partnering with a long COVID patient organization and ensure their involvement at every stage of the project.”

Echoing this recommendation, Spier, who also works with the [Patient-Led Research Collaborative](#), hopes to one day add a feature to the Long COVID Studies site that highlights which studies have patient representatives. If he was considering enrolling in a study, he’d find it important “to know that somebody like me was involved” in designing the research, he said.

Patient representatives can also advise researchers on how to make participating in studies easier for people with long COVID, particularly for those dealing with cognitive symptoms. For example, Putrino and his colleagues at Mount Sinai have put a lot of resources into “hands-on communication” with participants in trials there, providing people with different options for reminders about the study (phone calls, text messages, emails) and ensuring that they understand all the components of a trial.

Spier has other plans to expand Long COVID Studies beyond the data available on ClinicalTrials.gov, too, such as adding more details about interventions being tested, streamlining the process for potential study participants to contact researchers, and developing a dashboard that displays data like the statistics in this story, updated in realtime. He welcomes feedback from both patients and researchers, he said.

People with long COVID want to see more, better, and smarter clinical trials, advocate McCone said. Researchers could advance these trials by collaborating with patients, he suggested: Long COVID Studies is “an example of how one patient can step up to help” address challenges in this space.

To share feedback with Ezra Spier about Long COVID Studies, email him at info@longcovidstudies.net. He also has a newsletter to provide updates on the project, available at the bottom of the [Long COVID Studies](#) site.

[This article](#) was published by [The Sick Times](#), a website chronicling the long COVID crisis, on March 26, 2024. It is republished with permission.