

Long COVID Surveys From a FDA/NIH Initiative Ask Which Drugs Help Alleviate Symptoms

People with long COVID and their doctors can submit detailed information about which medications they've found helpful—or harmful.

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Last month, a U.S. government initiative launched a pair of surveys to collect information about how people with long COVID are managing their symptoms. Data from these surveys, one for people with long COVID and one for their doctors, will inform priorities for clinical trials.

Called [CURE ID](#), this federal initiative is a collaboration between the Food and Drug Administration (FDA) and the National Center for Advancing Translational Sciences, under the National Institutes of Health (NIH), along with other research partners. The agencies started CURE ID in 2019, aiming to identify how existing drugs might be repurposed for emerging and complex diseases.

After initial success in [helping doctors treat acute COVID-19](#) early in the pandemic, the CURE ID team started to develop a platform for long COVID in the summer of 2021. “As soon as long COVID started to be described by patients, we knew there was likely to be a lot of off-label use in the community as patients and healthcare providers tried to find treatments that might help,” the CURE ID administrative team wrote in an emailed statement to The Sick Times.

Now, people with long COVID and their doctors can submit detailed information about which medications they're using to manage the disease and what they've found helpful — or harmful. While participants are asked to share an email address with the platform, their data are kept anonymous when compiled for researchers. CURE ID worked with patient groups to develop the survey for people with long COVID, its first designed for patients as opposed to healthcare providers.

Some long COVID researchers and advocates, such as members of the Patient-Led Research Collaborative (PLRC), which CURE ID consulted in developing the surveys, have encouraged people in the community to participate. “There are many treatment surveys, but this one is special — the data will be used as evidence to help inform which drugs to study in clinical trials!” PLRC co-founder Hannah Davis [wrote in a Tweet](#) shortly after the surveys' launch.

CURE ID does not itself have the resources to run clinical trials, said Michael Sieverts, also affiliated with PLRC and a beta-tester for the surveys, but will share the data it compiles with FDA and NIH officials who can set federal guidance and make recommendations to drug companies. The surveys could also serve as a data source for the NIH's RECOVER initiative, which scientists and advocates have criticized for [failing to trial promising treatments](#). The CURE ID team will share findings with RECOVER leadership and officials involved with [last year's FDA meeting](#) about long COVID, they said.

Before starting to analyze the data from these surveys, the CURE ID team needs to collect at least 1,000 reports from people with long COVID and doctors, though the team expects that more reports may be needed to identify meaningful patterns. So far, 157 people have responded to the survey, meaning the program is about 16% of the way to this goal. Both patient and physician reports count towards the goal of 1,000 reports, the team said, adding, "We encourage anyone reading this to spread the word and help us reach this goal as quickly as possible."

To contribute to CURE ID, people with long COVID must first make an account on the initiative's online platform or phone application, utilizing either an email or social media account. Then, users can start a "case report," adding details about their experience with Long Covid and different medications. People in any country can submit their experiences to the platform; it's not restricted to the U.S.

CURE ID asks for some demographic details, information about the user's long COVID symptoms and duration of illness, their experience with acute COVID-19, vaccinations, and more. The most important part of the survey asks users to list medications they've tried for long COVID and describe whether that drug "improved, worsened, or did not change" symptoms.

"That's where it gets intimidating," Sieverts said, as many people with long COVID have tried countless medications. He recommends that people only "list the most significant" medications: "List the ones that you think have made a difference, that are really worth sharing."

The CURE ID team was "incredibly responsive to any feedback" during the beta-testing phase, Sieverts said, when he and more than 20 other people with long COVID tried out the platform. However, he acknowledged that the surveys are fairly clunky, given the complex information that CURE ID seeks to capture. The surveys also aren't compliant with the Americans with Disabilities Act, one community member [pointed out on Twitter](#).

The CURE ID team has met with some people who have had accessibility issues and is "seeking both short-term and long-term solutions to address these challenges," they told The Sick Times. In the short term, people who need support in filling out the surveys can request help from a clinical fellow who may walk users through the process over a video call or enter information on their behalf. "We appreciate the feedback from patients and will strive to continue to try to improve and make it more easily accessible for all who are affected," the team said.

Due to the surveys' complexity, Sieverts recommends that users take advantage of the CURE ID platform's ability to save one's progress and return later. "Don't feel like you have to go through it from start to finish all at once," he said. Users can return to add to their case report by going to

their account on the platform and then selecting “activities.” The CURE ID team estimates that the survey may take 20 to 45 minutes to complete in total, according to [their FAQ page](#).

People with accounts on the CURE ID platform, including those with long COVID, physicians, and researchers, can see the case reports submitted so far; these reports are anonymous, without any personal information. Once 1,000 people have submitted case reports, the CURE ID team will start to analyze the data. Scientists outside the FDA and NIH can use the information too. For example, PLRC may utilize the data for their research, Sieverts said.

Early in the pandemic, doctors used CURE ID to track how they were treating acute Covid-19, finding existing drugs that might work well for certain patients. With the long COVID surveys, the FDA and NIH officials specifically aim to identify drugs that have helped alleviate people’s symptoms and should be tested in more formal clinical trials.

Such trials could happen through other federal initiatives, like NIH RECOVER, or the agencies could encourage pharmaceutical companies to run trials that build upon hypotheses from the CURE ID dataset. This team is actively communicating with other FDA and NIH officials as well as clinical trial scientists outside the government, they told The Sick Times.

The CURE ID platform could potentially provide a model for studying other infection-associated chronic conditions (IACCs) as well, Sieverts said, though this would be a “heavy lift” for the research team. This team might also consider building upon existing surveys for people with IACCs, such as [#MEAction’s Chronic Illness Survey Adventure](#).

“The vision for CURE ID is to catalyze clinical discoveries for diseases with unmet need, including infection-associated chronic illnesses and rare diseases,” the team said. “This long COVID case report form is the first step towards having patients contribute their case reports directly.”

People with long COVID and doctors treating this disease can find the CURE ID surveys on the [initiative’s online platform](#), as well as on its apps [for iPhones and Androids](#).

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