**Long Covid Survey Partner social media TOOLKit**

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**March 2024**

**Link to CURE ID**: [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” mobile app from the App or Play Store

**CURE ID Long COVID FAQ Document:** <https://cure.ncats.io/assets/faq-long-covid.pdf>

**Accessibility note:** If users need assistance entering cases, please reach out to [curesupport@nih.gov](mailto:curesupport@nih.gov), we have staff who are available to assist by email, phone, and/or Zoom.

**Twitter Graphics**

A hand holding a phone

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A hand holding a phone

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**Sample Tweets:**

* Are you or someone you know experiencing symptoms of #LongCOVID? Help us understand the long-term impact of COVID-19 by participating in our treatment survey. Visit [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” app!
* Calling all #LongCOVID long-haulers! Share your treatment experience by taking part in our research survey. Together, we can raise awareness and drive progress in research and care. Visit [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” app!
* Calling all people with #LongCOVID! If you're living with the aftermath of COVID-19, your experience matters! Complete our treatment survey (it takes ~20-45 mins) - Visit [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” app!

* Attention #LongCOVID community! 📢 Your insights are invaluable! Participate in our survey to help understand potential treatments. It takes ~20-45 minutes to complete. Visit [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” app!
* We need your input! Participate in our research survey to help increase our understanding of #LongCOVID treatments and their impacts. It takes ~20-45 minutes to complete. Visit [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” app!
* Participate in the CURE ID TLC survey to increase our understanding of #LongCOVID treatments. Visit [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” app!
* Participate in the CURE ID TLC #LongCOVID survey - an initiative developed with @Dysautonomia, @patientled, @MEActNet @PlzSolveCFS, @LongCOVIDAllian, in collaboration with @NIH @FDA and @CPathInstitute, who host CURE ID. Visit [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” app!

**Tag:**

@id\_cure, @MEActNet, @CPathInstitute, @SCCM, @ncats\_nih\_gov, @LongCOVIDAllian, @PlzSolveCFS, @patientled, @Dysautonomia

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**Facebook/Instagram Graphics**

**A hand holding a phone

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**A blue ribbon with white text

Description automatically generated A hand holding a phone

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**Sample Facebook or Instagram Text:**

1. Attention all people with Long COVID!
   1. If you're navigating life after an acute COVID-19 infection and continuing to experience symptoms, your treatment experiences hold immense value! Participate in our research survey, as we aim to gain deeper insights into Long COVID symptoms and treatments, shaping the path for future clinical trials. Join us today by participating in our online research survey. Visit [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” mobile app now!
2. Calling all those who continue to feel the impact of COVID-19 – your perspective is invaluable! Take part in our research survey to illuminate the intricacies of Long COVID, sharing insights about its hurdles, treatments that worked, treatments that didn’t work, and personal journeys. Together, let's learn about potential treatment options and try to shape future clinical trials. Visit [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” mobile app now!
3. Is Long COVID affecting you or someone close to you? Your involvement in our online research survey can play a pivotal role in advancing our understanding of the symptoms and treatments of Long COVID. Your valuable input has the potential to drive improvements in treatments for those navigating the challenges of Long COVID and help to inform future clinical trials. Visit [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” mobile app now!
4. Join the patient and clinician partners, along with the NIH, FDA, and C-Path’s CURE ID platform to advance our understanding of the symptoms and treatments of Long COVID. What treatments are you taking and how have they impacted you? Take the CURE ID Treatments for Long COVID (TLC) Survey now by visiting [CURE-ID (ncats.io)](https://cure.ncats.io/home) or download the “CURE ID” mobile app now!

**Instagram Hashtags:**

#LongCOVIDSurvey #COVID19Research #TLCSurvey #HealthResearch #CommunityResearch #PatientImpact #LongHaulers #LongCOVIDAwareness, #TreatLongCOVID #LongCOVID #COVID19 #covidlong #LC #PASC #treatment

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**Email Announcement Text**

Dear [add person’s name you are emailing]!

CURE ID has developed a treatment survey for Long COVID patients which I’m encouraging people to contribute their experiences to.

The goal is to understand the symptoms Long COVID patients are experiencing, the medications they have tried, and whether they feel any of the medications have had an impact on their symptoms (positive or negative).

This data is meant to generate hypotheses and to help inform which drugs are studied in large, well-controlled, randomized clinical trials. Patients, care partners, and healthcare providers can all submit their experiences as case reports.

This is meant to be a community resource, so once a Long COVID case is entered in CURE ID, it becomes publicly viewable (the data is de-identified and the contributor’s name is not shown with the case if it’s a patient/care partner). All users can see the individual case reports, as well as the aggregate treatment experiences.

Please go to the CURE ID website (<https://cure.ncats.io>) or download the “CURE ID” mobile app from the App or Play Store and complete the Long COVID case report form. It takes most people ~20-45 minutes to complete, but you can save it along the way, so you don’t have to enter it in one sitting. You can also limit your entry to only the required data on the drug, symptom, and treatment outcome.

You must register to enter a case (so that you can be contacted if there are any questions by the CURE ID staff) and then can click the banner on the homepage to go directly to the Long COVID case report form. You can also access it through the Create menu by selecting the Patient/Care Partner or Healthcare Provider form and entering the disease as Long COVID. All patient and care partner case reports are anonymous and healthcare providers can choose whether they want their name displayed with their case. If you have any questions, run into any problems, or want to provide any feedback, you can email [curesupport@nih.gov](mailto:curesupport@nih.gov). You can also read the programs FAQ document here: <https://cure.ncats.io/assets/faq-long-covid.pdf>

If you have accessibility issues or require support in entering your case, CURE ID has staff who are available to assist in case entry. Please email the [curesupport@nih.gov](mailto:curesupport@nih.gov) address and the CURE ID staff can set up a zoom call or phone call, or answer questions via email, depending on your needs.

This platform has been developed with the input of patient, clinician, and research partners who have contributed to the development of this program including: the Patient-Led Research Collaborative (PLRC), Dysautonomia International (DI), Solve ME/CFS, and ME Action, among many others. It builds off the NCATS/NIH, FDA, and C-Path-run CURE ID platform. This research study has been reviewed by the NIH and FDA IRB’s and was determined to be exempt.

Thanks for your help!

[add your name here]

**Talking Points – CURE ID for Long COVID**

* CURE ID is a website and mobile app which allows the global community to hear from clinicians and patients about how Long COVID and other challenging diseases are being treated in the real-world environment.
* A special Long COVID reporting platform for patients and clinicians has now been included in the CURE ID website and app.
* The CURE ID Long COVID platform was developed as a collaboration between FDA, NCATS/NIH, and C-Path’s CURE Drug Repurposing Collaboratory (CDRC) along with Long COVID clinicians, researchers, patients, and advocates.
* It allows reporting of symptoms of Long COVID, their severity, the medications that have been tried, and whether the individuals feel any of the medications have had an impact on their symptoms (positive or negative).
* This will serve as an important surveillance tool for the clinical/patient community to understand the symptoms of Long COVID that patients are experiencing, those which they feel are most debilitating, and the drugs that are being used to treat them. This may provide clues about drugs or combinations of drugs that are potentially beneficial and may be studied formally in randomized controlled trials or suggest drugs that are not helpful, and which should not continue to be tried as treatments for Long COVID.
* Once Long COVID patients, care partners, or healthcare providers submit their case report to CURE ID, they are reviewed by CURE ID staff, and if approved, become publicly viewable (though the cases are de-identified).

**Direct Links to Long COVID Case Report Forms**

Long COVID **Clinician** Case Report Form:

<https://cure.ncats.io/create/quick-case?form-type=pasc&report-type=clinician>

Long COVID **Patient** Case Report Form:

<https://cure.ncats.io/create/quick-case?form-type=pasc&report-type=patient>

**Partners Involved and Who they are:A black background with blue and yellow letters

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1. **Critical Path Institute (C-Path), CURE Drug Repurposing Collaboratory (CDRC)**
   1. Role: Public-Private Partnership supporting CURE ID
   2. Communication liaison: Claire Bassetti • [cbassetti@c-path.org](mailto:cbassetti@c-path.org)
2. **A logo with text on it

   Description automatically generatedNational Center for Advancing Translational Sciences (NCATS/NIH)**
   1. Role: Hosts the CURE ID Platform
   2. Communication liaison: Meghan Mendick

• [meghan.mendick@nih.gov](mailto:meghan.mendick@nih.gov)

1. A blue text on a black background

   Description automatically generated**U.S. Food and Drug Administration (FDA)**
   1. Role: Created CURE ID in collaboration with NCATS/NIH
   2. Communication liaison: Heather Stone • [Heather.Stone@fda.hhs.gov](mailto:Heather.Stone@fda.hhs.gov)
2. A group of logos with text

   Description automatically generated with medium confidence**Dysautonomia International (DI)**
   1. Role: Advocacy organization. Helping bring engagement to CURE ID through community network.
3. **A close-up of a sign

   Description automatically generatedPatient-Led Research Collaborative (PLRC)**
   1. Role: Advocacy organization. Helping bring engagement to CURE ID through community network.
4. A red circle with white text

   Description automatically generated**#MEACTION**
   1. Role: Advocacy organization. Helping bring engagement to CURE ID

through community network.

1. **A black background with grey text

   Description automatically generatedSOLVE M.E.** 
   1. Role: Advocacy organization. Helping bring engagement to CURE ID through community network.
2. **A blue and black logo

   Description automatically generatedDiscovery, The Critical Care Research Network of the Society for Critical Care Medicine (SCCM)**
   1. Role: Supports CURE ID’s COVID-19 data efforts, including Long COVID